

Families planning together

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Introduction

Karrie is a young woman who is described by those who like and admire her as a helpful, hard worker, with great stamina. Not too long ago she was also seen (by the staff of the agency that supported her during the day) as someone who was difficult to employ and who needed a behavior program.

Karrie's mother, Bonnie, is like many parents we have met. She didn't agree with the agency staff. The Karrie that she knows and loves is someone that needs to have people who support her know how to approach her. Any job that she has must take into account who Karrie is and what she likes and dislikes.

Through a process called "Families Planning Together," Bonnie was able to gather what she and others who love Karrie

What is important to Karrie about a job?

What needs to be present

- A job that is clean and where she would stay clean
- A place where Karrie would dress nicely, maybe a uniform
- Daytime job
- Staff are friendly to her
- People welcome her
- Quiet slow pace environment
- Variety in job duties, not doing the same task hour after hour

What needs to be absent

- No cleaning, no dirt, no spilling
Food service, janitorial, gardening would not work
- Evening, late night and shift work
- Chaotic, messy, unorganized environments
- Fast pace, loud machinery and noisy environments
- Pressure to meet deadlines
- Absolutely no pet stores, farms, zoos, or anything to do with animals
- Environments that would place Karrie with crying, yelling, running babies and children
- The same job duty over and over

What kinds of jobs might work for Karrie

- Organizing, putting things in the proper places, where they belong
- Stocking shelves
- Sorting,
- Karrie has a great memory for detail, she can quickly pick up how things are in sequence.
- Stuffing envelopes, labeling, photocopying, picking up and delivering mail, putting mail through the

have learned about Karrie over the years. Bonnie was not only able to develop a detailed plan that describes Karrie but also a one-page description of what should be present or absent in any job that Karrie does. Bonnie says, "This plan gives Karrie authority; it changes the way people are required to do things with Karrie. We have found that some providers are able and willing to do things the way Karrie needs, others still just want Karrie to conform to the way they do things."

People with severe disabilities, who are unable to speak for themselves, need a voice. They need to be able to describe what is important to them. For those individuals, their families are often the best choice. But the families need to:

- Have structured ways to gather and organize what they know
- Be able to separate what is **important to** their family member from what they see as being **important for** their family member.
- Be able to take what they have learned and have a structured way to write it up so that it communicates powerfully to others.
- Have easy ways to continue to learn and reflect that learning in what is written
- Know how to use the resulting plans to accomplish their goals

Meeting the needs with Families Planning Together

In order to help families in meeting these needs, a group of us have developed:

- A "Families Planning Together" manual together with example plans that are posted on the web (www.allenshea.com) that can be down-loaded for free
- Seminars (and a manual describing the seminar) where we help families begin the development of plans by "walking through" the manual

- A process to help interested family members to become “family mentors”.

These are people who have completed plans with their family member and have been supported in learning how to help other families develop plans.

Some of what is needed is still under development. We know that many families are beyond the reach of the seminars that we have started. We have a few family mentors in Pennsylvania, Missouri, and Texas – we will need many more. We especially need to develop ways to help families from a distance, using the world-wide-web, and other distance learning techniques. However, what we have been able to accomplish is working. What follows will tell you more about those aspects.

Seminars – introducing people to the process and beginning to develop a plan

In Families Planning Together (FPT), families learn a structured way of gathering and organizing what the person they are planning with has told them (and others). They are shown a step-by-step process

that will enable them to develop an “essential lifestyle plan” with their family member. After attending either a one-day session or three evening sessions (6 hours total),

Kathy heard about the Families Planning Together seminar while talking with another parent who had already developed a plan with her son and that was being used at school. When Kathy read the plan she was amazed at all the information it contained and how clearly it described her friend's little boy. “I wanted something like that for my daughter, so I signed-up for the seminar.” After attending, Kathy had learned enough to start writing a draft of her daughter's plan. She now gives Justine's plan to Justine's teachers and other family members like Justine's grandma. She says that the plan has helped others to better understand and support Justine.

families know how to use the Families Planning Together manual to develop a plan with their family member. They have made a good start in developing a plan and know how

to get on-going assistance. The seminars are currently being lead by people trained as trainers in essential lifestyle planning but will be lead by family mentors as they get the experience needed to feel comfortable and competent.

Using the workbook in the seminar, families are encouraged to think about planning as occurring in four stages –

1. Think before you plan
2. Gather information
3. Develop a first plan
4. On-going learning

Think before you plan

Families are asked what they want to the plan to accomplish, what they want to learn, who needs to be involved and above all how to make sure the process is respectful to their son or daughter. Families consider these questions in relationship to what the actual purpose of the plan will be. Bonnie stresses that she developed a plan with Karrie because (in part), "All of this information was inside of the people who love and care about Karrie. No one else knew this – we needed to get it written down."

Some of the most common reasons families have for developing plans are:

- To have a place where it is all written down - the "just in case" plan
- To help others get to know the person better - it is used by people providing support.
- To help with a life transition - from school to work, or from their family's home to their own home, etc.

- To figure out what is important to the person and what types of support make sense, then use the information to create supports and recruit providers of services.

Gathering information

After thinking through what they hope to accomplish, families start stage two, information

When Bonnie started gathering information for Karrie's plan she says, "At first I was overwhelmed, how am I ever going to be able to do this? Then I realized, just a little bit at a time."

gathering. The first person to gather information from is their family member. Families learn how to ask questions without built in answers and questions that don't lead the person. The second part of information gathering is "learning from others." Families learn not only who to talk to but who to listen to. They listen to (and record) the answers to questions like what do you like the most\admire the most about their family member. Some of the people families talk to include: family members themselves, extended family and friends, others who know and care about the person, and people who have been paid to support the person. People have collected information in many ways, including phone conversations, e-mail messages, face-to-face interviews, and having information gathering parties.

For Missy, her parents, Jean and Don and her sister Donna, gathering information was fun and easy. While Jean and Don wrote down most of the day-to-day routine and ritual information, Donna and Missy sent e-mail messages to their two brothers in Hong Kong and Taiwan. To the question "if you could do anything at all to help Missy have a great day, what would you do, and what would she do?" By e-mail, Dave responded "If you had Kenny Rogers giving a concert in Missy's backyard she wouldn't want to interrupt her daily routine for it". Missy's 8-year-old nephew contributed to her plan when he said, "the best thing we could do is ask Missy." What Missy's brother and nephew talked about contributed to "What people need to do to support Missy." This part of Missy's plan lets people know that Missy is a very organized person. She doesn't like surprises in her schedule. One routine Missy counts on each morning is talking through what she is going to do during the day. Missy's family knew that; now they have shared it with the people who support her in her new home with her friend Ruthann.

Writing a first plan

Although the seminar walks the families through the process, most of the writing is done at home. Families write at their own pace, using all of the source information they have gathered. They organize the information into three primary sections:

- What do others like and admire about the person
- What is important to the person
- What others need to know or do to support the person (which includes what is important for the person such as issues related to health and safety and things that the person isn't paying attention to that are still important - such as "looking cute" for Katherine)

In the manual, families are given a blank plan format, which they can use to hand-write their plan. For families who are interested in writing their plan on a computer, a template is provided at the seminar. The template was developed in Microsoft Word, and it is an easy way to create a plan that can later be updated and changed as needed. Linda used the template for Logan's plan so that more people could contribute to his plan. Linda writes questions on the plan for his first grade teacher and/or day care staff to answer.

What is important to Logan-Most Important	<i>Tell us more - write your answers to these questions</i>
<ul style="list-style-type: none"> ▪ Having Independence and Responsibilities ▪ Likes to sing in worship services ▪ Likes to have little jobs at Bible class and school ▪ Likes to ride the school bus ▪ Likes to greet everyone at church ▪ Likes to help around the house 	<p><i>What responsibilities could/does Logan have at school?</i></p> <p><i>What are the things he is proud of that he can do on his own?</i></p>

Implementation: using the plan and ongoing learning

When families have developed a plan that is good enough to get things started, it is critical that they continue to work on the plan. Plans that are used must change with the person. As the person changes, as learning occurs, and as people's understanding of the person grows, each plan needs to reflect the new information and any changes to the existing information. The manual describes a number of ways to record new learning and keep the plan up to date.

Shelley has updated Katherine's plan over a dozen times in three years she has been using the it. One of the ways that she continues to gather information is to have the communication section of the plan travel with Katherine, in the back-pack on her wheel chair. When those who support Katherine see her telling us something new with her behavior they write it down.

Family Mentors

A family mentor helps other families develop plans with their family members. They help people learn and understand. They guide, connect and encourage. While they need to be knowledgeable and enthusiastic about developing plans, mentors are

not responsible for developing the plan and do not direct its development.

Being a mentor requires being

Bonnie found that "Writing a plan with the help of other families really improves your confidence. I don't think a lot of families would go through with this if they didn't have other family members encouraging them."

comfortable in a role of helping and encouraging rather than doing or directing. A mentor also needs to be comfortable with what they do not know and able to help people connect with those who do know. We are finding that it is easier for families to fill this role than it is for professionals.

A family mentor not only helps families develop plans but also helps them in keeping the plans alive. Mentors discuss the on-going support that the family thinks they may need and how that support can be obtained. Bonnie has decided to continue as the facilitator of Karrie's plan, using it for updates and reviews. Missy's family felt it made more sense for her service coordinator to continue updating the plan. The service coordinator was able to use Missy's plan to negotiate with her service provider to decrease the number of days she pays for day-time support. This money is then used by Missy to purchase other supports.

Being a family mentor is not for everyone. It not only requires the characteristics listed but it takes time and energy. Those who would like to be mentors first have to work on the plan with their family member long enough for it to be

Kathy, who is a family mentor in Missouri, says she loves supporting other families to learn about their sons and daughters and then seeing it make a positive impact on their lives. As she has helped families with the planning process she has seen the "light bulbs" go on for many families who have been struggling to figure out how to better support their children.

considered a good plan. Then they have the opportunity to spend time learning how to conduct the seminar, how to review the plans the others write, and learn some exercises that can help with things like building connections or finding a new place to live. This learning can be spread out so that it fits with busy schedules but it does take time. While they are learning we encourage them to start mentoring one family at a time and get support while doing it. We are also seeing if mentors can be paid for their time and/or their expenses by the states. Under some Medicaid waivers, paying one family to help another with planning appears possible.

Some mentors just want to help one family at a time while others are interested in working with larger numbers. Some are only interested in helping with the planning and others are interested in helping with implementation and advocacy. Once mentors have demonstrated the basic skills of supporting other families with planning whatever role they want is one that we will support. But this is still new for us and we have a great deal of learning left to do in learning how to recruit and support family mentors.

Missy's sister Donna pointed out that from her perspective as a sister and a daughter, it was very helpful "watching my parents go through the details step by step. It was the process that helped them accept the whole idea of Missy living on her own. Having the mentor (available) made us feel very comfortable talking about sensitive and private topics. My parents didn't get that feeling before." Many family members report that when talking about something different from what was already present, conversations with professionals always seemed to focus on the many things that could go wrong, as if nothing could be done to prevent risks. As a result, many families have been reluctant to try anything out of the ordinary. Missy's family, with the support of a mentor found that Families Planning Together "helped us plan for the details that would minimize the risks for Missy. When we knew how to pay attention to the details, we were all much more comfortable with planning around the idea of Missy living in her own place with a friend. Even as quickly as it all occurred, we felt better prepared."

Creating positive pressure for change

We want self-determination to be available for everyone. Making that happen not only requires that people have control over their resources but also knowledge. They need to know whether what is being offered will address what is important to them. They need to know what has been done in other places, not just what is on the local menu. This knowledge creates positive pressure for change. It is another piece of what is required for the system to change. Often, families have great ideas about how supports can be arranged, but the system resists the changes needed to make it happen. By putting these ideas into a plan, families can apply that pressure. Tracy, a service coordinator said, "Families are the best advocates for their family member; staff or professionals may overlook important details in what is important to someone or how best to support someone...families make sure the details are there." Ten families (or self-advocates), armed with the knowledge and confidence that comes from developing their own plans, are more effective than 100 support coordinators in advocating for change.

While we have been describing how families can learn to plan we want to emphasize that the same process works for many self-advocates. Where people can develop their own plans they should be supported in doing so. We are working on making this easier and more available, however, it is beyond the scope of this article. When you listen to the stories that families tell the importance of our current efforts are clear. Their stories are more powerful than anything that we could say. What follows are just a few of the many stories that we have heard.

Levi and Carol

After developing Levi's plan, Carol says, "...I always noticed that if I talked or wrote about a problem Levi was having, I found ways to solve the problem without too much help from anyone else. As I was gathering information and writing his plan it helped me focus on what the problem was, what caused it and how to go about making things better for Levi."

Brittany and Elaine

Elaine developed an Essential Lifestyle Plan with her daughter Brittany about three years ago. This year, Brittany started high school and her teacher has been very interested in making sure all students get to know Brittany. Since Brittany doesn't use words to communicate, her teacher uses her plan as a way to help others get to know her. Her teacher has shared Brittany's ELP with Brittany's friends, especially, her likes/dislikes, her dreams and her communication chart. Some really neat things have happened. For instance, one day, Brittany had nine freshman boys lined up along the hall serenading her before lunch. It was all because they found out her favorite groups were N'Sync and Back Street Boys. Brittany's teacher is also helping her do things that are important to her and to realize some of her dreams which are listed in Brittany's plan. For example:

- She wanted to join a club and help others....Brittany belongs to the FCLA (Future Consumer Leaders of America) at the school. She pays her dues. This club sponsors the school blood drive.
- Brittany wanted to help out with the breakfast bar at school.... She is the high school Breakfast Club Hostess in the morning.
- She wanted to develop her own line of purses....She has created a purse in her Family and Consumer Sciences class.
- Brittany wants to be a model...her teacher is producing a Breakfast Bar commercial and Brittany will star in it.

Elaine says, "Brittany is giving the best smiles in the world these days when she comes home from school."

Katherine and Shelley

Although Katherine had a person-centered plan since she was sixteen, it was really a plan that reflected what her dad and I wanted for her, not what she wanted, because, after all, she was a person with "the most significant support needs." She could not tell us what she wanted and we had accepted her fate of having to settle for less than most other people would want and expect in their lives.

Because Katherine and her Dad and I had some experience in planning, she was asked to volunteer to help some professional staff from our local service agency learn a newer way of planning, Essential Lifestyle Planning. Katherine and I went to the training where Katherine was the focus person for development of a plan by a facilitator/trainer named Michael Smull.

At the end of the two-day training, Katherine left the building her same self and having had a wonderful time. I left the building with a load of chart papers and a brain transplant. I stared at Katherine for at least two days, and kept apologizing to her for years of not listening to her. Encouraged by my husband to "get a grip" on myself, I entered all we had learned into an Essential Lifestyle Planning format on my computer, still amazed to see such new truths as "Katherine is a teacher...a food critic...a zen master...and, characteristics of people who should support her".

Having structured this information into a document that could be easily understood by professional staff, Katherine, her dad, and I took it forward to the agency supporting her. And her life changed.

That was 1998. Based on what we learned, and continue to learn, Katherine participates in hiring the people who support her. Her days are spent doing more of the things she enjoys doing as an adult. And one of the most powerful outcomes of listening to her is that we are supporting Katherine to develop her career as a teacher/trainer. She's taught workshops in Texas, in Florida, and later this year in Arkansas. She's taught teachers, support staff, and service coordinators. She's taught them how to listen to behaviors as communication, and she's taught them how to think differently about people they support. She's teaching person-centered thinking. She's changing systems.

Although her trainings allow Katherine to be Katherine, to do the things she likes to do, and to interact with different people at each training site, she is developing new skills. She's learning to press the button on the computer to change the presentation slides. Her co-trainer (whom she helped hire) says, "When I look at Katherine presenting her communication training, I see a person happy at work."

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Or

Go to www.allenshea.com, click on M. Smull and friends and look for the message to families, the Families Planning Together Manual and example plans.

Or

In Pennsylvania call 1-800-459-1838 and ask for Bonnie Miller

In Missouri (to be supplied by Amanda George)

For help in other parts of the country call 1-800-828-7839 and ask for Shelley Dumas