## **Family Support Best Practices**

- Best Practices Checklist
- What is Family Support?
- The 10 Commandments of Community Advocacy
- Important Information Concerning Case Coordination
- The State of Case Coordination Today
- Independent Service Coordination: The Past, Present and Future in Illinois

## **Best Practices Checklist**

- Focus on the entire family
- Change as a family's needs, roles, and ages change
- Encourage families to express their own needs and decide how their needs will be met
- Provide families and individuals with control of their dollars
- Treat people with disabilities and their families with dignity by respecting their individual choices and preferences
- Respect cultural, economic, social, and spiritual differences
- Encourage families to use the natural community resources
- Provide supports and services that are easy to find and easy to use
- Provide families with equal access regardless of where they live

## What is Family Support?

Doing whatever it takes for families that include a member with a disability to just be families.

**Family Driven**: Each family leads the decision-making process concerning the type and amount of support they receive;

**Easy To Use**: Families are not overwhelmed by paperwork and red tape; and **Flexible**: Families can choose supports and services based on their individual needs and preferences.

## THE MAIN GOALS OF FAMILY SUPPORT

- To keep families together until the person with a disability chooses to live independently;
- To enhance a family's ability to meet the many needs of their family member with a disability;
- To improve the quality of supports to families while minimizing the need and the cost of out-orhome placement;
- To allow the family to participate in integrated leisure, recreational, and social activities; and

• To make a positive difference in the life of the person with a disability as well as the lives of all family members.

*"Families must be at the center of the decision-making process" —Human Services Research Institute, June 1991* 

## **Quality Family Support Programs**

- Focus on the entire family;
- Change as the family's needs roles, and ages change;
- Encourage families to express their own needs and decide how their needs will be met;
- Treat people with disabilities and their families with dignity by respecting their individuals choices and preferences;
- Respect cultural, economic, social, and spiritual differences;
- Encourage families to use the natural community resources; and
- Provide supports and services that are easy to find and easy to use.

#### **Potential Family Supports**

Centered around the Person with Disabilities

- diagnosis and assessment
- therapeutic services
- medical/dental services
- home health care
- recreational opportunity
- special clothing and diets
- transportation
- adaptive equipment
- housing adaptations
- adequate health insurance

## Centered Around Family Members

- information and referral
- service coordination
- temporary relief/respite
- family counseling

- parent/sibling education
- day or child care
- financial assistance
- future financial planning
- mutual support groups
- housing modifications

## **Ask Yourself These Questions**

- How are you treated by your family support program? Do you feel welcome and heard
- How much control do you have over the supports you receive?
- How is information exchanged between you and the program? Do you get the information that you need, and are program staff asking the right questions?
- What actions are taken to plan for the supports you receive? Is planning a partnership process?
- Do the supports you receive suit your needs? Do supports change with your changing needs?
- Is the program having a positive impact on your life? How would you judge the results?

# **ISSUES THAT CONFRONT FAMILIES**

- Financial problems
- Marital stress
- Missed opportunities
- Fragmented services
- Confusing and contradictory
- Information
- Exclusion from decision-making
- Stigma
- Isolation
- Uncertainty

## **Natural Supports**

- Neighbors
- Extended family
- Friends
- Religious organizations
- Schools
- Community

## The 10 Commandments of Community Advocacy OR Getting Out of Systems and Into Your Community

by Kathie Snow, Parent\*

1. LOOK FOR NATURAL SUPPORTS. Before you go to a service provider for help, try to find what you need from the natural supports that exist in your community. Ask old friends, new friends, schools,

churches, scouts, park and recreation, community clubs, service organizations and any other "typical" community resource. Use the same opportunities you would use if disability wasn't involved.

2. BE SPECIFIC AND FLEXIBLE. You know what you want and need. Be bold and tell folks exactly what it is. At the same time, be willing to compromise for the best possible solution for all.

3. EXPECT INCLUSION. Attitude is EVERYTHING! When utilizing natural supports, expect that you'll get what you want. Stop apologizing for disabilities! When someone tells you "We've never done this before", reply with your biggest smile, "Neither have I! We'll learn together!"

4. EXPERIENCE THE "DIGNITY OF RISK" Face the fear of being told "No!" More people will say "Yes!" than "No!" Sometimes we have to dig a little deeper to find those folks. They're out there! Keep looking!

5. BECOME A "REGULAR" PERSON. Join the PTA, volunteer, help plan school parties, etc. Volunteer for typical community activities; scouts, church, fundraisers, cultural events. Join community organizations. Be seen, be heard, and become known! Let others see you as "regular" not just "special". Often people who are not connected to the disability community can be your best allies.

6. DEVELOP AND NURTURE RELATIONSHIPS. Offer yourself as a "natural support" to others in your community. Help others and they'll help you. We can't be just "takers," we must also be "givers". Trade your help for someone else's. "I'll help with your yard work. Can you help me with \_\_\_\_\_?" Be creative!

7. BE PROACTIVE, NOT REACTIVE. Plan for the future, anticipate issues/problems, and think long term. Be a problem solver not a problem-maker! If you have a problem to discuss, always have possible solutions. If you don't, others' solutions might be worse than the original problem.

8. THINK WIN/WIN, NOT WIN/LOSE. No one wants to feel like they've "lost". Allow people to save face. Use strategies that allow everyone to feel they've "won". The next time you interact with them, they'll be more likely to provide the support you need.

9. REMEMBER TO USE THESE "KEYS TO SUCCESS":

- Identify & Value Your Allies
- Combine Style and Substance
- Respect and Teach Your Adversaries
- Practice Finesse and Diplomacy

10. BE PATIENT. If you're a parent, what did you know about disability issues before your child was diagnosed? We have to teach others just like we had to learn. Remember, this is all about you or your family and the future! Stay focused on what's really important. It's NOT about egos, winning/losing, who's right and who's wrong.

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