

## Appendix C

### **PINPOINTING SUCCESS: DISCOVERING STRATEGIES THAT WORK WITH FAMILIES WITH MULTIPLE CHALLENGES**

by

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## I. THE PROBLEM

Increasingly, programs serving infants, toddlers, and preschoolers with disabilities are serving children whose families are facing multiple needs beyond their child's disability. A single family may be living in poverty, involved in substance abuse, experiencing violence both in and out of the home, and may have a number of other disabilities or health problems in other family members. Some early childhood programs located in disadvantaged areas are struggling to work with larger numbers of these families. Even in programs where families with multiple needs constitute a minority of their families served, they may pose special problems and require a disproportionate amount of the agency's resources to serve them effectively.

Regardless of the exact nature of the types of needs experienced by these families, the sheer fact of the *multiplicity* of needs creates a set of common characteristics. These may include a tendency toward chronic or recurrent crises in the family; learned helplessness; support systems that are either nonexistent or characterized by violence and negative messages toward family members; involvement with a number of health, education, law enforcement, and social service agencies; and – perhaps as a result of that involvement – distrust of any providers offering help. All of these characteristics pose a number of challenges to early intervention programs with a strong family-centered program philosophy. The primary question to be addressed in this presentation is:

**How can family-centered best practice principles in early intervention be applied to meet the needs of families with multiple challenges in early intervention and early childhood special education programs?**

## II. OUR PROGRAMS

This presentation will describe a process developed through Project IDEEA, an In-service Training Program at the Institute for Human Development at UMKC, to help service coordinators focusing on families with multiple needs to identify best practices as they worked with their families. Two projects in Kansas City, Missouri, were involved. These were:

**Team for Infants Endangered by Substance abuse (TIES) Program:** A demonstration project coordinated through Children's Mercy Hospital in Kansas City, to provide intensive services to pregnant and parenting drug-using women and their families. Its primary purposes are to nurture optimal child development, maintain the child in the home, and get the parent into drug abuse treatment programs. Families may be involved up to three years in the program, and service coordinators carry about ten families on their caseloads at a time.

**Family Preservation Services, The Children's Place:** Family Preservation (FPS) is a part of The Children's Place, which provides preschool and early intervention services, in-home interventions, therapy, and family support to families of children with severe emotional disturbances. The FPS program provides services to families referred from the Missouri Division of Family Services as at risk for or having substantiated reports of child abuse or neglect. The program provides family support and in-home parent skills training. Families

may be involved for six weeks in this short term training program, with service coordinators carrying only two families on their caseload at a time.

### *III. OUR RESEARCH: CRITICAL THINKING*

This study was a qualitative inquiry into the processes used by service coordinators in the two programs with their families. The process developed was called "critical thinking" because it was intended to help the staff learn from their own experiences and strengthen the natural process of informal debriefing. It provides a method for staff to analyze and organize the information exchanged in a more systematic way. Staff of the two programs were convened as "focus groups," and asked to provide examples and stories of families and situations illustrating a specific question or "puzzle" about strategies that had the most impact in those situations. Staff of the two programs were convened separately. The first sessions with each program considered the following questions which the staff had previously agreed presented issues or puzzles to them:

How do you establish rapport or trust with your families?

What breakthroughs or catalysts occur for those families that may be used to lead to positive change?

What are indicators or strategies to assess risk (i.e., potential harm or threats to the safety of the child)?

How do you teach families to begin to independently solve problems, cope with life stresses, and meet their own needs?

Comments from the staff of both programs were transcribed and sorted into logical categories based on associated comments, using qualitative content analysis techniques. The categories were shared at the next staff meeting and used as "take-off points" for discussion, elaboration, and expansion, to create increasing levels of detail or ideas for practice. After each session the new comments were re-sorted into the data pool and categories revised, expanded, or deleted as indicated. This method of using the developed data to guide further data collection is an accumulative process (Stainback & Stainback, 1984), to generate emergent hypotheses (Strauss & Corbin, 1990).

Altogether, we held 11 meetings with TIES staff and FPS staff over a period of about six months. The total of 457 individual comments collected fell into two broad or overarching categories: characteristics of families served, and strategies. The following discussion describes those results.

### *IV. CHARACTERISTICS OF FAMILIES WITH MULTIPLE CHALLENGES*

By definition, families with multiple challenges are facing more than one difficulty or stressor. More specifically, families with multiple challenges are typically described in the social welfare literature as simultaneously facing internal or intrasystemic problems, and external or intersystemic

problems (Kaplan, 1986). This proved to be true of families in our Critical Thinking Project as well. The following categories were derived from the 159 family characteristic comments in the study:

### Family Strengths

- 1) Every family has some strengths or resources, and helping to identify those is empowering.
- 2) There were inner strengths reflected by sometimes inexplicable positive changes – families explained simply that they were “sick and tired of being sick and tired.”

I see them as survivors. They go through hell and back. They can do things that I think I couldn't stand. They are strong. If we were suddenly thrown into their situations - well, I would probably die. They don't see that; they don't see it as a strength.

I try to share . . . that I admire them being able to survive in all this hell. I ask, “How do you do this?” It is just amazing to me how they can get through out . . . ask them how they do it, but they can't tell you how they do it because they don't feel it is important.

- 3) Children were a source of positive identity.
- 4) Families sometimes displayed shrewd abilities to meet survival needs

### Internal Challenges or Traits

- 1) Low self-esteem
  - a) Low self-esteem is pervasive
  - b) Peers were also sometimes perceived as failures
  - c) Fear of success
  - d) Guilt

They can tell you why they are worthless. If you ask them to say one positive thing, they can't think of it. Even when you can point out several positives, they won't see them.

Somebody will be really open, and then they withdraw. I think it scares them because for the first time, they have shared their pain with another human being, or else it is the first time they have shared their pain with themselves . . . they get a little startled or scared when they say too much right off, so they withdraw, and act more socially correct.

- 2) One or more disabilities or diagnoses, including:
  - a) Drug or alcohol addiction
  - b) Chronic mental illness
  - c) Cognitive limitations or learning disabilities
  - d) Physical disabilities or chronic illnesses

- 3) Families display a lack of trust in others
  - a) Trust may wax and wane over time
  - b) They may have a long history of betrayed trust
  - c) They may be suspicious of providers

For about six months [one mother] told me that the only way I could get to her apartment was from these rickety outside stairs. And then after I got to know her, I found out that the front door to the apartment house is open.

- 4) Some families displayed a lack of ability to empathize or identify with others, including their children.
- 5) Many families displayed an extreme passivity or sense of learned helplessness.

### External Challenges

- 1) All families experienced pervasive economic disadvantages.

We spend a tremendous amount of time trying to encourage them to get different friends. I am not friends with somebody who hurts me (but) their ability to accept (being hurt by friends) is one of the things that needs to be dealt with. They truly believe they are worthless.

- 2) Families had low levels of education and other resources.
- 3) Some families had a long-term experience with racial, ethnic, or sexual discrimination and oppression.
- 4) For most families, there was violence in the home and also in the community.

- 5) Social support networks were often abusive, destructive, or nonexistent.

- 6) There tended to be multiple involvement from a variety of human service, health, and law enforcement agencies.

He is saying she is strung out on drugs, and she is saying he is abusive. They could both be right. We do know they and the kids are homeless. We need drug rehab for her and anger therapy for him. We got this case because of educational neglect, but they have so many other things going on.

### Chronic and Pervasive Sense of Crisis

- 1) Families tended to experience crises that seemed to occur more often, and were more catastrophic, than typical families.

They live in crisis every minute of the day.  
They get scared when they don't have a crisis.

- 2) This continual state of crisis might be explained by:
- a) Crises may actually feel more "normal" to them.
  - b) Crises may satisfy a need for intensity in an otherwise boring life.

- c) Crises may be "convenient" distractions from deeper and more painful problems.
- d) The simple lack of resources and problem-solving skills means less "margin" to cope with unexpected situations.
- e) Some families may deliberately trigger crises to stay in the program.

They don't know anybody that doesn't have to have help with their electric bill.

## V. FAMILY-CENTERED INTERVENTION STRATEGIES

Given these characteristics, it is readily apparent that these families may require special consideration in any early intervention program. In the Critical Thinking study, the 298 comments coded as program strategies fell into 48 categories. For purposes of this presentation, these categories were compared and re-sorted into six commonly accepted best practice principles or indicators of family-centeredness in early intervention (Dunst, Trivette, & Deal, 1988; Shelton, Jeppson, & Johnson, 1989; Turnbull & Summers, 1987). Following is a general discussion of the primary implications of successful strategies for family-centered early intervention principles:

### Principle #1: All Families Have Strengths

Family centered early intervention programs primarily take a "strengths-based" orientation toward families. That is, families have strengths and resources to contribute toward the support and development of their child. It is the responsibility of early intervention programs to "empower" families by utilizing those resources in the design of interventions, so that families make a positive contribution toward their child's needs, and so that as much as possible, the sources of support for the family are natural (as opposed to paid or program-developed).

Sometimes if they want to buy me a pop, I let them. One woman said, "I want to feel equal to you because you are always giving to me."

In the case of families with multiple challenges, strengths may be less apparent, but are still there. More importantly, they may not be recognized by a family characterized by extreme low self-esteem and learned helplessness. Therefore, interventions to implement a strengths-based approach to these families include strategies intended to build the

With one family I have now, she is starting to praise her children, and telling them how much she loves them. I have been pointing out to her how much these things she was doing are helping the children.

family's recognition of their own strengths as well as the motivation to take action with those strengths. Specific strategies include:

Provide concrete resources to overcome immediate barriers

Encourage and empower

- Recognize and reward each step as positive
- Accept families without judgment
- Don't jump to conclusions
- Point out positives
- Provide opportunities for them to make comparisons
- Provide opportunities for them to make contributions
- Provide encouragement

Provide consistent program policies

Build positive social networks

- Encourage establishing healthy connections
- Work with significant others and extended family

When they get their housing, we often see lots of progress with the drug treatment and all, because they have something now, and they don't want to mess up.

## Principle #2: The Family is the Ultimate Decision Maker

Again, this principle is a primary cornerstone of family-centered programs. It espouses the philosophy that "a need is not a need unless it is recognized by the family." In the case of families with multiple challenges, however, concerns may be raised about this principle in the case of abuse or neglect. In these cases, sometimes parallel goals must be negotiated with the family, in which the program will agree to help the family with family-identified needs in exchange for the family's agreement to also work on goals to enhance child protection and safety.

One woman and her husband need marital counseling, and they didn't get it . . . Why go to a Saturday group on drugs when what they wanted was marital counseling? They need to get the things the person perceives as the problem more than the drug treatment. This may be because they are in denial, but we need to start where they want to be.

Further, for families with learned helplessness, the problem, as in the first principle, is one of providing families with both the motivation and the skills to become decision makers. Essentially, the process involves teaching the family to recognize their ability to influence their environment. To do that, it is necessary to first help them to influence their environment and then to help them recognize the influence they have had. The goal is to build in them over time a sense of trust in their ability to identify their own needs. Specific strategies for shaping the family as the ultimate decision maker for families with multiple challenges include:

In the beginning, I try to let them know they have options. I say, "Have you thought about this?" and talk about people they can call to get services. That's just giving them some information and help to take their own initiative.

#### Use motivational strategies

- Provide concrete services contingent on efforts
- Set deadlines
- Help families see a positive value to their efforts
- Find some "spark" or activity that interests them
- Allow families to experience consequences of their decisions
- Motivate families for love of their children

I talk about keeping life simple by doing things ahead of time. Utility bills cause crisis every month. I talk about, "OK, now this bill was this much. What can you do to bring your bill down?" I go into the house and see all the lights on and the heat full blast. With one it was a matter of teaching her to turn off lights. She never thought of conservation.

#### Shape appropriate problem solving

- Don't immediately give answers; help families think through the problem
- Teach planning ahead
- Provide resources families can use on their own

### Principle #3: Every Family is Unique

Family centered early intervention views families as infinitely diverse, differing in size, structure, resources, and cultural background. The implications for this principle are that family support services must be individualized with a wide variety of options as well as formats for delivery of those options, for information, education, and other support services. A further implication is that formal assessment methods are seldom effective in identifying the unique concerns, priorities, and resources of a family.

One mother . . . had to choose between utilities and the phone. . . She chose to keep the phone. Now the next crisis will be they cut her water off, and I am going to say, "You made that choice."

For one of my clients, the thing is, it was a whole composite of her life coming together at that time. It was just the conversion of the section 8 housing, those months in treatment, and her starting a job. Now when we talk, it is all about, "I have so much, I can't afford to use because I will lose everything."

For families with multiple challenges, the principle of uniqueness is doubly true. Complicating factors with these families may also include the presence of a range of other agencies in addition to the early childhood program; therefore, the numbers and players on the interagency and multidisciplinary team will vary even more widely. Further, the need for nonstandard approaches to assessment is even more important because of the extreme distrust

often displayed by these families and their consequent reluctance to fill out "paperwork." Other implications of this principle for serving families with multiple challenges are:

- ★ programs should expect to commit to longer term involvement, but be capable of fluctuating the intensity of that involvement over time
- ★ programs should also have a tolerance for individual staff differences, and attempt to match staff strengths with particular needs of families

They are passive because everything they tried to do never worked out. So you come in and you say, "Let's work on it," and "You can do it." We have a lot of successes with people when we are able to get subsidized housing. If they let you in the housing and you have been working with them, then all of a sudden they will say they want to get into the clinic. That's a big success.

- ★ interagency actions should be "timed" to converge at a time when it possible for the family to maximize the use of all services provided across the agencies

#### Principle #4: Program Should be Sensitive to Families' Emotional Needs

Early intervention programs sometimes underestimate the degree to which ALL families of children with disabilities look to professionals as a source of emotional support as they adjust to their young child's disability. Sensitivity, respect, and a validation of parents' emotions should be a pervasive part of these programs. Further, professionals need to recognize that, at times, simply providing an empathetic ear to let them "vent" is all the "intervention" they may want. Because of the importance of emotional sensitivity, the way programs are planned and carried out is as important as *what* is provided. In other words, *the process is the product*.

I went out with a mother every day, and we watched *Young and Restless* together. We didn't do anything until, finally, she started liking me. She was one of those who thought everybody was intruding in her life, and everybody's trying to take her baby. I just hung out and was her support, listening to her feelings and problems.

In a support group, they can empathize, but they don't want to be like those other women. But they do want to be more like us. We can be role models, and they will be motivated by us. We are something they can aspire to.

This maxim is doubly true for families with multiple challenges. However, providing that support may be more difficult to do because many of these families come armored in a tough shell of suspicion built over many years of perceived wrongs and/or lack of usefulness of the "system." Beyond negative experiences with the system, many of these parents may have experiences dating to their childhood of abuse, abandonment, and general neglect. As a result, they may have difficulty believing that *anyone* could possibly have good intentions toward them. Once this barrier is penetrated, however, the program staff is in a position to become a positive role

model and friend to the parent. As that point, a number of positive changes can be made. However, it is important for early childhood specialists to recognize that they are not trained clinical psychologists or clinical social workers; there is a need to recognize that one is listening as an untrained "friend," whose support can make it possible for the parent to get into counseling when he or she is ready to work on some deep-seated emotional problems. Some specific emotionally sensitive practices for early interventionists are:

Be consistent and persistent in establishing trust

- Be willing to come back many times
- Start where the family is and don't push too fast
- Be willing to pass "tests"

There is some response when their living environment changes, or when you are the last person left for them. They burn their relationships with everybody, family and friends, and when those are all gone, they know we will be there.

Be open and honest about real issues

I went over some things she could do, and point to other things she just can't do anything about. I kind of discussed how I deal with stuff. And she was looking at me like, "YOU have problems?" And I say, "Yes, and here's how I handle them."

### Principle #5: All Family Members are Equally Important

There is perhaps no other principle more central to the idea of family-centered early childhood programs, than the concept that the whole family must be served in order to meet the needs of the child. It has been widely recognized that encouraging a child to climb the developmental ladder does no good if the family holding that ladder falls apart. This typically means providing services, supports, and opportunities for decision making for all family members, not just the mother-child dyad.

I can pinpoint one time when a lightbulb just came on in my head while I was driving in the car. I had been beating myself up about trying so hard to get these families to do things, like bathe the children, getting them to take the kids to the clinic, and so forth. But finally one day I just realized - you know, you can't make these families do anything they don't want to do. And ever since then, this job has been a whole lot easier.

For families with multiple needs, this maxim is entirely applicable. Many parents may have experienced other social service programs as having interests *only* in their children. For many single

Sometimes it's hard to make them understand we're interested in them and not just in their baby. But once they get it, it's a big breakthrough.

parent families, a wide web of supports, extended family, and significant others may be difficult to discern at first, but need to be included as much as possible as more information about them unfolds. Strategies for implementing a whole-family orientation are:

Recognize the sometimes competing needs of different family members

- Provide support for a variety of needs
- Make sure the parent knows you are not just interested in her because of her baby

I lost a family because the guy never could understand what my role was. He thought it was checking on abuse. He hid around in the bedroom on the first visit . . . He came out on one my visits and handed me the baby and said, "Here, do you want to check it?" She became very elusive. She just basically dropped out of sight.

Recognize the interconnection of needs of family members, especially the parent and child

Interact with all members of the family – develop accommodations to the real life of the family – don't expect mother to change her life circumstances and her social surroundings

### Principle #6: Families are Constantly Changing

All families are constantly changing. Especially during the early childhood years, there is a need for programs to be flexible and responsive to rapidly changing needs of the child and family. In the case of families with multiple needs, the sense of changing needs is enhanced by the tendency for families to experience chronic or recurrent crises. In these cases, change is often too much – that is, the urgent need to attend to the crisis "*du jour*" impedes the ability to address longer-term goals that could help prevent future crises. It is, therefore, important not only to help families respond to crises, but also to help them keep sight of longer-term goals and to develop problem-solving skills that may prevent future challenges.

Relapse is a part of recovery, you know. With one family, I am waiting for the crash. We are sophisticated enough now to know there will be a crash.

You think on you way to somewhere, that you have something in mind, just in case her life is calm at the moment. When I get there, I sort of survey the situation and see where she is.