

## In-Depth Interview Protocol

- Thanks for coming, we appreciate your taking the time to talk with us again. My name is..... (introduce observer and role of observer)
- I want to remind you a bit about the project and what our goal is by talking to you today. The University of Southern Maine is holding focus groups and individual interviews in Maine and Connecticut because we want to hear directly from parents about their experiences having a child with special needs or chronic illnesses. We felt that the experiences you talked about during the focus group reflected those of many parents. We are now using these one-on-one interviews to build on the information we have already collected in the focus groups.
- (Confidentiality) Our goal is to help families with special needs by telling people who make the policies and programs about families' experiences. While we want to listen to and tell others about your experiences, I want to assure you that your identity and all information you give us is strictly confidential. We will not be reporting your name or any of your families' names, to anyone. We will not attach your name to any comments you make and will change identifying details if we use your information in any report.
- Tape recording: So that I can focus on our discussion, I will be tape recording the interview. Is that okay with you (if not, observer will need to take lots of notes!).
- Reports: The University of Southern Maine will be writing a report describing our findings, and in which we'll be making recommendations about changes. You indicated on the focus group registration form that you would like to receive a copy, (remind people it will take @ a year for the report to come out!)
- Do you have any questions about the project, or about what I've told you so far? (answer interviewees questions?)

I'm going to ask you questions now about your experiences caring for your child with special needs.

I'll also be asking about your life in general, and about your experiences with services for your special needs child.

We'll also talk about employment and child care regarding your special needs child, as well as how having a child with special needs affects your family, and how it affects you as a parent/caregiver.

**1. (Ask Only if interviewee has attended a focus group): Is there anything that has changed about your work or child care situation since we talked in the focus group?**

**2. We'd like to better understand the typical day and typical week in the life of you and your family. We'll start by having you describe and discuss a typical day. Please describe a typical day during the school year (we'll ask about summer and school vacations later.) Start from when you wake in the morning and end with when you go to sleep at night. *(Have caregiver describe schedule and tasks beginning with waking in the morning through to when caregiver goes to sleep, including hours and approximate amount of time spent on tasks, modes of transportation, and assistance she/he receives from others.)***

Probes:

- Do you have a car, or use public transportation, cabs, transportation help from friends/family, etc. (how does parent get to work, child to services?)
- How hard is it for you to stick to your schedule?
- Does your schedule change during the summer months and school vacations?

**3. Thanks for that description. Could you continue telling me about your experiences by describing a typical week in the life of you and your family?**

Probes:

- Are some days busier than others?
- What differences are there between weekends and weekdays?
- Are some weeks harder than others during the year?

**4. We're interested in hearing about services (e.g., OT, PT, speech therapy, counseling, medical care, etc.) your child receives. Could you tell me what kind of services your child receives for their special need?**

Probes:

- How did you obtain these services for your child? (listen for degree to which parent must advocate for access, whether they have to "fight the system", keep going back, keep calling, and otherwise "bugging" them til they get served, whether they enlist the help of others and whether there were others who may have been a special ally in securing services, waiting lists, etc.)
- How satisfied are you with the services your child receives in terms of how well they serve your child and how they serve you as a parent/guardian (listen for issues related to care worker turnover, quality of service, etc.)?
- Do you have a regular doctor for your child with special needs?
- Where do you receive these services (site of service(s) – do you have to take your child to various sites or does she/he receive all services at one site)?

- Are there services that you would like your child to receive that they don't receive currently? (listen for accessibility, barriers)

**5. We're interested in hearing about your use of child care (care provided by family member or neighbor, home-based, day care day care center, nursery school, pre-school, Head Start, etc.). Do you currently use child care for your special needs child? Could you tell me what kind of child care your child with special needs receives?**

Probes:

- How did you obtain this child care for your child? (listen for degree to which parent must advocate for access, whether they have to "fight the system", keep going back, keep calling, and otherwise "bugging" them til they get served, whether they enlist the help of others and whether there were others who may have been a special ally in securing child care, length of waiting lists, etc.)
- How satisfied are you with the child care your child receives in terms of how well they serve your child and how they serve you as a parent/guardian (hours, schedule, flexibility, etc.)?
- Are there child care needs that you would like your child to receive that they don't receive currently? (listen for accessibility, barriers)

**6. Thanks for telling me about that. I'd like now to talk about work and how it relates to your special needs child. In what ways does having a special needs child affect your employment?**

Probes:

- Can you talk a little about making ends meet since you had your child?
- Did you work before you had your child with special needs?
- Do you work now?
  - If not, if you had good quality care for your child, would you work?
  - If yes, what kind(s) of job(s) (occupational type)?
  - Have you had to work fewer/more hours?
  - Have you had to take a different (perhaps more flexible job but at lower pay)?
  - Does your employer allow you some flexibility in work schedule in order to get your child to services, etc.?
- Does your spouse/partner work?
  - Has spouse/other parent had to take a diff. kind of job, or a second job?
  - Does he/she have flexibility in work schedule?
- What are some ways you have developed to help you balance care giving and work?
- Have you ever left or lost a job because you couldn't balance taking care of your child and work?
- Have they ever applied for or received cash assistance?

- If so, have you been affected by the work requirements for cash assistance? Tell us about your experiences with that...

## **7. Who else helps you with your child with special needs (informal help)?**

### Probes:

- What is the relationship of each helper to you and your child with special needs (for example, spouse/ partner, other parent (custodial or non-custodial), other children, parents, siblings, friends, neighbors)
- What kind of help to they provide (direct care to child with special needs, direct care to other children, house cleaning, transportation, financial, emotional support, etc.)?
- How much help from (ask interviewee to estimate how much each of your helpers helps – for example, every day, a couple hours a day, a few times a week, once and a while, only in emergencies):
- Are you comfortable when they are caring for your child with special needs?

## **8. Now I'd like to ask you to talk about the effect of having a child with special needs on you and your family. How has having a child with special needs changed your life?**

### Probes:

- What are the challenges of having a child with special needs?
- What are the rewards of having a special needs child?
- How does having a child with special needs affect your other children?
- How does having a child with special needs affect your and your spouse/partner's relationship?
- How does having a child with special needs affect your family as a whole?
- How has having a child with special needs affected your relationship with your extended family?

## **9. What are your hopes for the future?**

### Probes:

- What do you hope for your child?
- What do you hope for yourself?
- What would you need so you could achieve these goals?

## **10. Is there any thing else you want to tell us?**

### Themes to be covered:

- **Work/Care giving/ time management** – employment of primary caregiver parent; impact of child with special needs on employment; strategies for balancing work and care giving; work history before and after; employment of other adults in household; employer flexibility; part-time/full-time; job turnover and job loss; the taking of a second job by other parent, etc.
- **Financial Well-Being/Strategies for Making Ends Meet** – impact of child with special needs on family financial well-being and security; income and financial well-being (self earnings, earnings from other household members, TANF, SSI, Food Stamps, Medicaid, CHIP or other health insurance programs, community pantries and soup kitchens, financial and/or in-kind assistance from family or friends, unreported work, etc.) before and after arrival of child with special needs;
- **Social network/support** – how much help from partners/spouses, family, friends, other children, teenage children, neighbors, non-custodial parent of child; what kind of help (direct care to children, household help, financial, emotional support, etc.); reliability of assistance and issues of trust.
- **Access to and satisfaction with services and care arrangements** – knowledge of available services; use of services; degree to which parent must advocate for access; quality of these services, degree of meeting child's needs, degree to which they meet parent's time management needs; any allies who have help parent advocate on behalf of his/herself and child.
- **Impact of special needs child** - on caregiver-parent(s), other children, family as a whole, the caregiver-parent's relationship to partner, etc.; what are the challenges of having a special needs child; stress (emotional, physical, mental); what are the rewards of having a special needs child
- **Aspirations/expectations** – the expected future of special need's child. the expected future of the caregiver-parent; hopes and wishes.