Family Perceptions of Transitions in Early Intervention

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Abstract: This article explores three broad themes about transitions that have emerged in a naturalistic study of experiences of families with young children with disabilities. Generalizations regarding early transitions include families going through a birth crisis have difficulty understanding all the information they are provided. Not only is their role unclear (“Should I stay with the mother or follow the baby?”), familiarity with medical technology is typically limited. In a crisis state the mind may take in nothing more once it accepts the concept of an extremely critical or life threatening condition. In addition, mothers who have had emergency Cesarean sections are struggling through pain medication and their own trauma. Secondly, parents may not feel comfortable assessing their abilities to care for their children as they transition from the hospital to home. Finally, the transition from home-based early intervention to center-based preschool can cause anxiety for parents. An IEP meeting may be the first introduction into the world of special education. Formality of public schooling involves new learning such as definitions, categories, and placement decisions.

Transition is the process of change in service delivery systems and life circumstances. Numerous authors have discussed factors that support successful transitions for families with young children with disabilities (Rosenkoetter, Hains, & Fowler, 1994; Trivette, Dunst, Boyd, & Hamby, 1996; Wolery, 1993). However, empirical research recording parents’ perceptions of the transition process is limited and largely composed of survey data (Hanline, 1988). The present research was undertaken to explore families’ experiences and perceptions of transitions that take place during the early childhood years.

This research examined family perceptions of three major early intervention (EI) transitions. The first transition was during the birth crisis and involved transporting the baby to a neonatal intensive care unit (NICU). The second transition was from the NICU to home, and the third involved the movement from EI to preschool. In addition, results of this research indicate that other types of transitions are frequent in the lives of families with infants and young children with disabilities.

Common methods for ascertaining the impact of service delivery on families use instruments to quantify such factors as social and resource supports, stress, needs, and program quality. These techniques provide narrow sets of data that are typically collected only once. This may leave the impression that states of being and perception are a constant and stable construct for measurement. A more accurate research assumption is that no situations or emotional states are constant for families. Families with young children with disabilities tend to go through many changes and transitions during the first few years of their children’s lives. The coping strategies they adopt may have significant impact on the intensity, duration, variety, placement, and quality of the special services their children receive. For example, parents who do not accept their child’s disability may delay accessing EI services (Haring & Lovett, 1995).

The very nature of a disability that can be identified at birth, or shortly thereafter, necessitates frequent and various contacts between family members and professionals from multiple disciplines. Changes in the types of services received and changes in the individuals...
providing those services are stressful to families (Johnson, Chandler, Kerns, & Fowler, 1986; Rosenkoetter et al., 1994; Turnbull & Turnbull, 2001; Winton & Bailey, 1988). Families of infants with disabilities seek security and stability but the nature of transition is change, and thus is inherently stressful (Haring & Lovett, 1995). This article describes transitions that families underwent during the early years of their children’s lives and provides suggestions for assisting families during transition.

Method

Findings presented in this paper are from the Family Systems Project, a longitudinal qualitative study. This research examined perceptions and experiences of parents and other family members of infants and toddlers who were identified at birth, or shortly thereafter, as having a disability.

Procedure

Qualitative interviews comprised the basic research strategy of this study (Kavale, 1996). The goal of these qualitative interviews was to reflect family experiences, perceptions, and recollections relevant to caring for their identified infant/toddler. Interviews were conducted in family homes with questions shaped to prompt recall of topics like transition and family/professional relationships of importance to the researcher (Whyte, 1982).

Key informants in the study were primarily mothers, fathers, extended family members, and close friends. Family members were interviewed at least twice a year over the five years of the study. In addition, a third interview was conducted each year with a significant other (e.g., an extended family member, service provider, friend, or neighbor) identified by the parents. Additional interviews, reviews of family photograph albums and memory books, participant observations, and records reviews allowed for the data to be triangulated from a variety of sources. That is, data from several sources was compared and contrasted to ensure validity, reliability, thoroughness, and alternative views in the data.

Forty-four variables emerged from the interviews, participant observations, materials and record reviews, and researcher attendance at EI staff meetings and parent support groups. All interviews were audiotaped and then transcribed. All interviewers were trained to develop critical interview skills and to ensure consistency across interviews. Interviewers were involved in identifying the themes, variables, and developing the interview protocol.

Interviews were semi-structured. This allowed family members to elaborate on topics of interest to them and thus, gain as much information about their perceptions and experiences as possible. Themes emerged and grounded theory developed around four key topics.

Communication. Questions in the interviews probed respondents regarding how they were first informed about the condition or at-risk factors of their child. Initial communication with various professionals, information on transitions (e.g., from hospital to home, between different service agencies, etc.) was described. This is a large theme because communication is transactional. Entire interviews were consumed with initial reactions (e.g., parents, extended family, friends, neighbors, and others). This theme broke down into two main types, professional and personal communications. The first involved how information was shared and received, contacts from professionals, referrals to additional services and resources, and suggestions for improved communication. Personal communication included reactions of family members and friends and interactions with persons in social support networks.

Self-perception and coping. Questions focused on the process of realizations and adjustments to the child’s needs. This theme looked at adaptations in roles and relationships and how self-perceptions were affected. Exploring productive and less functional coping strategies utilized as family transitions changed self-concepts.

Social support. Some questions explored if assistance (both professional and interpersonal) received was helpful, if support networks outside of the family (e.g., church, parent groups, therapy, etc.) were introduced or sought, if the parents/families felt well supported through this process, and what was most troubling.
Needs assessment and services. Additional questions examined how family needs and strengths were assessed and addressed by professionals. How information gathered impacted the nature of family involvement in the programs or services provided, and types and duration of special services.

Reliability

Traditional qualitative methods of purposeful sampling, member checking, and triangulation of multiple informants and data sources established the veracity, depth, and richness of data. However, quantitative techniques demonstrated reliability for each interviewer. A process of blind coding of interview transcripts for the 44 identified variables was used. Prior to reliability calculations, interviewers were trained to code, using actual interview transcripts. They discussed disagreements, alternative interpretations, and operational definitions for each variable. After training, interviewers conducted interviews and coded them individually. The primary researcher also coded each interview and percent of agreement was calculated. Reliability scores ranged from 92% to 100%. No transcription or interview portion was entered into the computer program for analysis until triple coding (two interviewers and the primary researcher) had established 100% reliability. If 100% reliability was not attained on a specific variable, it was coded as unknown and not included in the analysis.

Subjects

Primary data collected for this study was from parents and key informants regarding 48 children who were identified at birth or shortly thereafter as eligible for state/federally provided services. Families were identified primarily through two large urban public hospitals that housed tertiary NICUs. Families resided in a largely rural south central state and the EI services mainly were provided through a statewide system. Some families sought services in one of the four adjoining states. In addition, a small number of families were in the military and reported on services from numerous states and countries.

The sample was systematically selected to represent the characteristics of the state’s population and to obtain data from diverse home settings. Therefore, 72% of the families were Euro-western, 9% of families were Native American, 9% were African American, 6% were Hispanic, and 4% were Asian.

Socioeconomic status of the families was distributed as follows: (a) 10% of families were professionals with some post-graduate education and incomes of $50,000 or above and had adequate insurance; (b) 23% of families were considered middle income ($30,000 to $50,000), in a low cost-of-living state, and one or both parents had some college education. They also had private insurance or employer covered benefits; (c) 25% of families were high school educated, some had vocational degrees or military training, their incomes ranged from $20,000 - $30,000. These families tended to need some form of government assistance such as SSI, WIC, Department of Human Services support for childcare, and Medicare or Medicaid. (d) 41% of families had very little income, ($12,000 or below) and experienced a high level of dependence on government supports.

Geographic characteristics of subjects included: 23% (11) resided in urban settings, 26% (12) lived in suburban areas, 30% (14) lived in small towns, 17% (8) families lived in rural areas, and for two families this information was unknown (not agreed on with 100% reliability or moved frequently). These percentages mirror the geographic characteristics of the state population.

Fifty-seven percent of children in the study were male and 43% were female. Diagnoses are listed in order of frequency, Down syndrome (13 or 28%); brain anomalies (12 or 25%); anoxia or post neonatal traumatic brain injury (9 or 19%); complications from premature births (4 or 8%); myelomeningocele with myeloencephalic involvement (4 or 8%); three children experienced multiple sensory loss; two were considered generally developmentally delayed; and one was chemically dependent. Over 50% of the sample had multiple disabilities.
Results

Birth Crisis

One of the first themes evident in this longitudinal research is that families undergo many different types of transitions. The first type of transition, reported by 73% of the families in the study, was the neonatal medical crisis. Instead of experiencing the joy of childbirth, many families were faced with a medical crisis, thus they transitioned from a family celebration to a family crisis. Since there were only two NICUs in the state where this study was conducted, when a birth crisis occurred at a regional hospital, the child was transported by helicopter (med-flighted) to one of the NICUs to receive necessary medical services. For many families, med-flighting the infant from the birth site was the initial physical as well as emotional transition.

One mother described her experiences about this:

Sometime in my 8th month I went into distress. It was not noticed. I was a week and a half past my due date. I had an ultrasound in my 7th month, and everything was fine. When I was a week and a half past due, I barely started dilating. I went into labor, my water never broke. I was in labor for about 24 hours, very easy labor. I didn’t go to the hospital. I called the hospital at 6:30 Sunday morning on the 4th of February, and the doctor said it sounded like early labor. “You haven’t broke your water.” I said, “No”. I said, “I just haven’t felt it move in a while, he’s just so far down.” He said I had better come in. They put me on a monitor, and he was in distress. We don’t know what happened, but in my 8th month he began to shut down his bodily functions. His kidneys were no longer functioning. I had no fluid in me at all. So, they took him C-Section, and when they cut the cord he was not alive. It’s as though he fought for over a month just to lie there inside me. They think the majority of the brain damage was done before birth. When they cut the cord, he had a bowel movement inside of me, so he had merconium in his lungs. So it was very, very difficult to resuscitate him. The Apgar scores usually goes from bad to better, and it went from bad to worse and worse. He had a zero on both Apgars. They took him into the nursery, and they were resuscitating him for about five minutes and just about gave up. He responded...I forget what it was they injected straight into his heart, but that’s what he responded to, and that was the last thing the doctor was going to do. They flew him to Children’s. They brought him in a little incubator that they put in the helicopter. He was hooked up to machines and had tubes in him and down his throat. They said that they thought I not only had to say hello to him but goodbye too because they thought he was going to die. They thought he had Potters Syndrome because his kidneys were not functioning, which is fatal.

For the families in this study, only the identified infant and necessary medical personnel were transported. The father and other family members were torn between remaining with the recovering mother or attending to the critical condition of the transported baby. One mother described this situation:

My dad and step-mom left when the helicopter left and went and stayed at Tulsa, since I couldn’t go. Billy (husband) wouldn’t leave me. It was hard to decide what to do. I wanted to go, and I couldn’t go. I wanted Billy to go, and he wouldn’t leave me.

The 35 families who experienced birth crisis had infants readily identified as physically vulnerable and at-risk for surviving. Typically, medical personnel provided information to family members who were in crisis. Based on initial communication with medical personnel, family members experienced a general sense of confusion, dismay, and urgency. As a result, those who cared most about the well being of the infants received poorly understood messages from medical professionals concerning diagnosis, treatment, and prognosis. Of the families who experienced a birth crisis, 77% expressed negative reactions to how they were treated during the medical crisis. Although all the parents in the higher income group felt they were listened to by medical professionals, only 59% in the middle income group felt the same way, 55% of the
working class families felt their concerns were heard, and only 40% of the families below the poverty level believed the medical personnel listened to them.

Transition from Hospital to Home

Early transition, from hospital to home concerned the infants’ health status and parent comfort in caring for their babies. Developmental delay issues were secondary to family concerns about the children’s health and the families’ own security in handling their infants.

Most families reported that they received some type of transition support prior to bringing their children home. Most were invited to stay for two nights in the hospital and were expected to take over full care of their infants during this time. Almost all parents were trained in infant CPR and were instructed on how to use and maintain whatever medical technology their children needed. Of the families who had experienced a birth crisis and needed transition support to take their infants home, 51% reported they were comfortable with the process. Many of the comfortable families perceived the homecoming as a celebratory event. Twenty-eight percent of the families felt uncomfortable bringing their infants home and 21% had mixed feelings. The mixed feelings consisted of happiness that the children could come home but fear or anxiety about the degree of care they would require. The following examples represent a range of comfort levels.

A couple that did not receive specific training before they transitioned home stated:

There was this woman, a social service worker with Children’s. She didn’t like it that we didn’t know CPR, we really should have taken a CPR class before we took him home. She asked us all these questions, and we felt like we were taking tests, and if we didn’t pass them, we wouldn’t get to take him home. It was terrible.

Parents with mixed comfort feelings had reflections like this mother:

Oh, it was awful. So we got him home, and I was like, nobody touch him. I was so paranoid when we first brought him home. He had really been through the wringer at the hospital. They had put IV’s in his head because his feet and hands were getting so swollen. So he had a Mohawk when he came home because they had shaved both sides of his head. So he was a pretty scrappy little thing when he came home. It was hard. I was very frightened.

The following quote provides an example of parents who were comfortable with the transition but were still nervous that something could happen. They stated:

It was easy. We were in there so much of the time. They have a room. The NICU has two rooms set up for like home. Most of the time the parents would spend one or two nights in this room. We were there so much. We’d be there from 8 o’clock in the morning until 11 or 12 o’clock at night. They said by this time that they were sure we were going to do just fine at home. We were kind of scared - afraid we’d get home and something would happen, but it didn’t.

A mother who had to learn gastronomy tube feeding expressed these feelings:

They didn’t really prepare me. They were feeding her through a tube. They brought her to my room twice to teach me how to feed her through the tube because they didn’t know how else to get her to eat. And instead of letting me do it, the nurse did it anyway. She showed me how you know and all this stuff. But they wouldn’t let me do it. They took her back to the nursery, kept feeding her with the tube and only brought her whenever it wasn’t feeding time. Which upset me because I needed to learn and at that time I felt like she needed to be with me most of the time and not down in the nurses’ station being fed 10 seconds through a tube you know. She needed that feeding time to be close with me.

Transition from EI to Preschool

The transition from EI services (largely home based in this state) to Early Childhood (EC) center based preschool special education services is another major transition for families. The preschool placement at age 3 provided opportunities for families to comfort and cope
with developmental delays. The process of family decision making and the realities of limited placement options were discomforting to many families. During the study, 30 of the children had aged out of EI services and made the transitions to preschools. Of the families in this transition, 46% reported they were comfortable with the process. Comfort was defined in four ways: (a) the EI staff had prepared the families for the move and were helpful in setting up meetings with school staff, (b) parents felt they were involved in the Individualized Education Program (IEP) planning process, (c) parents were provided with decision making opportunities and given alternative choices, and (d) the families were happy with the placements.

Forty-three percent of families reported they were uncomfortable with the transition from EI to preschool. Parents who were uncomfortable felt unprepared and anxious. Many had complaints about being abandoned by the EI staff that they had grown to rely on. Uncomfortable families had a difficult time communicating with service providers, some reported they did not understand the process. These families reported that they did not feel like full participants in the IEP process and that they were not given choices about preschool placements. A majority of the parents who were unhappy wanted placements in a neighborhood school or in a preschool that served children without disabilities as well as children with disabilities.

Ten percent of the families found that their children were no longer eligible for special services when their children turned three (based on state or school districts’ definitions and evaluations). Some parents felt this was a wonderful success story highlighting the impact of EI. However, two of the families were very unhappy and felt that by the time their children turned five, and entered school, they would be eligible for special services again. Parents feared that two years without special services would result in regression.

Overall, parents were very grateful to be entering their children in preschool. The main advantage they discovered was that school services averaged 10 hours per week while EI had averaged one hour a week. The increased amount of service time was viewed very positively by the parents.

As previously stated, parents expressed mixed emotions during EI to preschool transition, below are examples of parental reactions:

You know, and now we’re ready to transition out of EI in March. Well, now I’m scared. I’m getting all these anxiety feelings again because what’s it going to be like in the public school? We’ve been with EI, we know these people. We know what they do. We know that they’re wonderful, that they listen to me first before they listen to a piece of paper that says it should be this way. Is the school going to do that? It’s scary. And then, we’re starting to think about kindergarten - what’s it going to be like in kindergarten? Is she going to have special class all the time?

A number of rural families found themselves unable to access a school program that met their children’s needs. Some families had to make major changes to find an appropriate preschool setting. Comments on this situation included:

We wanted her in school, but the special education cooperative was two hours away on the bus for her. She needs to be continually repositioned in seating. That’s the whole reason we moved. We had to completely relocate because that school system there had nothing.

Another parent said:

There wasn’t a school program out where we were so I decided to move us to town, I called beforehand and told them that we were coming and that I wanted an intake on him and everything. I didn’t want to lose any school time. So, we got in really quick. He ended up going into their infant stim program at the segregated preschool, which wasn’t teaching him enough. We decided that it would be better if he was in the school that was fully enclosed. And, they had an (educable mentally handicapped) EMH program out there, so we decided to put him out there. And, it was a little bit of a struggle at first. They didn’t want to take him. But, then, they changed their mind, I guess. And rescheduled and they went ahead and did the IEP, so he’ll be going out
there. He’ll go...we’re going to main-
stream him into a regular class in the after-
noon and in the morning he’ll be in the
EMH class, and he’ll have his interpreter
with him. So, we’re pretty excited.

For the most part, families in the study were
not difficult to accommodate, even when they
were not provided with their first choice of
preschool programs. One mother shared:

The school folks were wonderful, wonder-
ful. They are going to continue to do that
next year and try to mainstream her a little
bit more. And then, she will stay at the
segregated preschool. I was gonna try to get
her in school with her brother, but she’ll
stay and go through her grade school years
at the other elementary that has the segre-
gated cottages.

A typical comment from a parent that was
comfortable with the transition to preschool
was:

EI was really helpful in the transition to the
special education only preschool and they
didn’t hit me with any red lights. I didn’t
ever hear, “You can’t.” It was, “OK, we’ll do
this. We will do this.” And they’re the ones
that stepped in and they approached special
education and said, “This is what we want to
do, and this is why we want to do it, and we
don’t see any problems. Do you?” So, they
were a big help as far as making the transi-
tion early.

A number of statements provided below
summarize how most families experience transi-
tion:

EI could no longer give him what he
needed and um, it was pretty hard getting
everybody together. Getting the correct pa-
perwork you know for the public school
system, they never told me exactly what they
needed, and then they call me two days
before and said “Well, it doesn’t look like
he’ll be able to go, cause we don’t have this
such and such report.” I thought I’d given
them everything. So I got it, and I said “He’s
starting on that day, our lives are revolving
around it, so he did. But that was real hard.

I was very apprehensive, in fact, I didn’t
want him to go through it. I had visited the
classroom as I wasn’t comfortable with it. I
considered holding him out. But, once I
met his teacher I said, ‘let’s go ahead. It
can’t be that bad’. We started him and I’m
glad we did. I really am.

I don’t know about his transition, but
mine was really rough. He rode a big bus
that pulled up outside, and it swallowed him
whole and he disappeared. As far as him
being there, at first it tired him out, but now
he loves being around the other kids.

Discussion

The research described here identified some
of the transitions experienced by families with
young children with disabilities. Themes re-
garding these transitions include: (1) families
going through a birth crisis may have difficulty
understanding the information they are pro-
vided, (2) some parents may not feel comfort-
able in their abilities to care for their children
as they transition from the hospital to home,
and (3) the transition from home based early
intervention to center based preschool may
cause much anxiety for some parents.

The primary limitation of the study was the
small number (48) of families in the study.
However, the amount of qualitative data that
was collected from the families was substan-
tial. Depending on when the families were
included in the study they may have been inter-
viewed up to 10 times over the course of
the five years of the study. In addition, a sig-
nificant other to the family was interviewed
each year of the study. These interviews pro-
vided a rich amount of data to investigate
many themes regarding the families’ transi-
tions through early childhood. Another limi-
tation was that all of the families came from
the same state. Therefore, the findings may
not generalize to other states. However, the
families were representative of most of the
demographic characteristics of families in the
state. It should also be kept in mind that all
families are unique and the present research
supports the importance of gaining insight
into each family’s unique system to more ef-
fectively deliver appropriate services.

It is also important to remember that the
subjects for this research were willing volun-
teers and may have had different experiences
than those families that did not volunteer to
participate in the study. Thus, as such the findings of the research may not be applicable to all families.

Some recommendations for assisting families undergoing transitions in early childhood may be made based on some of the findings of this research. General guidelines include:

- Be reliable and consistent when providing information
- Anticipate anxiety and address it with a predictable schedule of preparation events
- Interpret unfamiliar language to families and check for understanding
- Be accessible and present at meetings
- Be factual, supportive, and nonjudgmental
- Help parents clarify and articulate their questions and expectations
- In preparing for transition provide guided trials and opportunities for family to practice new skills (especially important for medical and care giving routines)
- Allow parents (and children when appropriate) to experience new settings in a progression from neutral exposure (empty meeting rooms, classrooms, and offices) to active observation (attending other IEPs or teachers and students in the classroom) to partial and finally full participation. Even highly anxious parents may only require one neutral progression.
- Remember that highly emotive information (medical or developmental diagnosis) initially may be poorly comprehended by family members. Provide follow-up interactions to build understanding and foundations for coping with the information.

Personnel should bear in mind that transition for families does not mean only changes in placement or services received but also can mean changes in emotional states or their perceptions of their children’s and their own situation. By being sensitive to these changes in perceptions personnel will be able to communicate more effectively with families and help to address their goals.

References


