When my 2-year-old son, Lee, needed a hearing test, the audiologist invited me to wait outside the testing room. I explained that my son would be more cooperative if I remained in the room. The audiologist repeated “the policy.” I made it clear that we were hoping to test Lee’s hearing ability, not his readiness to leave his mother and follow a stranger into a cubicle. The audiologist told me, with a patronizing show of patience, that the results of the test might not be the same if I stayed in the room. I agreed with her wholeheartedly. I also wondered how—if I did not stay in the room—she expected to get any test results at all from a frightened, crying little boy. After completing the test—with me sitting in the room—the audiologist observed that Lee was unusually cooperative for a 2-year-old.

One of the basic principles of assessment for infants and children formulated by the ZERO TO THREE Work on Developmental Assessment states in no uncertain terms that “young children should never be challenged during assessment by separation from their parents or familiar caregivers.” This seems so obvious and such basic common sense is dealing with infants and toddlers. When I read this statement in the initial publication of the principles bulletin, Zero to Three, the memory of my morning with the audiologist came flooding back.

I also remembered a much more terrifying experience. In
1970, professionals tried to separate me from my nursing infant, Nancy (Lee’s older sister), as she was being admitted to the hospital on an emergency basis to be tested for what might have been a fatal neurological illness. My husband and I insisted on disallowing hospital policy regarding separation of child and parent during the three days of Nancy’s hospitalization. I stayed with her for the entire period, during which many invasive procedures and a drug error of potentially serious proportions confirmed to me that was right to follow my gut instinct. As a result of this experience, in 1972 a group of parents formed a nonprofit organization, Children in Hospitals, Inc. (CIH), with the goal of making 24-hour visitation an option available to all parents of hospitalized children in Massachusetts. CIH succeeded in achieving this goal and continues to help parents negotiate the health care system.

My twenty-plus years of work with CIH and more recent parent advocacy and training with colleagues at the Federation for Children with Special Needs have taught me some valuable lessons about what it takes to turn a “recommended guideline” into “accepted practice.” As parents and professionals try, together, to make our new vision of developmental assessment a reality, the following lessons may be helpful:

**Change is painful.**

When a newly hired head of pediatric nursing shared the insight that change is painful with me, I assumed that she was preparing to explain why she could not relax policies and remove barriers that hindered parents from continuing their parenting role when their children were hospitalized. To my surprise, this nurse, in fact, told me what she had learned about ways to pull people away from their tightly protected views and point them toward new ways of functioning that recognized the needs of families. While I had always focused on what I wanted changed, this professional showed me the importance of considering how to make change occur so that the people involved feel comfortable, not assaulted. This viewpoint is an essential ingredient of CIH’s materials and advocacy.

**Any individual parent advocate can be written off as a crazy, overprotective mother or father.**

When we defied hospital personnel so that I could stay with my baby daughter while she was hospitalized, my husband and I
decided on a strategy within the first hour of our ordeal: I would not leave Nancy’s side, and he would make sure that nobody insisted on enforcing the existing hospital policy of visiting hours for parents from 11 a.m. to 7 p.m. When we returned home three days later (with the finding that Nancy’s alarming symptoms “must have been caused by a virus”), word of our victory spread rapidly through the community, as well as through the La Leche League and other childbirth and parenting education groups in the Boston area. Parents with children facing hospitalization called and asked, “How did you get to stay?” After CIH was formed, hospital officials took parents seriously. A committee always gets farther than an individual—and committee members have the support and enjoyment of one another’s company.

Find supporters.

In CIH’s early years, the organization was discovered by an attorney, George Annas, who was interested in the new area of patient rights. He listened to our concerns and offered us legal arguments to match our parent instincts. (His book, The Rights of Patients (1989), discusses parents’ rights.) Legal arguments opened some doors.

We also found that psychologists and psychiatrists (Edward Mason, M.D., for example) had done research in the 1960s demonstrating the benefits of having parents stay with their hospitalized children (Mason, 1965). In fact, as a result of research findings, Massachusetts General Hospital had begun suggesting at that time that parents bring sleeping bags to the hospital so that they could sleep in their child’s room even if no beds were available. CIH did not need to set up a research project. We simply prepared a bibliography, disseminated key articles, and publicized examples that supported the research findings. We learned that peer pressure works on institutions as well as on children. In 1973, CIH published a Survey of Hospital Policies regarding this matter and has continued to do so every two years since then. The first edition attracted attention in the Boston newspapers, and, almost immediately, open visiting by parents became the policy at several hospitals.

Sometimes, supporters emerge from your own circle of contacts. In our case, Dr. T. Berry Brazelton told CIH that he needed consumer/parent support at a Boston hospital to accomplish changes within the hospital that some of his colleagues found
strange at the time. With his leadership within the hospital and our pressure from the outside (including newspaper publicity), it became possible to bring parents into the Neonatal Intensive Care Unit of the hospital for the first time.

Collaboration is powerful—among parents, and among parents and professionals together.

When CIH was established, few committees or task forces included parents as equal partners. The first task force I was invited to join was considering new pediatric hospital regulations, including a CIH request that parents be able to stay with their children as many hours a day as they felt necessary. This task force disbanded after I attended one meeting. Other members of the task force decided the group could not do its work with the participation of parents. Two years later, health department staff reconvened the task force. I was still a member (bringing along my newborn child, who was labeled “the consumer member”). Another CIH parent was included in the task force, along with physicians and hospital administrators who had been the only members of the first task force before I joined it. This second task force was successful because we all seemed ready to listen to one another. Perhaps the reason for this was that the health department staff who convened the group had carefully selected members who were open to change.

Consistent collaboration within CIH has been just as important as effective work with outside allies. We have needed one another as parents. We have also needed to demonstrate our capacity to follow through, commenting whenever our viewpoint has been invited and when we have thought an issue required parent attention, and then thanking people who helped improve conditions. CIH’s newsletters and brochures have encouraged parents to be active and to express their views in telephone calls, meetings, letters, and articles. Sometimes, it has seemed as if most of the calls parents made were to us. Countless crying parents have called us from pay phones in hospital corridors. They have felt dismissed, denigrated, and disdained by hospital staff, and have badly needed to talk to someone who would understand what they were going through. Many have been fearful of going directly to hospital staff and have asked for our support so that they could remain anonymous within the hospital. Since we began to publish our consumer directory of Massachusetts hospital policies and gained access to newspaper
publicity, things have changed. Some professionals have reported feeling “intimidated” by our publication.

Ongoing advocacy that may seem relentless (11 editions of the consumer directory have been published from 1973 to 1994) is sometimes necessary, but negotiation and collaboration are far more satisfying ways to achieve change. I have learned to enjoy the process of sharing ideas and working toward a common goal.

Prepare parents as fully as possible for their roles as participants in the developmental assessment of an infant or toddler.

We need to recognize at the outset that the notion of an “assessment,” whether it is the first examination of a newborn or a comprehensive developmental evaluation, triggers an impulse to take on one of two potentially conflicting parental roles—the child’s “guardian angel,” who protects the baby from all harm (including, perhaps, professional “pronouncements” about the child’s condition) or the knowledgeable, cooperative “good parent” ally of the professional. The potential conflict between these roles becomes clear the first time a parent wants to ask what he thinks is a “dumb question.” The parent wants an answer to a troubling concern but feels embarrassed at revealing limited knowledge or seeming “silly” or overprotective.

Well-trained, sensitive professionals—who share a “new vision” of developmental assessment—are aware of parents’ feelings and try to make every phase of an assessment an opportunity to share knowledge, observe a child together, and plan collaboratively. In these circumstances, professionals and parents see themselves as allies on behalf of the child.

Many parents continue to fight the same battles we in CIH thought we won conclusively 20 years ago, and, for years to come, many parents will be participating in developmental assessments in circumstances that are less than ideally supportive. The following guidelines for the parents’ role in a developmental assessment may help parents be effective advocates for themselves and their children, and, therefore, reliable allies for each other and for dedicated professionals.

1. Your role in an assessment is to be the parent. As a parent, you know your child best and in ways that others cannot. That is your expertise. Your own gut feelings and personal observations over time are valuable in ways that go beyond
what any test measures will provide. You do not need to become any other kind of “expert.” Continue to be your child’s parent, and make use of other team members’ expertise as it applies.

2. No matter what your educational or occupational background is, you will not know all the technical terminology that might be used during an assessment, and you do not have to. You can and should ask to have terms defined and explained so that you continue to understand the entire discussion. Your own familiar ways of describing your child are valid and will be understood by everyone.

3. You do not need to agree with everyone at the assessment—or with anyone at all. If you feel that the way your child is being described does not match what you see, say so. Accepting a picture of your child’s situation as described by professionals and following the recommendations of these professionals will not be useful unless they fit what you believe is true for your child. If there is no match between what others see and what you see, ask for more discussion as soon as possible.

4. Feeling “outnumbered” can be difficult. It can be stressful when a group of people are discussing your child with you and a family member, or just with you. Professionals are more comfortable with colleagues present, even if their own opinions vary from those of their colleagues. As a parent, you can designate a person to bring to any meeting or appointment concerning your child, at which you want support. The support person can help take notes, keep track of information, and review the discussions with you later.

5. As time passes, you may wish to be more or less involved in the process of assessment. Your level of involvement at any given moment will depend on your child’s needs, additional information you may have learned, and other life circumstances. Your decision will be accepted, not challenged. You should make it clear that you want to know if someone would like you to be more or less involved for a particular reason so that you can make a decision based on that information.

6. The process of making decisions at each stage of assessment will increase your ability to advocate for your child. Each assessment will give you new information that you can use as your child grows and will be a new opportunity to put infor-
mation to work when making decisions about your child’s care and education.

7. If you feel that an assessment is not adding to your understanding or helping you discover what you need to know, tell the team. Spending time on a process that misses what you are concerned about delays your ability to help your child. Make your needs clear, even if this means finding others with whom to work.

8. Find support for yourself over time, and find others who will benefit from what you have learned. Each parent who has gained some expertise should be prepared to share it with others. Parents who are in the process of trying to learn what you have already discovered need your help. Every parent who has learned from another parent feels a continuing bond with his or her “parenting guide.”

While each parent is concerned primarily with the experiences surrounding the situation of his or her own child, some parents have found that, as they continue to expand their knowledge, they become ready to participate in helping others in new ways, based on their experiences. They are eager to offer support to other parents, work collaboratively with professionals on committees, serve as speakers at conferences, and provide the parent viewpoint at every opportunity (as I am doing in this chapter). Even when not asked directly to participate, some parents have found ways to offer their involvement. This has led increasingly to new partnerships and a greater awareness on the part of professional groups and organizations of the fact that parents who are receiving services today are also potential partners in furthering an understanding of what families are seeking.
References


New Visions for the Developmental Assessment of Infants and Young Children

SAMUEL J. MEISELS and EMILY FENICHEL, Editors

ZEROTO THREE