

# Yes, There Are Developmental Emergencies



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 The author declares that she has no conflict of interest.  
 Received for publication October 7, 2013; accepted September 10, 2014.

ACADEMIC PEDIATRICS 2014;14:554–555

**1 AM:** Doctor, I was watching a special on TV about the early signs of autism and I recognized my 21-month-old son. I'd like to bring him to see you as soon as possible.

**2 AM:** I don't remember if I told you that he isn't talking at all, and doesn't point. He doesn't respond when I call his name. That isn't good, is it? Please call back as soon as possible.

**7 AM:** Doctor, I wanted to let you know that I just returned from the ER. Juan got angry when I said he couldn't have seconds of ice cream and threw a chair at me. I think I am ready to consider placing him in a group home. I'm afraid that I can't handle him anymore.

**Next day:** Doctor, they called from the ER to say that my arm is broken.

I am a developmental pediatrician specializing in the early identification and management of autism in the Bronx, New York. These were the first 4 messages I heard on my office voice mail upon returning from a 10-day vacation. Despite leaving an "out of office" message with a host of options for redirecting callers to other numbers, I found these and 75 other messages. After listening to the calls, I realized they were representative of the types of issues facing families of children with autism and other developmental disabilities.

Thirty calls came from parents whose children I had previously seen, though some not for several years. Most of these were related to frustration surrounding the lack of therapies for children or about problems with a school placement. These parents described concerns that their child had made no progress over the past year or had even regressed. Another lamented that her child was denied needed services, and another reported that her child was

found ineligible for various school programs for children with autism. There was a frantic phone call from a parent whose child had been thrown out of day care because he hit another child, and another from the parent of a young adult who had aged out of his special education program but who had not yet been placed in a supervised work situation. The parent did not know who would stay home with him because he could not stay alone and she worked. There was a call from parents desperate for a place in a group home since the father had become seriously ill. Another was from the mother of a teen with Asperger syndrome who had begun college but was having difficulty. There were multiple calls from parents asking for help in obtaining applied behavioral analysis services, an evidence-based treatment for children with autism that is expensive and can be hard to find.

Then there were the calls from frustrated, tired parents experiencing difficulties relating to their children's behaviors. One child had wandered out of his family's apartment, and another had run into the street on a family outing and was almost hit by a car. Other messages described children who were aggressive, hyperactive, or not sleeping, their parents pleading for medication. There was a family reported to children's services because the child cried nonstop, and another family who lost their insurance and needed a medication refill. The last message was from a family who wanted me to speak to their lawyer to help them obtain private school placement from the city. Almost every message was overflowing with raw parental emotion and stress. And the calls often came late at night or in the early hours of the morning, the concerns keeping the callers awake.

As I looked over the list of "emergency" phone calls, I remembered a conversation I had had with my pediatrics chairman 25 years ago. It was the day I told him I was planning to become a developmental pediatrician. This was a change in direction for me at the time, and the chairman, whom I admired and respected, expressed his disappointment. He used strong words along the lines of, "Pursuing child development as a specialty would be a waste of your training and your mind." It was a hard conversation for me, and I remember how I responded: I recounted to him the patient who had made my direction clear to me. While on rotation in the NICU, I had

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been involved with a baby born prematurely at 27 weeks gestation to a couple with a long history of difficulty conceiving. The baby's course was complicated by a grade IV intraventricular brain hemorrhage (IVH). I had been present when the attending physician had counseled the parents that the baby, if she lived, would very likely have a lifelong severe developmental disability. He recommended that they consider withholding the extraordinary measures often needed to keep a baby this premature alive. The parents were distraught. They thought that this baby was likely their only chance to have a biological child. I remember leaving the meeting and heading straight to the library. A search of the literature yielded one follow-up study on grade IV IVH. The article indicated that 50% of the children died and 25% had severe developmental complications, but the remaining 25% had only mild abnormalities. I brought the information back to the family, who chose to continue care that could benefit their baby girl. After her discharge from the NICU, I followed the little girl in my continuity clinic and watched happily as she proved to be one of the lucky 25%. In my 3 years of residency, this case was the first to send me on a quest—the one that incited my curiosity the most.

When my fellow residents learned about my plans to pursue developmental pediatrics, I took quite a bit of ribbing. Most of them were going into intensive care, emergency medicine, or cardiology. They would joke that while they were dealing with the real emergencies, I would get paged in the middle of the night by concerned parents with, "Doctor, doctor, my child isn't speaking!" These were so-called emergencies that could surely wait until the next morning, next week, next month, or even next year.

Yet as my messages reveal, emergencies need not involve blood, stitches, or surgery. The families of children with developmental disabilities often contend with daily practical challenges and looming long-term worries that, by their chronicity and consequences, also reach a level of urgency. The situations may be very different than those we generally associate with emergencies—but the sense of panic and isolation they produce are similar. The ability to alleviate those overwhelming feelings with advice, information, concrete services, and strategies can lend support to a family that can make a significant difference.

An emergency can be a worry about the present, a fear of the future, or the sudden collapse of the fragile house of supports that the family had constructed and relied on to make it through the days, the weeks, the years. Concern about a child's development is an emergency for a parent or a grandparent. Parents can be in great distress, worried that the life they pictured for their child is at risk, and that every minute counts. Research and public service campaigns have made it clear that early diagnosis is important and beginning therapy as soon as possible yields the best outcomes. But even with a diagnosis, the emergencies are far from over. Parents know they are fighting for the quality of life of their children—and their family—and that it cannot wait. They are fighting for educational and therapeutic services, against systems that make things unnecessarily difficult—systems that themselves easily become adversarial, with administrators that often seem not to understand the day-to-day struggles of families.

So yes, there *are* developmental emergencies, and I responded to each phone call in turn, crafting a plan to address the crises, near and far, one by one.