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## In-Home Support as “Life Support for the Soul”

By Lisa Ackerson Lieberman, MSW LCSW

*It is 8:10 on a school day morning. Your husband leaves early for work. Three kids must be out the door by 8:30 and you also need to leave for work by 8:45. For the past 45 minutes, your 13 year old daughter has taken sole ownership of the only bathroom in the house. Your 10 year old son frantically searches for his school project while he insists that you help him find it. And if that is not enough, your 7-year-old daughter who has a developmental delay, sits on the floor of the kitchen having a major meltdown because there is no more of her everyday cereal left.*

Sound familiar? Crying out, “Calgon, take me away!” is obviously not going to make this situation any easier. This is one of many ways having an in-home provider can make a seemingly impossible situation flow much more easily.

Let’s look at another scenario:

*It is homework time after school. Your 5th grader struggles with math and requires your help preparing for tomorrow’s test. Your 3rd grade daughter, who has Down Syndrome, cries as she longingly presses her face to the window looking out at all the neighborhood kids playing together.*

*You cannot possibly be two people at once. Although your heart breaks for your daughter in her loneliness, you realize you are faced with an impossible choice: to help your son with math, or to support your daughter’s desire to play with the neighborhood kids.*

In today’s complicated world, many families need some sort of child-care help, whether or not their child has a disability. Families of children with developmental disabilities find it even harder to secure adequate child care solutions. When traditional situations don’t work out, parents often feel like they are living life on half-empty; their fuse becomes even shorter as they attempt to do everything themselves.

For one reason or another, families of children with disabilities often overlook in-home support as a solution. There are many situations, from childcare to day-to-day activities, where an in-home provider could fill a needed gap. Let’s discuss some more.

### Child Who Needs More One-on-one Attention

If your child struggles with managing sensory input, a group child-care environment may be too chaotic and uncomfortable. Noises most children naturally screen out are

experienced as painfully loud by children with sensory processing difficulties. Typical movement and activity in a group child-care environment may overwhelm your child and cause him to shut down or melt down from too much sensory input of one type or another.

Even if your child can “hold it together” during school time he may be emotionally and physically drained from working hard to deal with his day and unable to continue beyond school hours. After a reasonably good day at school, you may hear reports that your child is “out of control” in his afterschool situation. The program staff may be at their wits’ end trying to make the situation work for everyone. By contrast, at home he may feel relief from the sensory over-stimulation characteristic of a busier, less-structured group situation. Activities, snacks, and personal needs are easily tailored to meet your child’s needs so he feels calmer and more in control.

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In addition, hiring someone to work in your home is one way to implement individualized teaching strategies, specific therapy approaches that work for your child, and to build self-help skills. This includes one-to-one therapies or activities, which are not easy to do in a group setting.

### Being a Part of Your Neighborhood or Community

When my family prepared for a move to Oregon, we purposely chose a family-oriented cul-de-sac with many small children. Even after our son, Jordan, was diagnosed with autism, our resolve for him to be an integral part of his neighborhood and community didn't change. Hiring an in-home provider to facilitate his involvement made it possible for him to interact more effectively with the kids on our block.

As your child grows, a provider or support person can help your child master essential life skills such as using money, riding a bus, seeking out emergency assistance, as well as becoming familiar with community recreation opportunities. This technique gives you the reassurance your child is safe as well as learning experiences as they naturally occur in life, a much more effective way to learn life skills.

We joined a local health club that agreed to allow Jordan's providers to accompany him, free of charge, to mentor him in how to use the facilities. This not only built a foundation for a lifetime fitness routine for him, it also opened the door for a possible future part-time employment opportunity. This is

just one example of how an in-home provider can set the stage to help establish stronger connections for a child as she becomes a young adult and starts moving out more into the community.

### "Life Support for the Soul" Increased Time to Devote to Other Family Needs, Including You.

If you choose to stay home with your children, having an extra set of hands around frees you to address other family needs and wants. Siblings without special needs often feel as though their needs are eclipsed by the demands of your child's many challenges. Having someone you trust there to support your child with developmental disabilities allows you to spend some meaningful time with your other children.

This "release time" has other benefits to your family as well. Spend some of this extra time on more than meeting the needs of others. Use it to take care of yourself doing things you have little time for, such as exercise, taking a bath, or working on the hobby you have been neglecting. These are important and essential activities to nurture your soul. Many feel frivolous using their release time this way. Don't. You will be a better parent and partner to everyone, including your employer, if you take some time for yourself.

### Creating Family Support

In today's highly mobile society, families are less likely to live near extended family members like our

parents did. By necessity, families pick up and move across country for jobs. As a result, families often must create their own "chosen" family where they live. This takes time and energy. Throw a child with special challenges into the mix of trying to establish yourself in a new community, and it can seem insurmountable. This is another situation where that extra pair of hands is extremely helpful.

My family moved to Oregon around the time of our son's diagnosis of autism. It made all the difference to have that person available to assist me, as I got physically settled in our home and researched community resources for our son.

### Perceived Barriers to Hiring In-home Support

Hiring someone to support a child in the home is not the right choice for every family. However, when you are brainstorming solutions, every option needs to be considered. What are some thoughts parents have that stop them from considering in-home support as an option?

#### **"It costs too much."**

In general, it does cost more to hire an in-home provider than to send your child to family day-care, child-care, or after-school care. However, there is an array of ways to get around the expense of in-home care, such as bartering for services, sharing a support person with another family, exchanging room and board for child care, and using respite funds and other government entitlements. Unfortunately respite

funding varies from state to state and needs to be explored through your own state's department of developmental disabilities.

Another possibility is to hire an interested high school or college student in your neighborhood to help before or after school for a few hours. Suffice it to say, there are creative solutions that can be explored to counter the expense of in-home providers.

***“What’s wrong with me? I can’t take care of my own children!”***

Regrettably, there are people who judge parents for not staying home to take care of their children. The bottom line is that each family must decide what is in the best interests of their own children and family. In today's world, families have enough to deal with in managing work, home-life, and parenting. Parents should not have to deal with the added burden of people imposing their beliefs about when it is or isn't acceptable to solicit help in caring for one's children.

Caring for children is hard enough in today's society where both parents often must work to make it financially. Even more challenging is the growing number of single parents who are required to fill the role of both parents. The responsibilities are even more difficult when your family includes a child with a developmental disability. This adds multiple demands on already busy schedules, such as fitting in therapies, doctor visits, and school meetings

into an already packed schedule. And if there are other children in the family (with or without special needs), the task becomes even more formidable. There are soccer games, piano lessons, after-school clubs, and sleep-overs, just to name a few. In short, there are too many holes in the dam and not enough fingers to plug them!

***“Other people have it so much worse than I do!”***

It is difficult to walk in other people's shoes and really grasp how they experience their own situation. The truth is, other people cannot possibly understand what you go through in your own family, nor you, theirs. There is no value in comparing how your difficulties match up to what other families face. There is also no point in comparing the impact of your child's disability with children who have other labels, or no label at all. It really doesn't matter if one child's disability is perceived as easier to manage than another. More important are the goals and dreams that your family holds, and what kinds of help your family recognizes would help you achieve them.

***“I’d feel uncomfortable with a stranger in my home.”***

Bringing a “stranger” into your home does require some adjustments for most families. If you tend to be fairly private, it is necessary to define clear boundaries from the outset. Boundaries include the role a provider fills with your child, and a plain definition of how involved

your support provider is in your family's daily life.

You might feel more comfortable to start out by hiring someone to come into the home for a few hours a week, so you both can get your feet wet. As comfort builds, the provider's role can be expanded into more hours and additional duties.

**My Family's Experience with In-home Providers**

Over fifteen years, we employed at least twenty-five different providers specifically to support our son, Jordan. The large number of providers can be explained because most of the time, having two people job-share was of greatest benefit in our situation. When Jordan was first diagnosed with autism, our provider was an incredible support to me as we explored available therapies. Together we learned what would benefit Jordan. She was my rock; I can still remember her kindness as she reminded me that he was a sweet boy and that he would be okay. Her ability to love him unconditionally was a wonderful balance to the intense sadness and fear that consumed me as I witnessed the gradual unveiling of his diagnosis.

For my family, what could have felt like a lonely and isolated journey instead provided ongoing reassurance. Should anything happen to us, people who love our son and understand his needs will likely be around to help him. This is especially important to us given the lack of extended family available. If a simple thing like a checklist can

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to provide the kind of support that would help Jordan live as independently as possible.



*The Ackerson - Lieberman Family*

*Photo courtesy of Vern Uyetake*

As I think about the number of wonderful providers who came into our lives over the years, I realize how blessed we were to have people who made Jordan a high priority. At the same time I believe we can take some credit for our good fortune. We mastered a complicated set of skills involved in hiring a provider. Once they were hired, we were accountable for our behavior and our mistakes, and treated people with fairness and honesty.

Hiring an in-home provider to support a

child with developmental disabilities can truly be “life support for the soul.” Parents must examine family needs and values in deciding whether in-home support is the right option; if so, it can change the landscape of your family’s life.

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