

“Willing to Try Anything,” “Nothing to Lose”: How Families Experience and Explain an Alternative Treatment for Autism

Dianne L. Ferguson, Professor

Louisa M.T. Silva, Visiting Professor

*The Teaching Research Institute
Western Oregon University*

In the last decade there has been an astonishing increase in the identification of children with autism spectrum disorder (ASD) (e.g., Chakrabaarti & Fombonne, 2005). Families of young children with ASD often face a bewildering array of possible interventions, with little guidance about which ones to select. These interventions include behavioral, cognitive, sensory, pharmaceutical, vitamin and diet therapies, some of which have a substantial amount of research available on their efficacy, while others do not (e.g., Green, 2007; Lovaas & Smith 2003). Moreover, a family’s community may offer only some of these possible interventions, forcing families to choose simply what is available or attempt to travel to find other options (Krauss, Gulley, Sciegaj, & Wells, 2003; Jacobson & Mulick, 2000).

Little is known about the decision processes parents use to choose some of these interventions over others. Some authors suggest that differences in identification of ASD as well as in the treatment choices made by families may be related to the family’s cultural interpretations and beliefs about child development, the symptoms of ASD, and their experiences with the health care and educational system (Bishop, Richler, Cain & Lord, 2007; Mandell & Novak, 2005; Webster, Webster & Feiler, 2002). Family choice may also be significantly influenced by the demands of the intervention, regardless of the research supporting it. Green (2007), for example, interviewed 19 families about their experiences with 3 specific widely used autism treatments (Applied Behavioral Analysis, Sensory Integration therapy, and a combination of Vitamin B6 and Magnesium therapy). She found that ease of implementation, time commitment, and perceived effectiveness were important factors in the selection and continued use of treatments, even those lacking empirical support.

In a similar vein, studies in the United Kingdom specifically focusing on the growing use of Applied Behavioral Analysis (ABA) are finding that despite some positive results, the

demands of the program may contribute to negative outcomes for families (Trudgeon & Carr, 2007). In one case (Schwichtenberg & Poehlmann, 2007) 41 mothers who had been running a home-based ABA program for at least 6 months revealed elevated levels of depression and personal strain. These levels of strain were lower for mothers whose children were in less intense ABA programs and programs that were school as well as home based, though they still reported more stress and depression than mothers of children with other developmental disabilities. Johnson & Hastings (2002), also working with 41 families conducting ABA interventions with their children with autism, identified lack of time and personal energy as significant barriers to their implementation of these programs, though they did not cite plenty of time and energy as a facilitative factor.

Better understanding the impact of educational interventions on family life, especially those that require a family follow-through or home component is an important dimension to the provision of educational and medical interventions in children with autism and other developmental disabilities. This study specifically explored families' experiences and understandings of Qigong massage as they participated in two different studies. Specific research questions fall within two broad topics: family experience of the intervention and family understanding of the intervention.

Study Context: Qigong Massage Intervention Research

A series of studies over the last 7 years has been investigating the effects of a Chinese medicine-based qigong massage technique on children with autism. The intervention is two-pronged, is delivered over five months, and involves direct treatment of children by trained therapists as well as teaching family members to do a daily follow-through massage that takes approximately 20 minutes. The massage is a global treatment for the child; it follows

acupuncture channels and points on the child’s body, and is designed to clear sensory impairments, improve sleep and digestion, and strengthen overall health.

The research to date has included two controlled studies that collected before and after data on sensory, sleep and digestive impairments, autistic behaviors and markers of developmental delay (Silva, Cignolini, Warren, Budden & Skowron-Gooch, 2007; Silva, Schalock, Ayres, Bunse & Budden, under review). An additional study demonstrated that the intervention is both portable and generalizable in that Occupational Therapists, Early Intervention and Early Childhood Special Education professionals were taught to effectively deliver the intervention, obtaining comparable results to when the intervention is delivered by a physician trained in Eastern medicine (Silva, Ayers & Schalock, in press).

The model upon which the qigong massage intervention is based draws from both Eastern and Western understandings of autism. From a Chinese medicine perspective, autism is a disorder – at least in part – of the senses. The senses are the “doors” and “windows” that, when open, allow us to take in the complex, and constantly shifting, social world around us. If these “doors” and “windows” are foggy, or partly closed, it is difficult for the child to perceive and connect with the people in their world. If the senses can be cleared and opened, children will have more access to their world, the people in it, and learning.

From a Western perspective, one symptom of autism is that the thresholds of sensory nerves are altered in some way that can differ for different senses. Thresholds might be so high that children are insensitive to what for others would be painful – children who fall and cut themselves, but do not cry. Alternatively, the thresholds can be so low that even gentle touch can cause painful reactions. The Qigong is designed to repair this sensory impairment so that children are more able to learn in typical developmental ways.

The studies to date have shown consistently positive effects in improvement of sensory, digestive and sleep problems, enhanced learning of developmental skills, and decreases in autistic behavior (Silva & Cignolini, 2005, Silva et al, 2007, Silva et al, in press, Silva et al, under review). As children receiving the massage exhibit reduced sensitivity to some sensory experiences and more openness to others, sleep patterns improve and bowels become more regular. Once the physical symptoms improve, children seem able to acquire developmental skills at a faster rate than do children in the control groups, first gaining in missing motor and living skills and then acquiring social, language, and communication skills (Silva et al, under review).

Methods

This study used interpretivist methodology and qualitative methods of participant observation and interviews to explore and document families’ experience of Qigong massage and its affect on family life. Interpretivist research has a substantial tradition of exploring families’ perspectives and experiences (e.g., Ferguson, Ferguson, & Jones, 1988; Harry, 1992; Harry, Kalyanpur, & Day, 1999; Kalyanpur & Harry, 1999; Lareau, 1993; Lareau, 2003). The power and utility of this approach is that it permits exploration of a range of variables that go into the social construction of family life. Thus, we were able to explore a range of topics regarding families’ experience of Qigong massage including how they incorporated the follow-through massage into their family life; whether they experienced it as a chore or something else; how difficult it was to learn; and how difficult it was to travel twice a week to the treatment site. We had two overriding research questions: How did families experience the Qigong massage intervention? And, how did families understand the massage treatment? Table 1 summarizes

these broad topics and some of the questions asked during both the participant observations and interviews.

Insert Table 1 about here

Forty families were interviewed and observed for this study of family experience and understanding. Twenty-six families from the most recent controlled study participated, and 14 came from the immediately previous study. Families were invited to participate in both studies through an invitation letter sent to all children between three and six years of age receiving autism services from two Education Service Districts. Criteria for selection of children to receive the massage treatment were: 1) under six years of age with an educational diagnosis of autism, 2) enrollment in early intervention services, and 3) no additional complicating medical diagnoses. In addition, families agreed not to begin additional interventions for autism during the study and to bring their children to the treatment site 20 times to receive the Qigong massage and to be taught how to do the daily follow-through massage.

For this study, data for the group of 14 families came from exit interviews. For the remaining 26 families, the qualitative researcher began data collection at about the 4th week of the five-month intervention. She accompanied families when they arrived at the treatment site, observed the massage and talked informally with family members present. Fieldnotes were completed within a day of these observations and informal interviews. This same process occurred 2-3 times for each family throughout the treatment phase of the study. In addition, the researcher invited families to participate in individual interviews and completed an additional 10 of these. A group interview with a mother and a couple was completed half way through the treatment cycle. Finally, the researcher participated in all of the exit interviews at the end of the treatment cycle during which the treating therapist shared results from the testing. All families in

the most recent study completed a stress index eliciting a stress rating in the areas of sensory issues, sleep, digestion, tantrums, aggression, social development, language, self-injurious behavior and concern for the future. These were completed at the beginning and the end of the treatment cycle and provided some useful insight into their experience of autism.

Field notes and interview transcripts were analyzed using established qualitative analysis procedures (Bodgan & Biklen, 2003; Maxwell, 1996; Patton, 1990; Seidman, 1998) The lead researcher read all transcripts and notes and organized them into broad categories such as “family life”, “family stress”, “changes”, “role of massage” and “change metaphors”. These broad categories were further explored individually and across categories for variation and commonalities across families that resulted in patterns. For example, families descriptions of how what doing the massage was like at home supports the clinical findings that children respond to the massage through a describable pattern and that this, in turn, influences not only families’ experience of the massage, but also their description of stress and family life.

Families Experiences

“Autism is stressful”

All of the families spoke to the challenges of having a child with an autism diagnosis. Of course, all of the children were different and presented different collections of symptoms. Family members characterized some of the children as having frequent “major tantrums, hitting himself”. Sensory issues disturbed many aspects of family life: anywhere from “high-pitched screaming and rolling on the floor holding his ears, whenever his brother cries,” to, “I can’t even take her to the store, much less on a family vacation. If there’s too much going on, she just goes into overload and has a meltdown.” Parents reported many tactile issues with clothing, shoes, and haircuts that were “a real bad fight.” More than one family had experienced a situation

similar to this one recounted by one family member. “She cut herself pretty good on a piece of glass and there was blood all over and she was fascinated by it and it didn’t bother her.” For other families, their children were distant – “kind of a cold duck” or “just wandering around picking up sticks” and not noticing people. A number of parents expressed sadness that their child with autism didn’t seem to notice their younger siblings. Some children talked and were described as “warm” or “cuddly and lovable” while others rarely verbalized or tolerated touch: “he liked it when you would rub his back, but that was the only time he would let me get close to him. Sometimes he just shuts the door and puts his little sign on the door to keep out.”

Life with autism was stressful for all the families in a variety of ways. “He wears me out because you have to get up and follow through with everything” was only one way this stress was expressed. Another family found their lives stressful “because you never knew what was going to happen. When we went out, we used to put a belt on him so that he couldn’t be free because you couldn’t trust that he wouldn’t get away.” Of the families that completed the stress questionnaires, all felt that worries over their child’s future created stress. One couple explained that “when they’re little kids, [they] can do almost anything. . . but at this point the differences are so obvious . . . and that’s where we’re petrified.” School and the need to move past early intervention programs represented for many of the families the most pressing worry since, as one dad reported, “we’re not sure how the school system will treat him, and we’re not sure how he will treat the school system, and so that carries a lot of anxiety.”

While the two most stressful behaviors for families were aggression and severe tantrums, nearly all of them also identified sensory issues, limited communication, diet issues, and sleep problems” as high stressors. All the families also identified concerns about the near and distant future as a source of stress. The participating families represented a range of experience and

family situations. There were 2 single mothers, and 3 families that had 2 children with an ASD label. Some families were professionals – lawyers, researchers, teachers, and one executive chef. Others were carpenters, gas station attendants, fast food workers, or sales people. A dozen of the mothers were full-time homemakers. A number of the fathers held positions in accounting, construction, technology, or were in school. About a third of the families had only one child. The rest had between 2 and 5 children. In some of the families, the mother was the primary caregiver, but for about half of the families, both parents shared caregiving responsibility and fathers came either alone or with mothers to the massage sessions. One child was being raised by grandparents, and two others had a grandparent as a primary caregiver along with a mother.

Qigong and Family Life

Families first had to learn the 12 movements of the Qigong massage routine, and most found that “learning the techniques and doing them at home was not complicated.” Compared to other interventions some of the families had tried, the follow-through massage was refreshingly modest as a demand. One mother explained,

I have done lots of different things to help Sarah¹ in different areas in the last four years and have seen minimal results and often only in a specific area...like I tried brushing [and] it's a huge commitment cause its every 2 hours for 4 weeks and then you taper down slowly to about 2 times a day. If you compare that commitment to this once a day for the massage it's a huge [difference].

Fitting It In and Getting It Done

For some of the families the follow-through massage was “fine, but you know its one more chore to do at the end of the day.” This “chore” interpretation remained for a few families

¹ All names used throughout are pseudonyms to protect the confidentiality of families and their children.

throughout the study. For others it was a matter of finding a way to fit it into an already complex family life routine. As one mother explained, “I’m not a very organized person in the first place so I’m not great at forming routines.” For her, and others, “it’s just a matter of remembering to deal with it” or “getting used to having that addition to the routine.” For most families, once they “established that it went on the schedule and we picked out a time of the day to do it, then there was no missing it.” One mother expressed it most clearly:

. . . learning the techniques and doing them at home was not complicated, it was just me getting it into our daily routine that took me a few weeks, but once we established that, it wasn’t a big deal at all.

The majority of the families found that bedtime was the preferred time to fit in the massage routine. One family reported that they had “slowed down” doing the massage toward the end of the treatment cycle but the remainder did the massage as part of the daily routine and only missed occasionally, when they were traveling, or just too tired, consistent with the original instructions to parents, which were to do the massage on a daily basis, unless they were unwell, emotionally upset, or simply too tired.

For some of the families doing the massage “was a complete pleasure and it wasn’t a chore.” But in part that related to how their children responded to the massage. Several had stories about times that “he didn’t want to do it at first” or that “giving him the massages at night for the first month was a pain.” For most, these difficulties resolved within the first month, but for 2 or 3, the difficulties continued throughout the study, as happened with Kally for whom “there were days when he would lay there and let me do it and then there were days when it was a trial and took me twice as long ‘cause he fought every step of the way.” For most families, at least at the beginning, there were specific areas that presented difficulties: “he’ll do it, but he

doesn't like his toes done,” or “he doesn't like his ears touched.” The child's adjustment to the massage made a substantial difference in how families experienced doing it. The tension is well expressed by one family this way:

It's a little easier now because he doesn't move as much. It's getting easier and he knows that he wants it...he grabs my hand and puts it on his stomach so I know that he's ready and he wants the massage, but there are a few points where you can tell that they are his sensitive areas and so as soon as we have to start doing that [movement] his interest level goes way down ... he knows that he's going to get the parts he likes too, but I just think that it's hard for him.

Once the massage was in the routine, many families found that their children enjoyed it or were able to “indicate to me that she's pretty comfortable with it and likes it pretty well.” Many of the families found that the massage relaxed their children and was especially helpful to prepare them for sleep when incorporated into the bedtime routine. As one mother explained, “they are more loose afterwards and . . . it starts a whole routine for the evening.” A number of children would ask for the massage: “Taylor liked the massage routine so much that he would go to the fridge where the technique sheet was kept, and remind mom every day to do ‘up, up, down, down,’ ‘cause that's what he called it.” Several parents reported their children giving the massage to other family members “I came out this morning and found him giving his dad the massage.”

All families, regardless of whether or not disability is present, craft very careful and often complex routines of family life. When autism enters the equation the routines can become dramatically more difficult to organize and the prospect of making changes in them once established can be daunting. These families were eloquent in their confirmation of the daily stress and struggle of living with a child with an ASD diagnosis. Any daily intervention can represent a challenge to that routine that families must carefully consider. Many home programs or other interventions requiring any kind of commitment from families for either delivery or

follow through could benefit from examination of the impact on family life before asking for family commitment.

The families in these studies did benefit from this prior consideration. What makes this particular intervention different from others is that not only did families find it possible to “fit it in and get it done” in the face of complex family routines, but family life *itself* benefited from doing the massage in a variety of ways beyond just the benefits that accrued to the child with autism.

Changes in Children and Family Life

Once both children and families adjusted to traveling twice a week to the treatment site and figuring out how to do the follow-through massage at home, benefits began to accrue not just to the child, but to others in the family. One mother explained that sometimes she would do the massage “when I start to get stressed” because then “the stress from both of us just goes.” Many of the family members found that “it calmed me down” and found that they looked forward to the massage “so we can both calm down.”

While the massage helped mothers and fathers “calm down” and reduce their own stress as well as their child’s, some also found that the massage created a special time with their child: “Tim and I have these few moments and we connect.” Another mother thought “it was fun little thing for mommy and son to do together every night ... and just relax. We both enjoyed it. It was really fun.” One of the mothers explained that the experience of doing the massage “made a different connection between him and me and his father. Before he had kind of a broken connection with his father and it’s just a lot better now.”

As the children began to respond to the massage intervention (see cites) by sleeping better and having smoother digestion, families began to experience a new dynamic. In one very

practical example, one couple explained “He’s sleeping better and so that makes everything better because we’re getting sleep.” For another family, the “schedule could be more relaxed. It didn’t have to be minute by minute, so it has just made a huge difference in how we live our lives.” As children began to have fewer tantrums and “meltdowns,” families could begin to relax. “Her attitude is improving. She’s not so horrible to be around, so that’s really rewarding for us.” For some the experience of the massage was dramatic: “There for awhile it was like he wouldn’t do anything and he was out of control and since we started this. . . you know, it’s almost like he’s a whole new kid again.” The changes for this and other families were “not baby steps, they are going by the leaps now. It’s just amazing to see them go that quickly.”

Certainly, the families talked most about changes they saw in their children. Some of these started almost immediately with the first massage treatment. Several families were astonished to report that their child passed dark green, blackish stools after their first treatment, “they pooped like racehorses and have been pooping every day ever since.” For other children, families did not report noticeable changes for several weeks – “It wasn’t until about a month in . . . he potty trained and the night terrors went away. . . several things happened all at once that we had been working on for so long!” Of course, different children experienced different changes and amounts of change. But across all the children, change fell into one or more of four categories.

Becoming Calmer. The massage itself calmed many of the children and it often translated into fewer and shorter tantrums and “meltdowns.” As one parent explained very succinctly: “Calmer. Less fits. Stopped biting also.” Several family members found the tantrums they still experienced to be “more typical” of a very young child. In fact, the new calmness made their children “just like any other child. His behavior is just great. It’s totally

different.” This change was the one most often mentioned as noticed by others, like bus drivers and grandmothers who found it easier to take the children out and about, “before they would be jumping off the walls, now they sit there and actually listen!” Barbers and doctors noticed.

When David “sat still and got his hair cut, even the barber commented ‘Wow, David’s behavior has really changed so drastically!’” One important outcome for many of the families was that other people *did* notice and having their children in public settings was less stressful as a result.

Other people that we know have noticed too. We can’t believe how his behavior had changed and how he has mellowed. He listens to what he has to do and they just go, “Wow!”

We’ve had people say it’s just amazing the change in her. She actually engaged in playing with her cousins over Christmas break instead of just standing there on the outside just watching. She actually got right in and got involved. That was great to see!

Our meltdowns have gone from about two or three a day to two or three a week, which is amazing. And we’re able to de-escalate him a lot easier now

Expanding Awareness. Once children began to become “calmer, he is more centered, he’s more focused,” other things begin to happen. In many different ways family members described “she seems to have opened up so much – started being more of a little girl trying to engage other kids, trying to play more than just observe. It’s been really great to see how far she’s come.” Children started to notice their siblings and play with them. One mother well expresses what many the families experienced as their children became calmer and more aware:

Prior to massage sometimes she would act like she was deaf even though she is quite the opposite. She has incredible hearing. She had a really low tolerance for learning stuff – she would get frustrated very quickly – very short attention span. She had a lot of sensory information coming in at once and it made it difficult to get through to her to communicate to her and it was difficult for her to concentrate, and it’s just like a fog has lifted. She’s able to focus and she’s not overwhelmed all the time. She has way less tantrums or meltdowns and when she does they’re not as severe and she recovers a lot quicker. She’s not engaging in

self-injurious behaviors. She will respond more frequently when you call her. She makes better eye contact. Things have really cleared up and she's plugged in and that affects every [other] area.

Feeling Better. Nearly every family reported physical changes in their children during the period of treatment. One mother explained “I’d set out with the attitude that if we [could] just get Lori off her laxative and going to the bathroom on her own, I would consider it a complete success [even] if no other benefits [resulted]. And we got that pretty much right away.” Sleep problems, bowel problems, picky eating, and sensory issues plagued family lives. And all began to change. Instead of waking up two or three times a night and staying awake, now “he sleeps well. Once in a while he will get up early at 5:30. . . but all you have to do it put him right back to bed and he’ll just go back to sleep.” Other children’s improvements were more “baby steps”: “the TV has to be on, but he’ll go in there and I don’t have to be there and I go back in five minutes and he’s asleep.”

Some children began to experiment with more foods – “he’s gutsier. We’re going to do a vegetable next week. . . sweet potatoes were about the only thing [he’d eat] and we mixed everything with sweet potatoes and he started turning orange! Now, he’s more open to other foods.” Another child “actually ate a few pieces of chicken the other night! And he’s eating cheeseburgers from McDonalds every time we go!”

Many of the children had unusual responses to touch. Some would shy away or even act hurt. During the period of massage treatment, more than one family member reported “now he *wants* to brush his teeth” or “he lets us brush his hair.” Once mom reported that her child who had always vehemently resisted haircuts, not only allowed her to use both the scissors and clippers, but when she was finished and reported to him:

Okay, we're done! And he said, "Well, I want to see it." So we got the mirror out and he said, "I'm not sure, I want it shorter." And I said, "How much shorter?" And gosh, his hair was almost gone, and I said I had to stop. And I said, "Oh my gosh!" He's lost all sensory problems on his scalp.

Children began to have normal bowel movements, and several became toilet trained during the months of the treatment, sometimes in a matter of days. Instead of constipation and diarrhea, children became more regular so that families were able to report that “out of the last twenty days I would say 14 of those we have had that child poop on the potty!” For one couple reported with excitement that “David is starting to go in on his own – just go in there. He’s still wearing a night diaper but daytime – it’s awesome!”

All of the children experienced some physical changes and for many of the families, these changes were most powerful because they made the most difference to family life. It was things like sleeping and eating better, getting potty trained, and complying with ordinary rituals and chores like haircuts and teeth brushing that made their children seem “just like any other kid.” When they started to eat a wider variety of food, there was less worry that their children weren’t getting enough of the right things to eat. It wasn’t so much that their children became “normal” or even less “autistic”, but the most challenging and stressful parts of the ASD experience were those that most disrupted family life. When that began to change, families were free to create a new family dynamic.

Learning and Doing More. A few children in the studies were slower to change and only experienced the kinds of changes described by the end of the treatment cycle. Most of the children experienced new skills development, sometimes at a very rapid pace. Children began “talking in sentences, expressing himself.” Others might only begin to say a few words or begin

to imitate so that “now we can understand what she’s saying”. The following two examples well illustrate the range in language development experienced by the children in the studies.

He’d always done a lot of baby babbling, but he wouldn’t be very clear. Now he’s intentionally trying to repeat what someone says whereas before he wouldn’t do that. It’s become, well not a daily occurrence, but a couple times a week he’ll come up with a word that he’s never said before....

About the last month he started singing, and dancing. So he’s singing, he’s dancing, he’s having conversational speech. He’s talking to us about his school day. He acknowledges he has parents. His typical peers didn’t exist before and now he’s [saying] “I met so and so in line”. He’s talking about school!

Other children develop gross and fine motor skills. “He learned to ride his bike,” or began to “pretend play with his action figures” or “write 1, 2, 3. We’ve known for awhile that he’s [known his numbers] but now he can say them or write the numbers or letters”.

Families’ Experience In Sum

Families mentioned changes in language and communication most often when they talked about skill development, but more than one reported that it was the whole package of change that they found most exciting. The mother whose criteria for success was getting her daughter off laxatives, found “all the others were just fringe benefits: Lori’s improved attitude, reduced aggression and tantrums, eating better, sleeping better, everything!” Another mother explained,

Well, I came in here really looking for sensory help for Sarah. She had some pretty extreme sensory issues. I had absolutely no idea that her communication would improve. I

had no idea these other areas would be affected – just had no clue. I mean... I’m just dumbfounded by the whole thing.

Overall families’ experience of the Qigong massage treatment was positive. Once they figured out how to manage the requirements of coming to a treatment site twice a week and fitting in the follow-through massage at home, they and their children began to experience enough change to encourage them: “We’re very busy, but we fit in the two appointments each week, and it’s well worth it” and for one dad, for whom the commute was one hour each way: “Driving out here twice a week wasn’t very fun, but the benefits were well worth it” As seemed clear from the fact that all 40 families attended all 20 appointments, and none dropped out of the study. It seemed clear that they found the Qigong massage program worthwhile. Even those that were not expecting much or were skeptical found the experience beneficial:

It was honestly a little strange at first. It was something a little different, unconventional. But we wanted to make a difference in Jack’s life and we were willing to try anything. We are very glad that we did. It has just made a huge difference and meant a lot to us.

More than one family reported that they appreciated that the treatment was “non-invasive” and while “I wouldn’t necessarily say that it was the silver bullet that solves all your problems,” it was “fun. . . it was good. . .it was a good investment. . . I’ve accomplished something.” In the end, without exception, the families reported they would recommend the experience to another family with a child with autism “do it...there is nothing to lose and ...so much to gain... look at our son.”

One Family’s Experience

One mother explained during one of the later sessions in the treatment cycle that she and her husband had been “pretty skeptical”, especially her husband. She described him as having a “very, very” conservative lifestyle, having been raised “very, very strictly”. She went on to explain:

When you’re raised the way that he was raised and even the way I was raised you just do what’s traditional. You go with traditional medicine [because] everything else is just hokey. We were very skeptical and I said, “You know what? I don’t care! I don’t care if it’s different from anything we’ve ever done, because I will do anything to make him better – barring extreme medical interventions. So I’m willing to try it.” Sam said “Okay, we’ll try it, but I think it’s a lot of hocus pocus” and I said, “Whatever. I really don’t care. Deal with it. It’s going to happen. Now, we’re both just, “Oh, my gosh, this is so amazing! I mean, we’re totally believers at this point. The skepticism is 100% gone. It works. It just works.

And my son is an amazing child now. He was amazing before, but he’s amazing and he’s easier to handle. . . I mean, I can do my hair! I have time to put on make up and stuff. . . If he has a meltdown we can de-escalate him in five minutes now, whereas before there would be nothing we could do. Now it’s so easy. I can just say, “Okay, Lance, let me help you.” He’s starting to recognize that he needs help and he’s starting to become aware that what this is doesn’t feel good and he doesn’t know how to stop it, so he wants help. . . It’s really cool, really cool. I mean, he’s still quirky. That’s okay. I don’t care if he’s quirky, I just love that he can have a conversation with me.

I mean, seriously, I’m going to start giving it to him (points to her other child) because he’s so hyper I just want to calm him down. And my daughter has been watching Lance – we slacked off for a bit and my ten year old says to me, “Mom, is Lance’s Qi bad again”? And I said, “Well, mom got a little lazy.” And she says, “Well, will you make him nice again because I don’t like him when he’s like this.” . . . Even my children can see the difference. They looking at him and saying, “Lance is nice now. Lance plays with us now and he didn’t used to be like this. He used to just beat us up, run away, and trash our room. And now Lance is nice to us and does stuff with us.”. . . It’s pretty amazing. I’ve never been happier about anything in my life.

We drove by a car lot [one day] and saw a giant gorilla and it triggered something in his head and he woke up with a nightmare last night and I was almost hurt because instead of screaming “mommy”, he yelled for daddy. It was really cool. And Sam said, “You know, I didn’t want to get up, but that was pretty cool”. So he got up and went in there and scared away the gorillas and came back to bed. It’s pretty neat. I mean, he’s going up and saying, “Daddy, give me a hug.” “Daddy, I want to sit with you.” And he’s giving Daddy kisses, he’s loving Daddy. Sam came into [Lance’s] life right at the time when he was beginning to regress. . . Sam’s heart bonded with Lance, but

Lance's heart did not go the other direction. All of a sudden, I've seen this relationship developing with them and it's just the coolest thing I've seen.

It's been incredible. It's like watching this child just open up. I mean, he's almost typical! He's quirky, but he's almost typical. I mean, I can handle this. I can deal with this. There was a time what I was going, "I don't know if I can do this." Now, you know what? He's just funny now. He's goofy and he doesn't do things like anyone else. I mean, he's fun and he's unique, and he's just great. He's a great kid now. He's not so difficult anymore. He's so much easier.

Families' Explanations

Qigong massage, like many other treatments that have come to the West from Chinese medicine, is often described as “alternative.” Given that most of the families had little or no previous experience with Chinese medicine or other forms of alternative medicine, we were interested in exploring what sense families made of the experience. Purposefully, the treatment team chose not to teach the families the Chinese medicine concepts directly, and instead the team listened carefully to how families described their children and what was happening with them. It seems important to develop a bridging language between the ordinary language that families use to explain their experiences, and the language of Chinese Medicine, which is foreign to most families, and utilizes words describing energy, like “qi” – energy, and “qigong” – the skill of working with energy. And while the Chinese medicine paradigm of helping children become healthier, and recover from chronic conditions with Qigong massage, is desirable to families, the model upon which it is based: a physiology in terms of energy channels and flow, a pathology defined by energy blockages and deficiencies, and a treatment based on correcting these, is far from familiar to them. By discovering the families' personal explanations and descriptions of the treatment process, the team hoped to find ways to communicate more effectively with families about Qigong massage in the future.

While the focus of this particular study was primarily on exploring how families were experiencing the massage treatment, we were able to gather some interesting information on how

family members understood those experiences. As one mother noted during an exit interview, families “find ways of understanding what’s happening with their children that work for them.” Three patterns emerged from the data: 1) no explanation possible; 2) no explanation needed, and 3) families’ change metaphors.

For a number of families *no explanation was possible*. For these families there were too many possible explanations for the changes they were seeing. Although children did not begin any new interventions during the study, apart from the Qigong massage, they were enrolled in early intervention programs and some also continued previous treatment efforts such as special diets. As this father said: “its hard to separate out what’s what, but we’ve definitely seen a lot of improvement...how much of its directly related to the massage therapy and how much of it is related to the [early intervention] classes he’s going through.... that it might increase the effect of both...I don’t know.” Or this father: “we just don’t know what to think about it. We’d like to think it was the [massage], but it might just be her growing too. I don’t know. We can’t tell.”

For these families, the difficulty was discerning a more normal *rate of growth with* the qigong intervention, from a more delayed *rate of growth without* it, in a setting where they were seeing the child every day. Growth always looks normal, and unless the growth rate is dramatically increased, or the parent is particularly attuned to the incremental developmental steps, it is difficult to discern a rate change. Of course, discerning such a change is further complicated by the fact that families don’t experience their children primarily in developmental terms, but in terms of who their children are and how they engage, or fail to engage the demands of family life and routines.

For a number of families, because the child had improved, *no explanation was needed*. The answer to the question “How do you think the massage worked?” was, “he is better.” As one

father explained, “massage works, Chinese medicine works.” Another father offered, “it’s 3,000 years old. They’ve done research on it.” Still another described the “lesson” of trying different treatments to be “...if improvements are being made, then...whatever it is that you’re doing is enough.” One mother explained that since families can’t just passively sit by and accept their child’s disability, their goal is to “try anything.”

There are so many theories on how to improve [the children] and we’ve tried a bunch of them – some with some mild success, some without success. So, I didn’t enter this with any kind of expectation that there would be any kind of success, just because so often there [isn’t]. There are so many different theories. . .

Families that try many different things, hear many different theories, sometimes contradicting one another, and ultimately, it is often not the theory that is important to them, but the result. As one mother said, “this is the first time that someone has taught *us* something that *we* can do to help our child.”

Two families didn’t see any change—at least in some areas. One boy was an extremely picky eater – only popcorn and sometimes American cheese – and “we’ve seen no improvement whatsoever.” For another child, while the teacher reported significant changes, the mother didn’t see any. She thought that the teacher’s perception was to be expected: “this has been the case every school year – as the year goes on, he is more settled.” So the changes the teacher saw were only a result of her son settling into the routine, and bonding better with the teacher. For her, it was unambiguous: “I honestly didn’t feel that there was a significant change that I would attribute to [the massage]. Most of the changes I attribute to the six months between four and four and a half.”

For the majority of the families participating in this study, there was change that they did attribute to the massage, but explaining that change was not straightforward for them, and we noticed that they employed *change metaphors* for what they were seeing in their children. Sometimes the description was a straightforward before/after: “Between when we first started and now, it is a huge jump...huge!” or, “he has become a little person now instead of being a closet child.”

This notion of “personhood” or “humanity” arose frequently as families tried to explain what was happening. One parent saw “the real *her* coming out...it was there all the time, but you couldn’t see it. I’m proud of her.” The notion of emergence or opening was another common theme to the explanations. In one case, the massage resulted in “his mind is open now,” and in another, “he has more force in his body, in his muscles. . . and his mind opened itself more.” A father explained his son’s “sense of presence was growing. . . over five months we’ve seen a lot more of him not being so tuned in to what is going on inside, but what is going on out here.” One parent described the massage as “stimulation throughout his body. I think it helped to integrate him as a whole human being rather than as a scattered collection of organs that aren’t working together very well.”

Children became “more typical”; their tantrums were now “typical” or “just like any kid.” A few families used a more external metaphor. Rather than their child changing, something outside of them changed. “I can see a switch go on.” “Broken connections” with parents and siblings reformed. Another mother described the change as “a shell that’s dropped off of him. He has a light he didn’t have before.” Two other families used a “fog” metaphor: “his teachers describe him as not really having a fog around him and I see that too.” “Something has cleared for her. I

don't know what the right word is, but some fog has lifted so she's able to focus better on what's going on in her environment.”

A couple of the families began to use the language of energy, and one mother melded it with her own faith and prayer. For her, it was the combination of her prayer with the massage that helped her son to improve. Another mother appreciated the notion of energy, but was less confident about how it operated. In describing what she would say to other families that were thinking of using the Qigong massage therapy, she explained “I would totally recommend that people look into it because I do believe that the energy force is really real. There is a lot that we can't describe in words. . .” Still another mother offered a little more explanation about energy from her professional experience:

I totally believe in energy forces. I see in my career with cardiac rehab that the energy force is crucial to the relationship between the patient, the instructor, or the doctor. I know that there is energy that we can't describe always in statistical terms.”

Perhaps this is the real message of these families' explanations. There are indeed forces – energy – we don't completely understand or can explain; very few of us understand quantum physics. But, the result *is* possible to measure, see, experience, celebrate, and enjoy even if we don't know all the things that contribute to that result.

Explanations and Experiences

Other articles cited earlier describe the controlled studies, and the significant positive results achieved by the children in the treatment group, in comparison to the control group. As important as the results of the testing, is what the families thought about and experienced from the treatment. The vast majority of the participating families reported good experiences, not only

with the commitment of treatments and follow-through, but also with positive changes in children and family life. By way of conclusion, perhaps the best summary is that offered by families as they thought about their children’s future at the end of the five-month treatment cycle.

Certainly, Qigong massage did not solve every problem for families or children. Families recognized that there was more to accomplish, and by the end of the study, each one had a number of new developmental goals for their child. But the difference was, they were new *developmental goals*, and the *behaviors and physical symptoms* that had scored high on the original stress ratings, and had so disrupted family life, were much improved.

Families were feeling much less stress about their child’s future at the end of the treatment cycle: “I don’t have too many concerns about his future other than, as he progresses through school, finding the right fit for him and for what he needs.” Some families had new options to look forward like “regular kindergarten” instead of a “life skills class” or at least hoped for school in a “regular classroom because I think that’s how she learns best.”

Seeing their child change, led one couple to explain that they were “not concerned about him getting to his age, but him reaching his potential –which he has a ton of now!” Another parent explained:

We used to think, ‘Oh, gosh! He’s autistic. Special Ed. all of our lives. We’re not thinking that about him [now]. I really think that he’s is going to go mainstream. He is really a very bright child and how he is able to express what he had in his head more. I think he is going to be just fine. He is probably not going to be a world speaker, he is probably not going to be out in front, but he is going to find his own niche and he is going to do well.

Seeing a different future didn't mean that families didn't expect ongoing challenges. But families generally begin with *who their children are* and inductively discover how they will operate in the family and the world. Professionals begin with *how children compare* to the larger group and deductively see how a child will operate in the world. Both of these perspectives are important. Too often, professional interventions fail to listen to families' understanding and explanations of their own child, of the changes they see, and of their interpretations of their children's reactions. However, when this effort is made, the partnership between families and professionals can be most powerful and effective in creating the learning conditions and supports that will result in growth and success for any child. Together family and professional perspectives can result in what any parent wants for their child whether they have a disability or not:

To be able to be somewhat independent and to have a relationship – to be in relationships. You want your child to be happy. . . to have some self worth. . . have a job and know that he has a purpose.

It is our intention to continue our work researching this intervention for young children with autism, and working in concert with their families, to better our communication and understanding of how this Qigong intervention can assist them during the long years of raising their children to adulthood.

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Table 1: Interview Topics and Sample Questions

Families’ Experiences	Families’ Explanations
How did you learn about the qigong massage?	How do you understand what happens with the massage?
What’s it been like for you participating in the study?	How do you think the massage “works”?
What’s it like for you to do the follow-through massage at home? T When do you do the massage? T Who does the massage? T What’s it like for you to do the massage?	How are you thinking about the next few years with your child? T What about when s/he grows up?
How does your son/daughter respond to the massage? T At home? With the therapist? T Does your son/daughter every “ask” or indicate that they would like the massage?	What would you tell another parent who is thinking about signing up for the massage?
Tell me what happened? T What did you think of the massage program? T For your child? T For you?	
Have there been any changes in your family life that you think is related to participating in the study or the massage?	
What do your other children think about the massage?	