

Teaching Positive Living Skills to a Family with Special Needs

Melissa **Klingenberg** and Terry **Orlick**, Canada

Melissa Klingenberg is a mother and educator who has a wealth of experience teaching children and families with special needs. She completed her Masters Degree thesis entitled, “A qualitative case study approach to examine the process of using mental skills in a family with special needs,” under the supervision of Terry Orlick at the University of Ottawa in 2001.

Email: klingenberg@zwiers.ca

Terry Orlick is a Professor in the School of Human Kinetics, Faculty of Health Sciences, University of Ottawa, CANADA

Email: excel@zoneofexcellence.com

Abstract

The purpose of this study was to introduce positive living skills to a family with special needs. A qualitative single case study was used to discover whether positive living skills would be advantageous as tools or resources for one family with special needs. Activities, from Orlick’s Positive Living Skills Program for children, were adapted and presented to the family, at their home on a weekly basis. Information was gained through observations, conversations, interviews and interactions. Weekly notes were gathered and reported. Interviews were conducted mid-way through the program and at the end of the program. The interviews were transcribed and analyzed to see if the positive living skills were useful tools or resources for the family. A detailed description of the responses of the child, the parents and the researcher are given. Through the intervention the family was equipped with a common language and positive actions for dealing effectively with stressful situations. An extremely valuable family discovery was that despite their many demands, there was time to spend together which could re-energize each of them. Family coping was improved and they viewed themselves as functioning at a much more satisfactory level than before this program began. This article presents one family’s journey of interacting with each other while discovering that positive living skills can help them all to face the special demands and stress of their unique family.

The Purpose

The purpose of this study was to introduce a positive living skills program to a family with special needs. Through the study we sought to discover whether Orlick’s positive living skills program could provide relevant tools or resources that were advantageous to the family.

Much literature supports that raising a child with disability creates a special challenges for the parents (Cummings, Bayley, & Rie, 1966; Dyson, 1991; Rousey, Best, & Blacher, 1992; Simons, 1987;). Evidence in the literature supports that each family has a special combination of strengths, stressors, vulnerabilities, and coping strategies. The

family structure and the members of the family are of utmost importance as they:

“...often represent the only long-term responsible, and caring people in the life of a child with a disability. The family is of vital importance; interaction with family members deeply influences the child’s opportunities, barriers, challenges, expectations, ambitions, frustrations, and general quality of life. Whether the family is nuclear, single-parent, or extended, it plays a powerful role in the child’s social, emotional, behavioural, and academic development and progress” (Winzer, 1993, p. 571).

People who care for the disabled often see very little in the way of measurable outcomes as these special needs people live and function in a society which places an emphasis on higher levels of individual success. The eyes of society often view disabled persons as unsuccessful, which leads them to no achievement at this level of individual success, Cordonni (1990) makes a power statement concerning families who have disabled children:

“It is a sad cliché that having a handicapped child too often results in a handicapped family. A handicapped family is one that does not function as well as it might” (p.39).

Families may set out desiring to function “as well as they might”, but this goal is not always achieved. Families need to be challenged and assisted to mobilize resources to fulfill the needs of their unique situations and to develop positive coping strategies for present and future situations.

Intervention Approaches

A search of the literature related to intervention programs aimed at providing resources for disabled family needs reveals there is a lack of information in this area. Interventions exist primarily in two areas. First, a teacher’s perspective on how to aid the disabled child in integration. Second, a counselors perspective on how to gain understanding of differing phases and changes that occur within families. Children in today’s society experience numerous stresses: to excel in school, to fit in socially, and to cope with potential stressors within their families (Winzer, 1993; Zeitlin & Williamson, 1994). Much of the research and available interventions take a public institutional approach (school or hospital).

Special populations of children also experience stress, such as fear of the unknown, loss of control, and the uncertainty of their futures (Siegel, 1995). Teaching children effective methods to deal with stressful events can reduce feelings of helplessness and anxiety by equipping them with positive life skills along with practical methods for coping (Gilbert & Orlick, 1996; McDonnell & Bowden, 1989, Orlick, 1998). Previous studies have shown that normal school children are able to apply these strategies across a variety of settings, such as school and the hospital (Cox & Orlick, 1996; Genevro, Andreassen, & Bornstein, 1996).

In my review of the literature, I did not find any approach that empowered both the child with disability and their family together, at a familiar location such as the family home.

“Since changes in a child’s development are intimately and directly impacted by the care giving that a child receives, it seems especially important to consider how the care giving aspects of the family system

operate in relation to a child's development" (Bradley, Parette, & VanBiervliet, 1995, p.3).

How a family functions, whether positively or negatively, impacts on the child's development; thus positive functioning should be further examined within family environments.

In my encounters with families who have children with disability, the medical diagnosis is the beginning of a long journey of support and care for all involved. The family still faces the reality of living with disability every day. Very little alters after spending time searching out a piece to the puzzle by going from professional to professional. What does a family need? I have posed this question to parents with special needs children and have learned that among other things, these families desire to create more supportive environments for each member of the family, including the child with disability. The family is committed to supporting each other and there is a willingness to take the steps necessary to achieve their goal of a positive, high-functioning family. Often these families feel that the family unit is divided and unable to be fully supported. In their attempt to meet the challenges and demands of life they are often unsuccessful and thus further disabled. Greater levels of support can be achieved when a family with disability and a supportive society work together, thus preventing the family from becoming a "handicapped family".

The Process

The method chosen for this study was a qualitative single case study. Creswell (1994) summarizes this type of research as consisting of "a single entity or phenomenon ('the case') bounded by time and activity (a program, event, process, institution, or social group)[in which the researcher explores]

and collects detailed information by using a variety of data collection procedures during a sustained period of time" (p. 12). The task was to build upon and explore each participant's responses. Individual family members were asked to describe personal experience with an adapted life skills program and subsequent topics under exploration namely, positive living skills and family functioning. With this single case study approach it was necessary to have a varied and fluid context, dependent on the family's situation week by week.

The sampling decision in this study involved the selection of a single case, in this instance, an individual family with a child who has a disability. I chose to find the potential case family through the Ottawa Children's Treatment Centre, knowing that the clients at the centre would be most representative of families who have a child with disability in the Ottawa area.

The study was conducted with one family who has a child with disability. The family participants included a single child with a physical disability and a cognitive delay, and his parents. A part-time caregiver was also involved in the sessions when present in the family home at the time of our meetings.

Ten sessions were conducted in the participant's home. Meetings were conducted on Saturday mornings for four months. The average time spent in the home per visit was one hour. During our time together we reviewed the events that had happened the previous week. Following this review I introduced a new activity for the family to try together (training both the child and parents). The family was encouraged to use the activities presented to them as they felt necessary during the following week. Taped interviews were conducted on the fifth and tenth session meetings.

The Positive Living Skills Program

The program used during the sessions consisted of activities from Orlick's (1998) positive living skills training program. Brief overviews of all the audiotape activities selected for use during the sessions are presented in Table 1. The parents were given copies of two books: *Nice On My Feelings* (Orlick, 1995) and *Feeling Great: Teaching Children to Excel at Living* (Orlick, 1998). This program is intended to teach children valuable mental skills through the use of games, activities, and audiotapes. I examined the program resources prior to meeting with the family and chose activities based on this family's needs and the child's level of functioning and mental ability.

Mental Skills training was incorporated through Orlick's Positive Living Skills program which can be adapted from the school setting to the home and family environment. Orlick's program provides the parents, child and caregivers with resources for continuing to learn how to live, cope and interact effectively together in unique family situations.

Analysis

Observation and interviews were the tools for examining the perspectives and impressions of the individuals with respect to the mental skills resources, personal growth and family interactions. During sessions five and ten (of the ten week program) we conducted an informal interview (Fraenkel & Wallen, 1996) or what Rubin and Rubin (1995) termed the topical interview. This approach consists primarily of posing open-ended questions. The task is to build upon and explore the conversational partner's (in this case the individual family member's) responses to the questions along with a description of his or her experience.

In addition to the interviews, non-participant observation, journals and field notes were used during every session. The observation

was in the participant's home or another family member's home, given the particular circumstance. I asked the family to pay specific attention to family functioning, and the use of mental skills, as a potential personal resource throughout the weeks of the study. I gained information on weekly interactions through the parents verbal recollection. Field notes were recorded following each session with the family.

Results and Discussion

There was a vast amount of information gained in this study through observations, conversations, interviews and interactions. To organize this information and make it more understandable, I two charts were constructed to display all the vital information in a logical format. The chart indicates the activities which of Orlick's (1998) positive living skills program were used during this study. Audio taped activities have been noted by capitalizing the entire name of the activities. Activities that were found in Orlick's written materials but not presented on audiotapes were noted by the capitalization of the first letter (Capitalized). (The descriptions of these activities are brief in the charts. However, detailed descriptions follow after the charts in the summaries of each session.)

The weekly session overviews, presented in the following pages, are a combination of descriptive results and discussion. Given the vast amount of information and the unique progression of interactions, we felt that presenting the information on a week-to-week basis would be helpful for the reader. Interview extracts have also been included to strengthen the depth of understanding. It is hoped that as a result of this format, the reader will have an opportunity to gain a deeper understanding of this particular case.

Overview of Program Activities and Impact: Weeks 1-4

Week	1	2	3	4
Date	February 12, 2000	February 19, 2000	February 26, 2000	March 4, 2000
Where	family home	family home	family home	family home
Who	Dad, Mom, Adam, Caregiver	Dad, Mom, Adam	Dad, Mom, Adam, Caregiver	Dad, Mom, Adam
Activity	initial meeting HIGHLIGHTS (simple pleasures, little treasures of life)	share HIGHLIGHTS JELLY BELLY (fill up your stomach and empty it- abdominal breathing) LAUGHING (listening to an audiotape of laughter) Workbook -Highlight pages for colouring	share HIGHLIGHTS CHANGING CHANNELS (change mental channels from negative to positive, worried to relaxed, unhappy to happy) JELLY BELLY Workbook -Cat Scales (a subjective measure of stress vs. relaxation. See figure 1.)	share HIGHLIGHTS STAR TRACK (imagine yourself on a space voyage floating in space) Imagine Light-Imagine Heavy (imagine holding different objects and the effect they would have on muscular response) Adam frustrated. He used Cat Scales to communicate then chose CHANGING CHANNELS to do together.
To Do	look for HIGHLIGHTS	Family choice	Family choice	STAR TRACK SOARING (Imagine yourself soaring like a seagull)
Notes		Mom gone all week “know-all-ogy” (Adam’s definition of Mental Skills)	Mom gone all week Adam and Dad wrote and coloured Highlights in Workbook Adam understood personal quiet times and SPECIAL PLACE (Imagine your own very relaxing place) Adam taught JELLY BELLY to Aunt and Uncle and Caregiver. Adam defined family. Only wanted to do activities with entire family present.	Activities done before bed every day of the past week. Incorporation of CHANGING CHANNELS into everyday family language with examples given. Adam excited to share HIGHLIGHTS. Adam frustrated today but able to choose CHANGING CHANNELS to refocus.

Overview of Program Activities and Impact: Weeks 6-9

Week	6	7	8	9
Date	April 1, 2000	April 8, 2000	April 15, 2000	April 22, 2000
Where	Grandmamma’s	family home	family home	family home
Who	Mom, Adam, Caregiver	Mom, Adam Caregiver	Dad, Mom, Adam (sick)	Dad, Mom, Adam, Caregiver
Activity	<p>share HIGHLIGHTS</p> <p>Sound Listening (attentive to the sounds around us)</p> <p>GREAT LISTENER (teaching children how to focus in listening)</p> <p>SOUNDS (audiotape of sounds for identification)</p>	<p>share HIGHLIGHTS</p> <p>Visual Connection (focus on an object such as a leaf, in order to choose it from a group of the same)</p> <p>Shadow Movement (focus on the movement of another and repeating it)</p> <p>DUAL FOCUS (audiotape of two stories overlapping, need to focus on one story)</p> <p>SOUNDS</p>	<p>Share HIGHLIGHTS</p> <p>Adam showed me what it he did every night before bed: got the audiotape, listened to Jelly Belly, Changing Channels and Floating on Clouds.</p> <p>MAGIC WANDS (story to help children have some sense of control over their lives and how they feel physically)</p>	<p>share HIGHLIGHTS</p> <p>MAGIC WANDS</p> <p>QUIET LAKE</p> <p>RAINBOWS (story to help children have some sense of control over their lives and how they feel physically)</p>
To Do	Family choice	Family choice Imagery exercises in Workbook	QUIET LAKE (Imagine yourself relaxing next to a beautiful, quiet, calm lake)	Family choice
Notes	<p>Last two weeks missed because of a flood in the family home, leaving them living in other homes.</p> <p>Adam’s attention and focus increasing.</p> <p>Adaptability of activities continues to be a key component of interaction.</p> <p>Adam challenged his parents to see Highlights.</p>	<p>Adam chose favorites this week: Jelly Belly, Changing Channels, and Floating on Clouds</p> <p>Adam integrated thinking of Floating on Clouds into everyday situation of driving in fog.</p> <p>Adam used Cat Scales to show how he feels regularly</p> <p>Adam imagined and expressed a story of living on the bottom of the ocean.</p>	<p>Adam described “dark side” and fear.</p> <p>Adam eager to show what he did with audiotapes and relaxation.</p> <p>Adam felt badly that he was sick.</p> <p>Adam initiated and reminded parents of the activities.</p>	<p>Activities done before bed every day of the past four weeks.</p>

Condensed Notes

Week 1

Adam was excited to tell me that his birthday was March 17, 1992 and that he was born in London, Ontario. He asked if I knew where London, Ontario was. Adam was determined to teach me the names of all his doctors, therapists and teachers. Following each name he would instruct me, “you better write that down.” This statement: “you better write that down” enlightened me that this child has been required to share personal information many times, probably with numerous professionals.

In addition to Adam’s physical limitations he experiences cognitive delays. I noticed that he had a difficult time focusing on my initiation of discussion through direct questions. I knew from my past experiences with other special needs individuals that a significant amount of time was usually needed for effective communication to occur between the special needs individual and myself. It requires the learning of sounds and gestures on my part to have the ability to communicate effectively. Mom helped Adam communicate with me and me with him. Adam did understand that he can have large problems and frustrations and not know how to fix them.

Adam told me that he did not like to play. Mom explained that Adam found play could be hard work because of his limitations and so he preferred not to have this kind of work at home. School, in Adam’s mind, was equated with work in various forms because he attends school at a centre. At O.C.T.C., all levels of treatment are incorporated into the student’s educational plan. Physiotherapy, reading, and play all happen at school. For Adam and his family home was outside school, and therefore did not require structured play, which was “hard work” for

Adam. He was uncertain that our “play” time together would help him with his frustrations.

When I asked Adam what made his family special he said “that my Mom and Dad know how to support me.” Adam is a sensitive child who understands that he has limitations. He recognizes that his family is unique and that both his Mom and Dad have made good efforts to help him and the family. Mom and Dad care deeply for Adam and have been his greatest advocates.

After our time of acquaintance I presented the concept of HIGHLIGHTS. We discussed that looking for Highlights is to place emphasis on noticing, recognizing, feeling, appreciating and recalling simple joys, many of which otherwise go unnoticed or unappreciated (Orlick 1998, p.18). I asked Adam to remember one thing from the upcoming week to tell me next Saturday when we shared Highlights.

Week 2

I asked Adam if he understood what it meant to feel scared, tense, afraid, or worried. He did not seem to be focusing on my questions and I probably asked too many. Dad shortened my questions and gave an example that Adam knew personally. Dad reminded Adam of his visits to the hospital and how it was that Adam felt when he had to have some tests. I expanded the discussion by asking Adam if he knew what it felt like to relax. Adam was now listening attentively, but did not seem to understand. This time Mom helped by asking Adam what he did on Friday afternoons after school. Adam told us that he would get out of his wheel chair and lay quietly on the couch. Mom asked him what he thought about when he was laying on the couch. Not much could come to Adam’s mind. Mom explained to Adam that laying on the couch was his way

of relaxing after school and that relaxing was letting our minds slow down from all the busy things that go on during the day. I explained to Adam that one of the ways we can help our bodies relax is by breathing better. We practiced our breathing together and I explained that we need to learn to breathe deeply. I proceeded to put in the relaxation activity audio cassette. We laid on the floor and listened to JELLY BELLY, an activity to help children learn how to do diaphragmatic breathing. Adam and Mom were laughing and had trouble focusing on the activity right away. I laid beside Adam and over-emphasized the breathing and had him mimic me in this. He seemed to like it, but hadn't caught on completely. Adam expressed that he would like to do it again, only later. I left him the audiotape and encouraged him to try Jelly Belly later in the week.

Adam created a word for what I had done with him and his family; he defined everything we had done as “know-all-ogy”. I asked Adam if he liked “know-all-ogy” and our time learning it together. Adam responded with a very positive “Yes!” I was encouraged to see that Adam was now taking ownership for the activities we were doing together and hoped that his dislike of play at home would change during our time together. That Adam was creating a word to describe our interactions was beneficial to his remembering what we had done together and for his subsequent learning of the positive mental skills we were doing. I was reminded that it is important to have fun activities in order for children to have enthusiasm when participating.

Week 3

We started by sorting out what had happened during the previous week. Mom had again been away all week for work. I was told that the previous Saturday after I had

gone, that Adam's aunt and uncle had come by for a visit and that Adam insisted on teaching them the Jelly Belly activity. On Adam's insistence they all went down to the basement: Mom, Dad, Adam, Aunt and Uncle; where Adam taught them Jelly Belly. The next day he was again determined to do the activity with Mom and Dad. Mom had gone out of town on Monday morning. Dad and Adam talked about the activities as they drove places during the week. Dad asked Adam if he would like to do them, but Adam said not until Mommy returns home.

It was very evident to me that Adam had been thinking about these concepts all week as Adam's attention and interaction during this week's session was more focused and expressive.

When Adam needs to get some space he goes to his room and shuts the door. His parents can often hear him talking to himself in the mirror. Adam's parents have put mirror doors in other rooms in their home to help Adam access them more easily because of his physical limitations. Adam is able to crawl with his arms to a mirror door close by; he will look at himself, talk to himself. The mirror is a device that helps Adam to refocus his emotions and change his perspective.

I introduced the concept of mental channels, such as a television remote control. This was not a difficult concept for Adam to understand and he enjoyed explaining how the television works. We listened to the Channel Changers activity on the audiotape. Adam laid on the floor, very quietly and relaxed, listening attentively: He focused well on the activity. Following the exercise we talked more about how we control our minds. Together, we tried to think of some specific examples of when we might need to change our mental channels.

Week 4

The family was quite excited as they had reached a important moment during the past week. They found that doing the activities before going to bed helped Adam to fall asleep. At night Adam has difficulty relaxing in order to fall asleep because his disability makes muscle relaxation very difficult. Tight musculature makes closing his eyelids almost impossible and he has had great difficulty falling asleep quickly because of this muscle tightness. The family discovered that for them the best time to wind down with the relaxation activities was at bedtime. During the week the family listened to Jelly Belly, Floating on Clouds and Changing Channels everyday before bed. At one point during the week Adam was asleep before the audiotape was finished (the audiotape I made for him had only the three activities on it: Jelly Belly, Floating on Clouds and Changing Channels). Mom and Dad were ecstatic to have discovered a way to help Adam sleep and thus help them function better as a family.

The effect that Adam's falling asleep had on his parents was very encouraging. As a family the parents then had more time to devote to other things, including each other, instead of trying to help put Adam to sleep by reading him stories and continuously rubbing his back.

The effect on Adam and his capability to fall asleep better was positive. He even commented that he liked to do the activities before bed. He also told me that he had looked at the cat pictures (although he refused to colour or draw in the Workbook) before and after the activities. He described how he would lie in bed with the workbook on the page of the Cat Scales and: "I would point to the cat to tell Mommy what mood I was in. Then after the tape I would point to

the sleepy cat." Mom would then watch as he drifted off to sleep every evening.

This family has incorporated Channel Changing into their everyday vocabulary. The family was glad to gain a common expression to use in frustrating family situations. They commented that using a verbal cue such as "let's change channels" along with the gesture of snapping their Channel Changing fingers was effective for them all. The family explained how they had used the activities twice in the past week.

Week 5

The choice to conduct an interview during week 5 was motivated by my curiosity to see how Adam would describe what we had done in the previous weeks. I chose to do this first interview at what was the halfway mark of our time together. The second interview would be our final interview during week 10. This first interview was done with the entire family where as the final interview was done with Adam individually and then with the entire family. I decided to conduct the first interview with the entire family because I did not know Adam very well and I had some difficulty understanding entirely what he would try to express. As the weeks went by and we became better acquainted, I felt much more confident that I could understand him. Thus, part of the final interview was done without Mom and Dad present. Not knowing how Adam would be with a taped interview, his parents purchased a toy microphone and had him practice speaking into it the week before our actual interview discussion. When I arrived at the home Adam was thrilled to use the microphone and we amused ourselves by speaking into it to see how our voices sounded amplified. Adam was also very excited to listen to the audiotape of his voice and our discussion. He

asked often throughout the discussion if we could listen to the audiotape.

Aware that Adam had a short attention span from our previous weeks together, I chose to keep the interview informal, as a discussion. I followed his lead in the conversation. The objective of this interview was to discover how well Adam could answer questions by his remembering the activities we had done together. I hoped to learn what he could recall from the ideas and concepts we had examined together. I was interested to see how much Adam remembered from the past weeks and how well he could describe our time together. By the end of our talk Adam was extremely tired and fell asleep on Mom's lap.

Although Mom had been away all week for work, it was still possible for the family to find Highlights. Adam remembered some of the most immediate ones, such as going out to get the mail that morning, and the happenings of the week, such as his first homework, Dad getting a job promotion, and having a shower in the new shower stall. The ease with which Adam brought these events to mind indicated that he clearly understood what Highlights were. This is an excerpt from our discussion:

Adam: I think that I might say that Highlight was a huge one

Mom: What Highlight was a huge one?

Adam: The homework one

At one point Adam and I spoke about his homework and it was evident that he understood what qualifies as a Highlight because he mentioned something that could happen, but had not necessarily happened that week. Adam's thoughts about potential homework Highlights:

Melissa: That is excellent and you took it back to school the next day?

Adam: Ahhh yes, I did because my teacher always wants to see it.

Melissa: And was she happy with what you had done?

Adam: Ahhh yes.

Melissa: What did she say to you?

Adam: She always writes "good work" because I do the right answers you know...so Ahh that is one of the Highlights.

Melissa: That is a good Highlight.

It was also evident that Adam had an understanding of when he could mentally change channels. The family used the snapping of fingers as a special signal for changing channels. It was a Highlight for both Dad and Adam that neither one had formally Changed Channels this week. Remembering that Dad was the only physically-present parent this week, as Mom was away with work, it is positive to recognize that Dad and Adam functioned well in the midst of many demands and responsibilities:

Dad: But we didn't have to switch channels this week, did we bud?

Adam: We didn't have to switch channels once this week!

It also became clear though, that Adam was still unable to transfer what he had learned at home with his Mom and Dad to school. Even though Adam and his parents could use gestures and reminders to Change Channels, Adam still felt that he was still very reliant upon the audiotape to help him

implement the concept of changing channels:

Melissa: Yes, do you ever think about changing channels or doing relaxation at school?

Adam: No, I might use the tape.

Melissa: Just when you have the tape, eh?

Adam: I don't even do it at school, because I might use it.

Mom: Do you think you could think about changing channels without the tape, or do you think you need the tape to help you change channels?

Adam: Mmm, need the tape.

When asked if he had done Changing Channels at home without the audiotape Adam remembered that he had and he also remembered that the family had a special signal to help them remember:

Melissa: Okay... I think you have done it before without the tape. Haven't you, with Mom and Dad reminding you: Adam gotta change the channel?

Dad: How do we change the channel?

[**Adam:** shows with fingers]

Dad: Yep!

Mom: That is very good.

Melissa: Cool. That is a good move.

Adam: When I move my fingers...

Melissa: That is a good idea. Good job!

Dad: Do you ever stop to snap your fingers at school?

Adam: To get their attention sometimes.

Dad: Oh, but not for you to change channels? ... when you snap your finger...

[**Adam:** snaps fingers repeatedly]

Adam was also able to describe a time during the past week when he had been upset, because his mother was not home. Mom was surprised to discover that Adam had used the Cat Scales as part of his plan to remedy the situation and thus to feel better:

Mom: You haven't looked at any of those pictures of those cats that look, umm, rather upset.

Adam: Yah!

Mom: Did you have to look at that this week while Mommy was gone?

Adam: Yes, I did.

Mom: Oh you did.

Melissa: When did you look at them? Do you remember?

Adam: Mmm...

Adam: Were you upset that day?

Adam: Umm, kind of.

Mom: Can you think of why you did? What made you upset? And after looking at the pictures did you...

[**Adam:** interrupts]

Adam: Because you weren't there.

Mom: That is a good reason I like that reason.

Melissa: So you looked at the cats and said “I feel like this cat”?

Adam: Yeah.

Melissa: Did you think that in your head?

Adam: I thought that in my head.

Melissa: Then, did you do anything different? Did you think differently or did you talk to Mommy on the phone and then look at the cats again?

Adam: Umm, yes. And I watched a bit of movie and did homework and umm watched some more of the movie.

Melissa: That made you feel better?

Adam: Yeah

In an attempt to see if Adam could define relaxation I asked him directly if he could tell me what relaxation was. Adam began to describe the concept in an abstract way and then completed his explanation using an example of an overexcited dog as an example of not being relaxed. His understanding of relaxation is very good. I was impressed with his creative way of describing relaxation:

Melissa: Okay Adam, I know we have talked about this before many times. Can you, into the microphone, cause it likes to hear what you say, can you tell me again what relaxation is? How you relax and what does that mean?

Adam: Ahh well much of it means that you don't do as much that you don't get hyper sometimes because Gerry has a dog that is

really very hyper.

Melissa: And it is not very relaxed? [the dog]

Adam: No.

Melissa: What word would you use to describe the dog?

Adam: I would describe hyper.

Melissa: Hyper. Stressed?

Adam: He kinda is.

Adam further described the concept of relaxation with a more personal example. He was able to identify when he had not been overexcited, hyper or stressed and told about those moments. He understood that those moments were relaxing:

Melissa: When are times when you like to feel relaxed?

Adam: Umm, well on the day that I feel like it.

Melissa: Okay, what about when you are in bed? Before bed do you like to feel relaxed?

Adam: Ahh, yeah.

Melissa: Yeah.

Adam: Like on Friday nights.

Melissa: Friday night, that is a good night for you?

Mom: What do you do on Friday nights?

Adam: I lie on the couch; that is a real Highlight.

Lying on the couch on Fridays after school is wind-down-time for Adam. He plays an imagination game to help him relax and he spends time alone before supper:

Mom: When you are lying on the couch hey what are you playing? Couch...

Adam: Potato.

Mom: Right.

Melissa: Oh, that is a great name for it! You feel like a big sack of potatoes, do you?

Adam: Because I go [acts out a potato by laying as flat as he could]...

Mom: Potato!

Adam: Then I go [acts out a stretched potato by putting his arms and legs in a star shape]...

This first interview was very beneficial for gaining understanding of the present stage of learning of Adam and his family. In four weeks the family was able to incorporate some major conceptual ideas into their everyday living. Highlights were shared in abundance. Channel Changing was used as a positive reminder when people were beginning to become frustrated. Relaxation was included before bed and at other times during the week and Cat Scales was used to help Adam visualize emotions. The family had made great efforts thus far to embrace the learning of mental skills for the increase of positive family functioning. The family has integrated the new activities and concepts into what they have previously used. Wrestle study breaks, tub wars, mirror time outs and Friday couch potato are activities that the family has used to cope with their situation. Now they have included new understandings to these activities.

Week 6

It was a very good session and most encouraging as Adam's attention was completely focussed for the entire time. I felt much more comfortable with the length of activities and the adaptation required to keep Adam interested. I realized how important it was to have a good mix of hands-on and still activities as well as a good balance of talking. Adam is very focused when listening to the audiotape which is useful for his learning of activities and concepts. Adam is not distracted when listening and wants to listen to the audiotape activities on his own. Adaptability continued to be a key component of our interactions. I had to be ready to follow Adam's lead for discussions and for his attention. I found it useful to have set out what the session would include but to be flexible with the order in which the activities are done.

Week 7

Arriving at the home I was excitedly greeted by Adam. He moved around busily on the floor, telling me all about what he was doing. He had almost finished watching a Star Wars movie and was thrilled. The movie was completed about 10 minutes later. During that time, Adam was listening to the television but watching me and telling me all about the movie. Adam's hearing is much better than his eye sight and he can focus with his ears on many different things, but can only focus on one visual cue at a time. Knowing that Adam's hearing was better than his vision, I chose to do hearing focusing the previous week and leave vision focusing for this week.

We talked about what had gone on through the week and Adam was excited to tell me that his favorite audiotape sessions were still Jelly Belly, Changing Channels and Floating on Clouds. Mom recounted a time this past week when it was extremely foggy out and

Adam had imagined while they were driving that they were walking on the clouds. He likes to do the activities while lying in his bed in the evening, with Mom and Dad present. He looks intently at his Workbook but has trouble drawing in it because he doesn't want to "spoil" it by drawing on the clean pages. The Highlight's of the week were learning to read and not having homework because he had worked so hard at school.

Adam and I talked for a short while which was a good opportunity for me to ask Adam about some of the things we had done together. I had previously noticed that Adam would occasionally touch his belly button when I was over and Mom had commented that he did this at other times. During our short talk I asked Adam what he thought about when he was doing Jelly Belly. He said nothing. I asked further, and he described that he uses bedtime as an opportunity to really focus on listening to the audiotape, his breathing and his belly button. Adam finds that Jelly Belly is a relaxing activity for him. Adam would touch his belly button as a reminder to breathe better when he needs to relax.

Week 8

Today when I came to the home I was greeted by Dad, Mom, and Adam, who was sick. Mom commented that they did not want to postpone our meeting because they thought that something good would come out of us getting together.

Adam wanted to demonstrate for me what he does to think better and how he has learned to relax with his fears. As Adam was busy with the tape player buttons Mom, Dad and I discussed that Adam had not worked on anything new but that every night he had listened to the audiotape. Mom and Dad commented: "He likes to start with Chang-

ing Channels, then Jelly Belly, and finally Floating on Clouds. He even does the wiggling of his fingers and holds his finger to his belly. It has been great! He had trouble falling asleep for years, but he is asleep within 5 minutes of listening. You can hear him focusing on his breathing. It is so encouraging, we have even listened to the tape after midnight to get to sleep. It was always on Adam's initiative!"

Adam displayed knowledge and understanding of mental skills and how certain resources such as Jelly Belly were useful for him to think positively, relax and face his fears. Mom and Dad were really glad to discover something that has been so effective with Adam.

Week 9

Mom commented that Adam was persistent with the activities before bed each day. Adam had discovered that this time was not only family time, but it also helped him get to sleep. The family felt equipped to face their apparent challenges at this point and was able to now choose the particular activities that met their needs.

Week 10

This week was our final meeting. It had been arranged for us to record some of our discussion time. As we started our discussion Mom and Dad were in the room, but quietly left once Adam was comfortable with the tape recorder. I noticed that prior to Mom and Dad's departure Adam was preoccupied with both the tape player and his parents' presence. Adam paused frequently and did not focus until his parents had relocated to another room.

Melissa: What kind of things might we be afraid of?

Adam: Ahh...

[Pause]

Adam: Ahh, Mmm...

Mom: What makes you scared, honey?

Adam: I'm trying to think.

[Pause]

Mom: I can think of one thing and then you can think of another. I remember when we went to the hospital, and what happened? You didn't want to go some place because you were afraid. Do you remember?

Adam: Yeah.

Mom: Do you want to tell us about it?

Adam: [fumbling with tape player]

Melissa: Do you remember that we talked about stress and relaxation?

Adam: Yeah.

Melissa: I thought you did. What kinda things make us stressed?

[Pause]

Melissa: Not sure? Okay well then what kinda things help us relax?

Adam: [Unrecognizable words]

Melissa: We can talk into there [microphone] and then later we can listen to it. So let's think about relaxation for a minute, Adam. What kinda things help us to feel better and relax?

[Pause]

Melissa: Did we do anything together that helps us remember what it is like to relax?

[Pause: parents leave room]

Adam: Why did you go, Mom?

[Pause]

Adam: Yup [*answering my previous question about remembering what it is like to relax*].

Adam and I were both sitting on the floor for the rest of our discussion. Following his parent's departure Adam took the tape recorder in hand and turned his back to me. I had seen Adam do this before in our discussions and I understood it to be a strategy for decreasing the number of distractions that were in his visual field. Adam faced the wall with the tape recorder in his hand so that he could speak directly into the microphone. I proceeded to ask Adam if he could recall the many activities we had tried together:

Melissa: Remember, we lay on the floor sometimes and we do some special breathing?

[**Adam:** starts to breathe]

Melissa: What were we trying to do? Were we trying to make ourselves feel better?

[Pause]

[**Adam:** continues to practice breathing]

Melissa: Adam?

[Pause]

[**Adam:** is completely focused on breathing and his hand is on his belly]

Melissa: Were we trying to make ourselves feel better?

Adam: Ahh.

This made it very evident that Adam remembered what we had done with breathing. It was also evident that he had practiced the breathing exercises many times and was now able to do them without the aid of the audiotape. His hand on his belly demonstrated what we had done many times together when we did Jelly Belly [a breathing activity on audiotape].

I continued to probe Adam's memory regarding the activities we had done together. My intent was to discover what Adam could tell me about our time together during these past months. Adam remembered what we had done and expressed that he did the activities before bed and that this was helpful for him in trying to fall asleep.

Melissa: Can you press the buttons by yourself on your tape player?

Adam: Um, no because I am usually lying in bed.

Melissa: Is it good to lie down and listen to the tape?

Adam: Yeah.

Melissa: What are your favorite ones on the tape?

Adam: They're really secrets.

Melissa: They're secrets?

Adam: I said they're secret-ish.

Melissa: Do you like Jelly Belly?

Adam: Yeah.

Melissa: What about Floating on Clouds?

Adam: I do.

Melissa: What do you think about when you Float on Clouds?

Adam: Hmm. Not really nothing because I'm usually asleep by then.

Melissa: You are usually asleep by then? What about when you are listening to Jelly Belly what do you think about?

Adam: I am usually asleep by then too.

Melissa: Oh, okay. Did you listen to Quiet Lake, the one with the lake and the birds and the water?

Adam: Yeah.

Melissa: Did you like that one?

Adam: Um, I am usually asleep by then.

Melissa: They put you to sleep!

Adam: Yes.

Adam and I spent a large amount of our discussion time on the topic of family. Family is very important to Adam and he has consistently defined his family as his Dad, Mom and himself.

Melissa: Can you remind me and tell me what a family is again?

Adam: In this [tape recorder]?

Melissa: Yeah, you can talk in there.

Adam: Ahh it is when you... why do you sometimes forget?

Melissa: I do, I sometimes forget. And I know that you have a very good memory.

Adam: It is when people go together and pick out some stuff or something like that.

Melissa: Who is in your family?

Adam: My Dad, my Mom and me.

Adam, when asked, did not think that his family had any stress, a very different perspective from that of his parents. Adam went into a lengthy discussion with me about what his family would be afraid of:

Melissa: What do you think is one stressful thing about your family?

Adam: Nothing stressful in my family.

Melissa: No? It is all happy all the time?

Adam: Yeah.

Melissa: Is there something that your family is afraid of?

[Pause]

Adam: Tiggers.

Melissa: Tiggers? Are there tiggers around here?

Adam: In the forest.

Melissa: Tiggers?

Adam: Tiggers, yes.

Melissa: Wow, have you seen one?

Adam: Wolves...

Melissa: Wolves. Yes, that is what they are called I think.

Adam: Vicious dogs...

Melissa: Yeah I would be scared of those too!

Adam: They are like a vicious pet.

Melissa: They are, aren't they.

Adam's age, combined with his parents' priority of putting family first and the supportive community around them made it unlikely that Adam would recognize the unique strains on his family. Adam's parents have done extremely well in their pursuit of providing him with a supportive environment. Adam's parents often have put him first, and their own needs second. When Dad and Mom filled out a questionnaire of their individual Life Time Zones it was apparent that Adam's needs took priority over their own. The first question was for Dad and Mom to record when they had time for themselves individually. Both parents left the space completely blank. It was evident that Adam's parents sought to put Adam and family life as their priority.

Adam verified this family priority when I asked him if he liked that Dad and Mom listened to the audiotapes with him before bed. Adam had chosen the time and place for the activity as well as insisted from the beginning that the whole family be together to do the activities.

Melissa: Do you like it that Mom and Dad listen to the tapes with you, listen to Jelly Belly?

Adam: Yes. Maybe we could listen to it.

Melissa: We gotta wait Is it good that Mom and Dad listen to the tape with you?

Adam: Yeah.

Melissa: Are you glad that they know what you do?

Adam: Yeah.

Melissa: Are you glad that you do it together?

Adam: Yes because that I know it is my choice to do it with the whole family around.

Melissa: You like your family, don't you?

Adam: Yeah.

Knowing that Adam had learned and discovered much during our sessions, I thought it would be helpful for Adam to try summarizing our entire time together, if he could. I discovered that he initially had difficulty putting his ideas into complete sentences and engaging in directed conversation.

Melissa: I have one more question for you: If you wanted to teach me one thing, what would you tell me?

Adam: Something is in my memory... the only thing I think about is my family.

Melissa: Okay, that is good.

Adam: If I was yours [teacher], I would ... I would give you all that I remembered and more remembers. I would do that.

Melissa: Would you?

Adam: But if anybody had something else to do I would let them do it, if they were busy. Then they don't know that they are doing it is a little bit of work a problem, but so far it has been umm good. But in all this somebody is working or something, you gotta let them do that if you don't you'll get in big trouble and if guess what's going to happen? You are going to get into deep, deep trouble.

I thought it might be a good approach to ask Adam what other children would find useful from all the activities we had done together. Adam was very focused on this discussion and let me know that he understood the primary purpose of my time with him and his family. The discussion we had was very lengthy given the difficulty that Adam has in communicating. The following are some excerpts from our discussion to help show how well Adam understood:

Melissa: Do you think other little boys and girls would like to learn what you and I did?

Adam: Yup!

Melissa: Yup.

Adam: Just tell them ... make a tape for them [*activities and speaking*] ... record a tape of themselves.

Melissa: Is that the fun part?

Adam: Yes.

Melissa: Little boys and girls like to do that?

Adam: Yes. So you should do it with other kids. Record tapes.

Melissa: Is it important for little kids to listen to that [*activities*]? What does it teach them?

Adam: To teach them how to relax .

Melissa: Kids like that. Don't they?

Adam: Yup. Don't go to kids that already know how to relax, go to kids that don't know how to relax.

Melissa: What kind of kids are those?

Adam: They were like me I couldn't [relax].

Melissa: Now can you?

Adam: Yeah.

Melissa: That is great. Isn't it?

Adam: So, you will have to teach the other kids that [activities] ... I would do that if I were you.

Melissa: Will that help them be more positive and see more Highlights?

Adam: Ahh, if they know what you mean by Highlights if they're smart kids they will know what Highlights means. They will know what you are talking about, so you'll have to be careful looking for other kids that don't know how to relax.

Melissa: Do I tell them a Highlight is something bad?

Adam: Good!

Melissa: Something good that they think about in their day?

Adam: Yes.

Melissa: Would you like to help me teach sometime?

Adam: I could now that I am smart!

Adam: If you let the child know what he doing [in the activities] you will discover what the child is doing [in s/he's mind]. If you don't discover it [what the child is capable of doing], there is going to be a big problem.

Melissa: That is for sure. Isn't it?

Adam: So, it's your only choice to discover the child's possibility.

Melissa: That is right. Did I discover Adam's possibility?

Adam: My possibility would be different than theirs. If their possibility is different then it would be sensitive that you would let the child know what he is doing [it would be necessary for the child to know what they needed to learn to discover their possibility]. If they don't understand just tell them [help the child learn the activities]. So they know what you are doing and they know what you are up to, but if you don't tell them they won't understand what a Highlight is.

Melissa: That is right. Did I tell you?

Adam: Yes.

Melissa: Did we discover what your possibilities were?

Adam: Yes.

Melissa: Yes. What are your possibilities?

Adam: My possibilities are what we are talking about.

Adam and I had a very good discussion and he spoke clearly about the ideas that he had racing through his mind. He communicated the importance of my spending time with his family. He summed up the process of discovery that we had ventured into these past months. It was evident that Adam had been empowered through our time together and that he was keen to continue learning about himself and others ("now that I am smart!"). Adam understood that he was a unique child, not because of his special needs but because he was a special person, just like others are special and unique.

After our special discussion time together, Adam and I invited his parents and his Caregiver to join us in the living room. We had a good discussion and Adam was very keen to help his parents in their use of the microphone. I intended for this discussion time to provide a taped response from Adam's parents to a few key questions. The questions were important to gain a better understanding of the parents perception of the usefulness of our time together.

The first areas we explored were the importance of me coming into their home and having all the familiar home supports, and the importance of the family working together. Mom commented that there was greater comfort and confidence available by meeting at the home. She also felt that doing things together as a family allowed for the preservation of all information and experience. This in turn would allow for a better reinforcement of relevant program concepts and activities.

Mom: I think so [*both are important- at home and family involvement*]. There are often cases when you try and do things when the family is not all together. Then you have to try to share the information with the other individual [*who wasn't present*]. It [*the information*] can get kinda lost. Doing it at home also makes things a bit more comfortable and confident, probably even more relaxed in his [Adam's] own environment so that he can do the exercise.

We then discussed whether each participant felt that his or her individual involvement in the sessions was beneficial. Both parents agreed that the consistency and the time together were beneficial:

Mom: For each one of us, Dad or I, have taken on the role of lying with him [Adam] when it comes to the evening and listening

to the tapes with him. It becomes so relaxing that we fall asleep.

Dad: I think it was important that there was consistency because we keep the same strategy. When we got upset we knew, or we just talked about this or that. So, to try that strategy as a family was good.

The family noted that their participation together aided greatly in their communication with one another and particularly with Adam. They were able to try different strategies to help improve individual situations:

Mom: One person could relay it [*the information*] if we found out that one [*activity or strategy*] wasn't working. We wind up communicating that to each other. We would ask each other...[interrupted by Adam]

Adam: You [mom] have to talk into the microphone.

Mom: Okay. So, I would ask the question to Daddy: Did you find that that [*activity or strategy*] was working better than the other? Then we would discover: yeah, one was working better than the other and then we would stick to it [*the activity or strategy*].

The family described what resources or activities were most useful for them. They discussed what resources or activities promoted mental skill concepts that we were trying to teach and learn:

Mom: The book that you had [workbook], the scribbler in which he could relate the pictures with his feelings, that we found useful. Mind you, Adam couldn't use the tool [workbook] like we had anticipated but found a way to express his feelings. Although he could easily express it verbally,

he found it almost exciting to see the feelings through a picture [i.e. Cat Scales].

Melissa: Yes.

Mom: Adam, I think is very visual. Also, the book for him was his so it was ownership.

Dad: The same with the tapes to, but more so with the book.

Dad said that the resources were good because it was possible to use some activities and to leave some activities for another time. He was impressed in the flexibility and adaptability of the resources and activities. This flexibility was useful for Adam and for particular family situations; it was not necessary to do more than was needed.

Dad: I think that this resource is a good resource because some [*activities*] are used more than others. This [*use of different activities*] will probably change from child to child.

Melissa: It would change from stage of life to stage of life too.

Dad: Yes, exactly.

Mom noted that with Adam and many special needs children there is a need for great repetition to achieve learning, even in small areas. For Adam the learning was a gradual process and it was important to have much repetition to help him discover what activities could help him in different situations.

Mom: One thing with Adam, is that you introduce something and he becomes familiar with it right away. If you try and change him and introduce him into something else too soon you have already lost it.

So, you have to continue on with one thing for a little while and then you can make the change. Jelly Belly for instance has stayed because it was the first one that he had listened to. It has stayed with him throughout the whole ten weeks and he still talks about it. He is more familiar with Jelly Belly than Quiet Lake, for instance. Floating on Clouds is the other one.

Dad: For him to interpret them and the other ones [*will take time and repetition*]. We will just keep trying and there will be times for the others [*activities*].

Mom: Magic Sword is starting.

One of the greatest benefits of participation for this family was the positive time it provided for them to spend together. This family was pulled and stretched in many directions with multiple challenges; participating in these activities as a unit brought them together. Adam clued into this early on and set the rule that he wanted all of them to participate in the activities. If everyone could not participate then Adam was not as interested.

Melissa: Can you describe any changes that might have happened either individually or as a whole family since we started?

Mom: While we're lying on the bed!

[laugh]

Mom: If I look at in the sense of where it has brought the unit together, at a special moment for him [Adam], which is his resting time. It is Mommy or Daddy or all of us, we all lie together and listen to the tapes. In a good sense it makes him calm-down as well as us calm-down. At the end of the day we are all exhausted, we realize we have a lot of things to do still, like we have to get

supper or lunch ready and we have to get clothes ready, but at the same time it brings the unit together and it actually calms you down and makes you relax....What do you think hon?

Dad: I agree. I agree, I think it also makes us a little more aware during stressful times. We actually think about it [activities] and we remind ourselves and we remind him to use some of the methods to calm down and to think about it. It just adds another dimension to think about which is good.

For this family finding time, for things other than daily living, was and continues to be the most difficult thing to do. Whether it is finding the time to read a book, spend time alone, spend time together as spouses or spend time doing meaningful things as a family. That time is hard to or sometimes impossible to find. Time together, as a family, had been allocated in these past 10 weeks. Adam was attempting to maximize and extend this time together in the evenings before bed. Adam and his parents found the time together to provide great benefits for them all and they found it to be meaningful time.

Mom: I think that is why right now the comfort zone is that bedtime, because that is the quiet time, that is the time to tone down. The rest of the day is a busy time and he has other things on his mind and so do we, but then that time brings us together.

Mom: The one thing we can't do right now is take the time out to read the books that you gave us to read, It is all a matter of trying to...

Dad: Make time.

Mom: I think that has always been the hardest [finding time]. When you have a

child that is physically challenged your arms and your legs, as a Mom and a Dad, need to become eight instead of four. [*It is necessary to help your child accomplish daily living tasks that his arms and legs are incapable of, i.e. eating or using the bathroom*]. For both of us, I think that is the biggest challenge that we find. Perhaps bringing in those times when we can all lie down and listen to Jelly Belly or Floating on Clouds makes you realize that we all have to tone down. That we all have to realize you can have control, that you can make it better, you have to make it better.

Melissa: I'm sure you can sometimes feel that you have ten other arms that you need when trying to meet all the needs of Adam. Some days you can't even stop and consider what your hands and feet are to suppose to do.

Mom: Oh, exactly.

Melissa: It is good to know that there is a space, however small to just stop together, for however long and to be refreshed by that time.

Mom and Dad: Um Hmm.

Mom: What he [Adam] has wound up doing is not just having us listen to two at the night time. Now it has turned into four or five.

Dad: He is trying to extend the time.

From the parents and Caregivers perspective, activities such as the one's we had tried together should be included in school and in other homes with families who have special situations. It was expressed that a partnership of home and school would be the most effective for the children and families.

Caregiver: I think it would help some of the teachers to know about Changing Channels and stuff like that. So, that when Adam is stressed out they can say something that might trigger something [*to help him refocus*].

Dad: It might be something for the school to consider. I know Adam's first two years there [*at school*] were really heavy in the social skills and how to handle complex situations or stressful situations. This type of resource will be good at that time too.

Personal Reflections on this Journey

It was a cold winter day when I arrived at this new and different home in the country. As I pulled in the drive I considered how much I didn't know and curiously awaited the discovery of these things. Parking the car I breathed out my anxiety and breathed in the confidence of knowing that all experiences provide depth to life. Now was the time to dive in. I looked up at the house, which could be anyone's home, but noticed something which set it apart from other homes. Beside the front step through the snow a wheelchair lift was visible. I was quickly reminded that this house was special to me and that I was on the verge of discovering how. This house contained three people who called it home. I treaded up the steps with excitement to meet this family. As I did this I reminded myself that I was here to learn and that thought thrilled me.

I was fifteen minutes earlier than we had arranged. As I rang the bell I contemplated whether I should have or not. Weighing the option of driving around in the snow or moving ahead and starting what I had set out to do; I chose to arrive early and begin this encounter.

What lay behind the door I could only imagine and my imagination was failing me.

Upon ringing the bell there was a flurry of activity from within. After waiting a brief moment the door was opened to me and I was greeted by enthusiasm. Mom promptly greeted me and instructed me to join them in the kitchen, not really paying attention to my apologies for being early. "Never mind that, we are finishing up lunch, come and join us." She turned and led the way. Entering the kitchen was a superb moment as I was introduced to Adam who was wide eyed and bursting with questions for me. He did well to hold his questions back as I took my seat at the table. Little did he know that I too was bursting with questions. We quickly discovered our questions were of the same intent. Mine to discover him. His to discover me. Over the next few months Adam and I, along with Mom and Dad, would attempt many ways to answer some of our questions. We would soon discover though that some of the answers came before we knew that we had questions. Our journey to learn was the same and the path we discovered continues to grow.

Adam was interested in knowing why I was there and what it was that I do. Explaining to a seven year old child with multiple disabilities of which I know not the limitations was my first and deepest challenge. It was a profound challenge because it demanded that I simplify my task for the one whom it mattered most. It demanded that I have a clear intent, however unknown the means and the end would and had to be. It demanded that I embrace our interactions and believe that the end really didn't matter but that I was there to learn and to discover with this particular little boy and his parents. I expressed to Adam the importance of being aware of our situations, of knowing what we faced, of the challenges and the joys of our individual lives. Having come from such different places, we were able to agree to start out on a journey. Our journey was one

of learning to live better in the midst of all the different things we faced. We agreed to try some new things together.

To Adam this was initially a process of learning to play some new things. How quickly the play turned into an every day necessary reality. How quickly Adam discovered that this play was different and how he desired and orchestrated this play to meet a need in him. What was initially unknown became known and termed as “know-all-ogy” by Adam. He finalized our intent as being the process of discovering possibilities through knowing new things about ourselves. The one to whom this mattered most, namely Adam, was the one who defined the process most profoundly and simply. Towards the end of our time together, I asked Adam what I should do if I were to offer the program to other children. His response: “it is your only choice to discover the child’s possibility!” For Adam, our time together was the discovering of possibilities. This is the journey we found ourselves in and this is the journey that will continue beyond our time together. Adam had a deep interest in knowing all that he could about himself and others. Our task each week was to deepen the “know-all-ogy” and to discover our possibilities.

The everyday reality of incorporating the mental skills play, thoughts, words, and activities did not take Adam long. Our meetings every Saturday started with the sharing of Highlights from the previous week and a discussion on how possible resources or play activities had been used. The sharing of Highlights was a special time, it enabled Adam to learn that play didn’t have to be work as he had previously thought. A child with particular mental and physical needs finds that simple play or thought takes much work and thereby requires constant effort; play can become

work. Adam though was able to prepare for Saturday morning Highlight sharing and so it was not work. He had already formulated the thoughts and the words to share and was now able to focus on the excitement of sharing his particular Highlights. The discovery here was that the possibility existed to communicate more easily and to more effectively communicate things which were important; things that he and his family desired to share when adequate time was provided along with a specific purpose.

The discovery of a common language was valuable to this particular family. Having an understood vocabulary with some key phrases which prompted important strategies for stressful situations promoted more positive family functioning. The use of changing channels was effectively used by Adam and his parents. Adam created a physical symbol to help him remember to change his mental channel. When he was cued either by a parent or by his own initiative, Adam would attempt to snap his fingers as best as his muscles would allow him to. The process of changing his thoughts and behavior from one that felt and acted out of control, to one that was in control was of great value. This required that Adam discover how much time he needed to accomplish something. It further required Adam to be patient with himself in order to behave in an unfrenzied way. Adam was able to spend less time calming down from a high level of frustration and instead attempted to take the time to recognize the situation he was in and his specific limitations and needs. In doing so Adam discovered that he was able to problem solve within his abilities.

The presence of a common language also emerged when the family was moving through daily living. Simple imagination, which can bring much joy, moved out of blowing up ships in the bathtub to more

complex and profound uses. One morning as he and Dad were driving to school in a dense fog Adam commented: “clouds”. Dad, not being sure what Adam was commenting about, continued to question and dialogue with him. Adam had made a connection between a cloud imagination activity that he had done with me and was now integrating the idea into life. Adam was able to see beyond the fog and it’s driving frustration and to remind his father that they were in the clouds, that they were driving on the clouds, that they could relax at this very moment as they thought of the Floating on Clouds activity and relaxation.

Quite moving was the wisdom of this seven-year-old boy. A common language along with the patience and opportunity to explore his thoughts was discovered to be useful in promoting family understanding. His parents were able to see more clearly the struggle it was for Adam to express himself. His parents also recognized the depth of thought that existed in their child’s mind in the form of imagination and his growing philosophy of life long discoveries. Adam, in responding to the program activity of Magic Wands and integrating his thoughts on the movie Star Wars, was able to share his fears. Adam expressed to us his knowledge of how a Star Wars character moved from the side of light to the dark side. He, for our benefit, simplified the moving factor to fear. Adam then went on to describe his own fears and how he would choose not to go to the dark side in his thoughts. He described Highlights as a way of keeping himself free from fears.

Many of Adam’s fears showed when thoughts of hospital visits or activities that seemed too difficult to understand were talked about. Highlights and common language were such a valuable discovery for Adam. Adam and his family were told by his present school that the coming school

year would have Adam in a new school. Upon visiting the new school with his parents and hearing his parents expressions of concern for Adam at this much larger school, Adam was able to express that he was not afraid. He was able to express that, yes this was new and unknown, but “Mom it is a Highlight for me.” Mom was not as enthusiastic about the change and recalled to me what Adam had told her “you have to have faith in other schools Mom!” Great insight and words from a seven year old who has faced many difficult challenges in living. Adam had discovered that he was able to embrace a new challenge and to see the positive in this move, even if it meant leaving the known and suitable school.

Adam’s physical limitations made it incredibly difficult for him to close his eyes because the attaining sleep was a long and frustrating process. Adam’s parents had decided to give Adam the freedom to decide when and where they would participate in the activities that I presented to them. Adam decided that he would like to do them lying in his bed. Adam was able to inform his parents of the particular activity on the audiotape that he would like to listen to. First he might choose Changing Channels, and then he might choose Jelly Belly or Floating on Clouds. One night in the process of this choosing, the chooser became silent. Mom and Dad looked at each other with smiles. Adam had fallen asleep in less than fifteen minutes on his own. This had never happened before in his seven years. The following Saturday the parents were filled with thanks to me for helping their family, most especially Adam realized a solution to a problem that until then had always seemed a mystery to solve.

Other unsolvable problems which found solutions existed for this family over our time together. Adam’s limitations had him

very congested and at times he found it difficult to breathe. Rather than have a panic attack, be it Adam or his parents, they were all able to put the breathing techniques that they had learned to good use primarily through Changing Channels.

Of immeasurable value was the discovery by this family that despite their many demands, there was time to spend together which could re-energize each of them. Although the parents were stretched beyond what they could manage effectively, they could recharge for a half hour each day with Adam before bed. Although there were still numerous tasks to complete for the day, the family could pause and enjoy a few joyful moments together. This family discovered the joy of relaxing and learning together. The coping of this family was improved and they viewed themselves as functioning at a much greater level than before this program began and before they chose to take this time together.

Discovering their possibilities for these weeks was a true exercise in “know-all-ogy”. They were learning to recognize the areas in their lives which required some attention in order for them to all live more positive lives. They were able to better know what their needs were as they discovered answers to questions they had not previously asked [i.e. relaxation before bed can help]. Through this process the family was able to take an honest view of themselves and to evaluate the patterns of communication and behavior that they had acquired. This family was able to equip themselves to face their specific situation and to discover that their possibilities were greater than they had realized.

The Path Ahead

Participation in this research study was enlightening for this family. The family

enjoyed the Positive Living Skills program and was very pleased with how well they could incorporate the activities into family life. Orlick’s program provided valued, fun activities for Adam and his parents. The program was adaptable to their specific needs and the parents felt confident in their ability to use the activities together. Adam was excited to participate and when he discovered that the activities were beneficial for helping him to relax; he used them on his own initiative. Throughout this program the family learned more effective methods of communicating with one another. For example, Adam was able to express his feelings in a more visible way by using the Cat Scales. As well, activities such as Changing Channels allowed the family to communicate in stressful situations through the use of cues and gestures.

Of great importance was how the program empowered the family. From the beginning, Adam was inquisitive and creative with the information presented to him [creating a word for it: know-all-ogy]. In our final discussion Adam expressed that he had become a “knower” and that he perceived himself as smart [“I am smart”]. It is valuable for Adam, a child with many challenges, to consider himself as smart and able. Adam exhibited great learning and insight with respect to mental skills and their use in many different situations throughout our weeks together. For Adam’s parents the use of the activities provided greater opportunity to meet the needs of their family and to support one another.

The knowledge of how this one family experienced this program can be of value to other families who may have similar stresses and demands. Each family is a unique combination of individuals and thus unique demands and stresses exist in families. How individual families interact and relate with

one another is different, but it has been discovered that the activities and resources used in this study have great adaptability. Individuals have the capability of learning mental skills, regardless of their personal demands or stresses.

The information gained in this study could be of value to professionals who work with and support families who have children with disabilities. It is clear from this study that it is possible for parents to become the teachers in their homes with respect to positive mental skills and coping strategies. Families supporting a child with disabilities are interacting often with professionals for things such as treatment or care support. Professionals, such as teachers or doctors, can present positive skills as a viable resource to families in helping the family cope effectively with demands and stresses.

At the beginning of this investigation I was challenged to consider that children are intimately and directly impacted by the people who are closest to them. From my family experience, as a daughter of parents who continue to directly involve themselves in my life, I am profoundly aware of their impact on my outlook and subsequent life choices. From my work experience, supporting persons with special needs, I have witnessed the impact my involvement with them can have on their lives. My experience with Adam and his family provided further evidence on how much our life can have an impact on others.

Families with increasing demands and stresses can have the opportunity to be empowered from within to experience success in dealing with the pressures. Not only is success increased when the family is able to confront the demands placed upon them, but success can be achieved by decreasing the gap between home and other

supports. Positive living skills programs can potentially be adapted to fit into any family situation, with the parent or caregiver as the principle educator. In meeting the many needs and demands on families, it is necessary to move forward in integrating the roles of all supports: home, school, or medical. All areas of support need to strive to work together in finding the best means of support for individuals in families, if our society is to see more positive ways of functioning. In my study I have seen how beneficial the learning and use of positive living skills has been. I hope that this family is able to communicate to the larger support community how best to help them face the unique stresses of living with a child who has a disability. In turn it is my vision that this project will increase awareness and knowledge for the larger society in the continuing attempt to foster healthy families and to help decrease the occurrence of “handicapped families.”

Through many interactions over a significant period of time I have come to see the great necessity for support that special needs individuals and their families require. I have witnessed the struggles that the special needs community faces when trying to function positively in a health and social support system that is unable to completely meet their needs. Families need to confront the issues surrounding the support that their children receive either in a school setting or through home care. These special families struggle when advocating for the needs of their child and family within the community. Although I have seen some extremely positive interactions between parents and their children, there is often an underlying “stress” or “demand” placed on these parents. They are faced with some ongoing “unique demands” that few parents with non-disabled children confront. More programs and research designed to support

these children and their families is warranted.

Petr, Murdock, and Chapin (1995) conducted an interesting study which explored the relationship between stressful events, the family's help-seeking behaviour, professional response, and crisis resolution in four families who depended upon home care for a child with disability. They recommended that "professionals need education about the coping processes and experience of parents, and about how important empowerment is to that coping process. Training programs should utilize parents as trainers and require trainees to actually spend time with the families in their homes. The comments of [these] families encourage professionals to focus more on the strengths of families and the positive, character building aspects of the process" (p.20). This study draws attention to the need for further applied work with special needs families. Research is needed which focuses on training the

trainer; the parent. It would be beneficial to further examine how families can best support their children with disabilities from within the home.

Families are in need of resources that can aid them to function better within the family unit. Among these are positive living skills programs which can open doors to more positive interactions with one another. Programs can potentially be adapted to fit into a family situation in which the parent or caregiver can be the principle educator. The goal would be to increase both the caregiver's and the child's coping strategies and positive living skills, and therein promote more positive family interactions. Delivering support to families with special needs, along with the curriculum and ideas behind positive living skills programs for children and adults, can provide a valuable resource for any family facing unique stress or pressure.

References

- Bradley, R.H., Parette, H.P., & VanBiervliet, A. (1995). Families of young technology-dependent children and the social worker. Social Work in Pediatrics, 21 (1), 23-37.
- Bruusgaard, D., Smedmaten, B.K., & Natvig, B. (2000). Bodily pain, sleep problems and mental distress in school children. Acta Paediatrica, 89 (5), 597-600.
- Creswell, J. (1994). Research Design. California: Sage.
- Cohn, E., Miller, L.J., & Tickle-Degnern, L. (2000). Parental hopes for therapy outcomes: children with sensory modulation disorders. American Journal of Occupational Therapy, 54 (1), 36-43.
- Cordoni, B. (1990). Living with a Learning Disability. Southern Illinois: University Press.
- Cox, J.L., & Orlick, T. (1996). Feeling great: Teaching life skills to children. Journal of Performance Education, 1, 115-130.
- Cummings, S., Bayley, H., & Rie, H. (1966). Effects of the child's deficiency on the mother: a study of mothers of mentally retarded, chronically ill and neurotic children. American Journal of Orthopsychiatry, 36, 595-608.
- Dale, N. (1996). Working with families of children with special needs. Partnership and practice. London: Routledge.
- Dane, E. (1990). Painful passages: Working with children with learning disabilities. Silver Spring, MD: NASW Press.
- Dunst, C.J., Trivette, C.M., & Deal, A.G. (1987). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline.
- Dyson, L.L. (1991). Families of young children with handicaps: parental stress and family functioning. American Journal on Mental Retardation, 95 (6), 623-629.
- Fraenkel, J., & Wallen, N. (1996). How to design and evaluate research in education. Toronto: McGraw-Hill.
- Genevro, J.L., Andreassen, C.J., & Bornstein, M.H. Young Children's understanding of routine medical care and strategies for coping with stressful medical experiences. (1996). In M.H. Bornstein, & J.L. Genevro (Eds.), Child development and behavioral pediatrics (pp. 59-83). New Jersey: Lawrence Erlbaum.
- Gilbert, J.N., & Orlick, T. (1996). Evaluation of a life skills program with grade two children. Elementary School Guidance and Counseling, 31, 139-151.

Leske, J.S., & Jiricka, M.K. (1998). Impact of family demands and family strengths and capabilities of family well-being and adaptation after critical injury. American Journal of Critical Care, 7 (5), 383-392.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. California: Sage.

McDermott, S., Valentine, D., Anderson, D., Gallup, D., & Thompson, S. (1997). Parents of adults with mental retardation living in-home and out-of-home: caregiving burdens and gratifications. American Journal of Orthopsychiatry, 67 (2), 323-330.

McDonnell, R., & Bowden, E. (1989). Breathing management; a simple stress and pain reduction strategy for youth on a pediatric service. Issues in Comprehensive Pediatric Nursing, 12, 339-344.

Maxwell, J. (1996). Qualitative research design. California: Sage.

Mostyn, B. The content analysis of qualitative research data: A dynamic approach. (1985). In M. Brenner, J. Brown, & D. Canter (Eds.), The research interview uses and approaches (115-145). Toronto: Academic.

Orlick, T. (1995). Nice on my feelings: Nurturing the best in children and parents. Carp, Ontario: Creative Bound.

Orlick, T. (1998). Feeling great: Teaching children to excel at living. Carp, Ontario: Creative Bound.

Orlick, T., (2003). Positive Living Skills for Children: Series of CD's for Children, Zoneofexcellence.com.

Owens, J.A., Spirito, A., McGuinn, M., & Nobile, C. (2000). Sleep habits and sleep disturbance in elementary school-aged children. Journal of Developmental and Behavioral Pediatrics, 21 (1), 27-36.

Palermo, T.M. (2000) Impact of recurrent and chronic pain on child and family daily functioning: a critical review of the literature. Journal of Developmental and Behavioral Pediatrics, 21 (1), 58-69.

Petr, C.G., Murdoc, B., & Chapin, R. (1995). Home care for children dependent on medical technology: The family perspective. Social Work in Pediatrics, 21 (1), 5-22.

Ramritu, P.L., & Croft, G. (1999). Needs of parents of the child hospitalized with acquired brain damage. International Journal of Nursing Studies, 36 (3), 209-216.

Rousey, A., Best, S., & Blacher, J. (1992). Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities. American Journal on Mental Retardation, 97 (1), 99-109.

Rubin, H., & Rubin, I. (1995). Qualitative interviewing. California: Sage.

Seidman, I. (1991). Interviewing as qualitative research. New York: Teachers College Press.

Siegel, J. (1995). Commentary- Children's reactions to aversive medical procedures. Journal of Pediatric Psychiatry, 20 (4), 429-433.

Simons, R. (1987). After the tears: parents talk about raising a child with a disability. New York: Harcourt Brace.

St. Denis, M. & Orlick, T. (1996). Positive perspectives: intervention with fourth-grade children. Elementary School Guidance & Counseling, 31, 52-63.

Winzer, M. (1993). Children with exceptionalities: A Canadian perspective. Scarborough, Ontario: Prentice Hall.

Zeitlin, S., & Williamson, G.G. (1994). Coping in young children. Toronto: Paul H. Brookes Publishing.