

CHAP[®] Connections

Spring/Summer 2004

CHAP Program — respiteservices.com

Volume 2, Issue 1



A Parents Perspective

Here am I, but 43
Have lots of time
But none for me.
My kids, my house, my job attended
But I need to get myself mended!

My eldest daughter, away she goes
So much to do and how she grows!
A social life that I once knew
It's incredible what she can do
She swims, she dances, she sings, and can draw
Takes music and drama and leaves me in awe.

My other daughter has special needs
And away I go, every where she leads.
There are doctors and therapists of every kind
If I recited her list, it would blow your mind!
She makes you go that extra mile
But her adorable face makes it all worthwhile.

The day is full, routines galore
I do them all, but I want more
I adore my kids as you can see
But I've forgotten what to do with me

Around and around and around I go
I'm on the wrong treadmill—this I know.
I must get off and start something new
A little time off—I need you!

Written by a parent receiving respite

What's Your Opinion!

It's hard to believe that Spring is just around the corner and the CHAP Program is entering its' fourth year of operation. Back in April 2001 an evaluation form was sent out to families asking them to comment on their experiences.

Of the responses received, parents included both comments about the CHAP Program as well as the workers that families were connecting to. Parents strongly expressed a desire to connect to enthusiastic and knowledgeable workers who are dedicated to the care and support of their sons/daughters.

Parents who had connected to workers commented that they are very pleased with the worker and the support being provided to their son/daughter.

CHAP has since strived to build a database of workers who have the skills families are looking for and who have a professional attitude towards their work.

But what about the workers? Are you satisfied with the connections you have made? and the job opportunities that are available? Some of you have been in touch and have shared some of your experiences

and told us your interests. Well we would like to hear from all of you!

Part of maintaining a successful program is having workers that feel good about what they are doing and who feel they are gaining the skills and experiences they are seeking.

Included with this newsletter is a CHAP Program survey. This is your chance to share your experiences, your goals for joining CHAP and your ideas on what would assist you in your work with families.

We encourage you to complete the survey and help us to provide an exciting opportunity for workers and a fabulous service for families and individuals.

A summary of the results will be shared in a future Newsletter.

"One of the deep secrets of life, is that all that is really worth the doing, is what we do for others."

Author unknown



News and Bulletins

“Contact a CHAP Coordinator for a new classified posting.”

My CHAP Experience

My name is Deedee Edelstein and I've been a CHAP Worker for a little over a year now. I work for five families and every day about an hour is spent planning what I'm going to do with my clients in the two hours that we play and work together. I leave at about 3:00 P.M. and get home from 6 – 6:30 P.M.

My background is acting. After obtaining a Fine Arts degree in dance and drama from York University I performed on and off for about 30 years. I started teaching drama while working as an actress and taught for various schools and institutions while pursuing a career and taking care of my family. I'm a mother of a 16 year-old boy and five step children who range in age from 23 – 31. They have all taught me a great deal.

What I trained for and always wanted to be was an actor. I've had my ups and downs and two years ago during one of the down times a neighbour asked me if I would do her a favour seeing that I had some time on my hands. She asked if I would shadow her four year-old daughter at daycare. Her child had just been diagnosed with autism. I said sure. What could be so hard? From the moment I started working and trying to play with this beautiful little girl I felt the powerlessness of wanting to help and not knowing how, the burning of a new passion, and a desire to relate to this special and mysterious child. She seemed powered by an interior motor that propelled her forward, that kept an aura of noise and

busyness around her strong enough to block out everything; me, the other teachers and the children who wanted to get to know her. She wouldn't make eye contact, was constantly trying to lose me and wouldn't acknowledge or play with any of the other children even when they came over and hugged her or gave her toys. She would put a puzzle together upside down with an almost military precision, then move on to the toy cars and send one down the ramp, then run to the plastic vegetables and arrange them in some kind of pleasing order. She would then go to the book corner, get a book throw it down and move on to something else.



Nothing seemed to hold her attention for very long. She continually made a low whining sound and flapped her hands. Anything could set her off into a tantrum of banging her head

against the floor, biting herself or biting me. Yet there were times where I felt very close to her. She would allow me to hug her and share a toy for a short time. I would catch her looking at me from across the room. Once she caught my eye, took her hand and swept all the water toys and the water off the desk and on to the floor. That was a definite communication. I don't know why she did it but I found it exhilarating because she was saying something to me with her action and her eyes. She has now moved on to a special school and I'm told that she is learning new skills and progressing. I felt that I wanted to continue to work in this field and called Geneva who told me about respiteservices.com.

My first job after Orientation was shadowing a 7year old boy at Holiday Camp in Thornhill. When I met with his mother I was amazed at how definite she was about what she wanted. He was not to go to the bathroom alone, nor was I. He had to be followed everywhere, never left unattended. She was very concerned that he not be left out of physical games like soccer, dodge ball and basketball. She said he needed help to play and I was to

Welcome! Join us in welcoming three new people to the respiteservices.com team. Marilen Miguel as Executive Assistant, Lorna Powers as CHAP Coordinator and Megan Blunt as Access Facilitator for Autism.

Best Wishes! We wish Ingrid Clifford, CHAP Coordinator and Access Facilitator all the best as she leaves us on maternity leave.

Classifieds! Please note that the classified ads for workers have been changed. They will only be posted for a month from the date of input. All worker classifieds that were on the website before December 2003 have been removed. If you would like your classified put back on the website, if there are changes or if you would like to extend the ad, please contact us.

New Policy! Please note that in order to alleviate family frustration over contacting workers that do not return their calls we are implementing a new policy. If a family contacts the CHAP program to say that a worker did not return their call we will be making that worker profile inactive. The worker will remain inactive until such time as we have been contacted or an update of the profile has been received. CHAP Coordinators will call workers with this information as it occurs. So please remember to return those calls.

Resources! In an effort to take advantage of some of your creative and innovative ideas, a new resource page will be coming to our website. The resource page will assist CHAP workers in being able to find new ways to benefit the individuals that they are supporting. Keep watching for further information.

Recruitment! Look for us at your University or College's career fairs. CHAP will be there actively recruiting workers. Don't forget to pass on information about the CHAP program to your friends and family members as well and encourage them to send in a resume.

be his guide, his coach. She wanted me to try to engage him with other children and to keep him involved in group-activities. Max is a very sweet and delicate child. He is small for his age and when I started working with him he seemed to be in a world of his own. He desired no involvement with the other children. He would join in an activity for a few minutes and then he would try to escape by hiding under a piece of equipment, playing with his face and talking to himself in the mirror or running out of the room into a busy community center. It was very challenging just keeping up with him, pulling him out of tiny places and lifting him when he chose to throw himself on the floor kicking and screaming. He was also not toilet trained and screamed when I would suggest that he go to the bathroom. We spent most of the time walking around the center watching the swimmers, squash players, reading books I had brought or drawing with markers. To keep him involved we sang songs, and made up stories about the people we saw. He seemed to hate being in a crowd of children. The noise in the gym seemed to upset him and he became confused and overwhelmed by fast moving games. He was happy when we went off on our own and played a quiet game rolling the ball back and forth. Often other children would want to join us and he was oblivious to them. If I tried to get him to respond or take part in an activity he would tantrum. He loved swimming and would carelessly go into deep water, go under and gulp his way up only to go under again. I had to stick to him like glue, pulling him up and keeping him from the deep end. The first two days I was nonplussed.

I felt like I was letting his mother down, as I didn't seem to be able to accomplish anything that she requested I do. Then I realized that maybe the goals were too high. I started counting. I counted seconds and minutes that he could be engaged, then tried to extend the time.

The young counselors got more involved and helped to involve him. Too much activity and unclear instructions upset him so we tried to simplify. We worked in breaks for him to get away from the hub bub. We would promise him a walk, a book or special outing if he would join in for a specific amount of time. The counselors gave him lots of attention and praise for his work.

I now tutor Max once a week. He has matured since then and is greatly changed. He's able to concentrate for longer periods of time and does not tantrum when asked to do his work. He connects a bit more with children his age and is not so isolated in his own world.

My job is to do homework with him. He prints well now, learns his spelling words very quickly, is good at math and enjoys reading with me and to himself. It shows that his mother's hard work has paid off. She makes sure he gets extra help at school and at home. She spends hours working with him, enriching him with activities, games, books and family outings. Max was just a little slow getting started but he's developing into a curious, expressive and bright child.

Each child that I work with is very different. I've had to take my time understanding each one and based on the expectations and instructions from parents have attempted to tailor personalized programs for each.

Tod is 9 years old and in a regular class with a full time worker. His mother, who is very knowledgeable about autism and all the treatments available, is determined to keep him in the stream of normally developing children. His passions and interests are Disney videos and reading and writing words. He is constantly reciting lines from videos he has seen and he loves to read. He enjoys printing and writing as well. He has a beautiful singing voice and often sings the songs from the videos. When working with him I have to urge him to attend, to really listen to the story and look at the pictures. His mother has a list of activities to do in order to strengthen his knowledge and skills. Our routine starts with a story from a short picture book. I write out work sheets from the story getting him to copy sentences, learn vocabulary and answer questions. We usually draw and paint a picture from the story trying to tie all the ideas together. We also do a word search which Tod loves, sometimes a dot to dot, we look at pictures and discuss them, play Fish, Uno, sing songs, learn telling time, using money, exercise and listen to music. Tod would much rather sit and "stim" on a Disney book, or just be allowed to be lost in his own fantasies, but he must be drawn out of that. His eye contact is much improved and he comprehends the stories and answers the questions himself. The trick is to get him to become more verbal, to express his feelings and of course join in. Everyone works very hard with Tod, his parents, teachers, speech therapist, E.A. and other tutors. His mother has taught me most of what I teach him and has done an incredible job researching, running his program and informing all of us as to what needs to be done.

Mike is 6 and is in a regular grade 1 with a one-to-one worker. His autism is not that apparent but he has had a challenging time adjusting to school and the demands that are made on him. He is acting out, having bursts of anger at the teacher and the other children. He still

needs an afternoon nap and is quite exhausted having to cope. I help him with his homework which he hates doing. He has trouble concentrating for any length of time so we work in very short intervals with lots of breaks and fun things to look forward to. He loves cars and racetracks so we spend time on these interests, having races or admiring and describing the cars.

Alice is a terribly anxious 9 year old girl. She has a hard time relaxing enough to concentrate but loves to play Fish with her mother and I. She also loves to read books. We share reading. I read the words that are difficult for her; she fills in the words that she can recognize. She is afraid of a lot of things and does not like to write or draw. She repeats herself over and over and claps her hands constantly till they are raw and split. She will not go for a walk, or go outside to play in the snow, but her favourite book is "Saidie and the Snowman", which is about a little girl who builds and rebuilds a snowman all winter long. Alice bounces around without any direction, twisting her body, bending her fingers and crunching her teeth. I try to stay calm and redirect her anxiety when she gets upset over a word I might say or an idea expressed. Her mother is almost housebound as the child is afraid to go anywhere. She is in a special class at school but is having a difficult time there. She tells me she has no friends and does not seem particularly upset about it. She loves her videos and television shows seeming to prefer to be on her own or with her mother or her cat Sammy. So far I have not had a session with this girl where her mother has not been involved. It is my goal to occupy Alice for the full two hours so that her mother can have a much-needed break. I would also like to introduce some new activities like dancing as she has a lot of physical energy.

I always bring a bag that is full of books, games, toys, cards, material for costumes, paints, markers and blocks. Most of this stuff can be bought at the Dollar Store. It's important to have new things every once in a while as I find children are often bored with their own toys.

The respite that we provide is so important. These parents need a break so desperately either to be with their other children, to take a much-needed nap, to make dinner or to attend to other matters. The faster you can pick up what is needed from you the better for all concerned. These parents are always working to help their children deal with their autism. They are either attending classes, reading, working with the school designing programs, making appointments with specialists or

helping with homework. For the time we are with their children, we need to take over.

Reading books about autism has helped me a great deal in understanding the children that I work with.

Some suggestions are:

- ◆ Donna Williams autobiography "Nobody Nowhere"
- ◆ Temple Grandin's ideas on teaching autistic children which you can find on the web
- ◆ "Let me Hear Your Voice" by Catherine Maurice
- ◆ "Behavioral Intervention for Young Children with Autism" by Catherine Maurice
- ◆ "Autism and Asperger Syndrome" by Uta Frith

The **Net** is also a great provider of information on activities you can do with autistic individuals. You can find puzzles, colouring sheets, lesson plans and themes that can be incorporated in your sessions.

I've also found **classes** very helpful in giving me confidence and insight into how to understand what people with autism experience. These classes give you concrete skills and ideas, how to track behaviour and what the child is learning. Classes are offered at Geneva Centre for Autism and through respiteservices.com.

work. With Mike I find it helpful to go to the park. Tod depends on the routine so we do the same thing every day. That gives him comfort. When I see him getting anxious I give him a big hug by pressing down on his body with all my weight. It helps him to feel grounded and safe. If he's upset, we may sit in the bean bag chairs for a while and just rock back and forth. I talk soothingly to him and tell him it's all right to feel upset and to cry if something sad or hurtful has happened. His



mother suggested this physical contact to me; I did not come up with it myself. I would be careful of physical contact until I got permission from the parents.

him down, another child might require a squishy toy, a favourite doll, a drink or some food. The instructor brought in a box full of ideas from slinkys to rubbery toys that are soothing and calming to the touch.

Max has difficulty with balance and walks on his toes. He loves to run and play but he needs to set the pace. We throw the ball back and forth gently from a short distance away. Every time we play I try to increase the distance from him and the force of the ball so he can build his confidence and maybe start playing ball with the children at school. Mike on the other hand, loves throwing and kicking the ball. He's just not keen on rules so I try to interject a rule or two so he will understand turn taking, goals and scoring points when playing with others.

Life at school for these children can be very hard. Any skills you can teach them will be helpful for them in order to fit in. The "Skill Building Series" that respiteservices.com offered last summer was very helpful in giving ideas on what to teach and how to approach the individual you are supporting. One of the best pieces of advice was to become a keen observer. How do you know what to do? **Observe, Wait and Listen.** You not only listen to the child but to the parents. Watch them interact, the parents can model for you. They've spent so much time with their child and they've probably done a lot of the early intervention training. They will be helpful in suggesting things to work on and approaches to take.

It's very important to have fun with the child,

"Sometimes it's the "melt down" that teaches you how far you can go and what not to do."

A class that helped me a great deal was called "Anxiety – Autism Spectrum Disorders". Understanding the anxiety these children experience is very important in giving insight into how to relate and approach different situations. Their anxiety is much more severe than we think and they have no easy way of expressing it or seeking help for it. It's important to recognize the signs of their anxiety so that you can avoid an attack and lessen the effects. I've learned the hard way but I'm not sure there is an easy way.

Sometimes it's the "melt down" that teaches you how far you can go and what not to do. It may be too much for the person you are supporting to do their homework right when they get home from school. They may have had a bad day or a stressful time. With Max, we always take a half hour walk before we start to

The other course I found helpful is called "Sensory Processing and Behaviour". Sometimes these children are anxious because their senses are overloaded or over active. Noises

are too loud, smells too strong, eye contact is too harsh or touch is too invasive. Tod hates the phone. When it rings it totally destroys his concentration as he sits there covering his ears and rocking back and forth. Sometimes the music I bring in is annoying for him so we put it away. Other days he enjoys it. I try to be sensitive to what he is experiencing at the moment. Sometimes what we're doing is too much, too much writing or listening or reading. If he is getting anxious he starts to bite his hand and rock back and forth. I quietly put what we are doing down for a moment and encourage him to use words to tell me what is bothering him. For him a quick hug will calm

to explore what they love to do and to help them build confidence in the things they do well. When I tried to teach Tod the song "Where is Love" I sang a line and asked him to repeat it. He insisted on singing a song he knew from one of his videos. I sang "Where is love", he sang "Our time, our place", I sang "Does it fall from skies above", he sang "Sing a little song", I sang "Is it underneath", he sang "Our place, our song." We continued like this to the end of the "duet". Tod was singing his song and I was singing mine. The songs strangely enough blended perfectly, like they were meant to be sung together. At the end of the song he turned to me, applauded and exclaimed "Well Done!"

by Deedee Edelstein, CHAP Worker

*The names of children have been changed

Upcoming Events and Workshops

Jan 12—May 3, 2004

Event: **Snoezelen Training**

Agency: Bloorview Macmillan Children's Centre

Mar 1—Mar 8, 2004

Event: **Behaviour Management**

Agency: Reena

Mar 16, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

Apr 14, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

Jun 9, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

Jul 21, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

Mar 3, 2004

Event: **Emergency First Aid and CPR**

Agency: respiteservices.com

Mar 26, 2004

Event: **Intro to Total Communication and Programming**

Agency: Reena

May 11, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

Jun 22—24, 2004

Event: **Summer "Skill Building Workshop Series"**

Agency: respiteservices.com

Jun 29, 2004

Event: **CHAP Orientation**

Agency: respiteservices.com

CHECK THE WEBSITE FOR MORE INFORMATION ON WORKSHOPS & EVENTS!

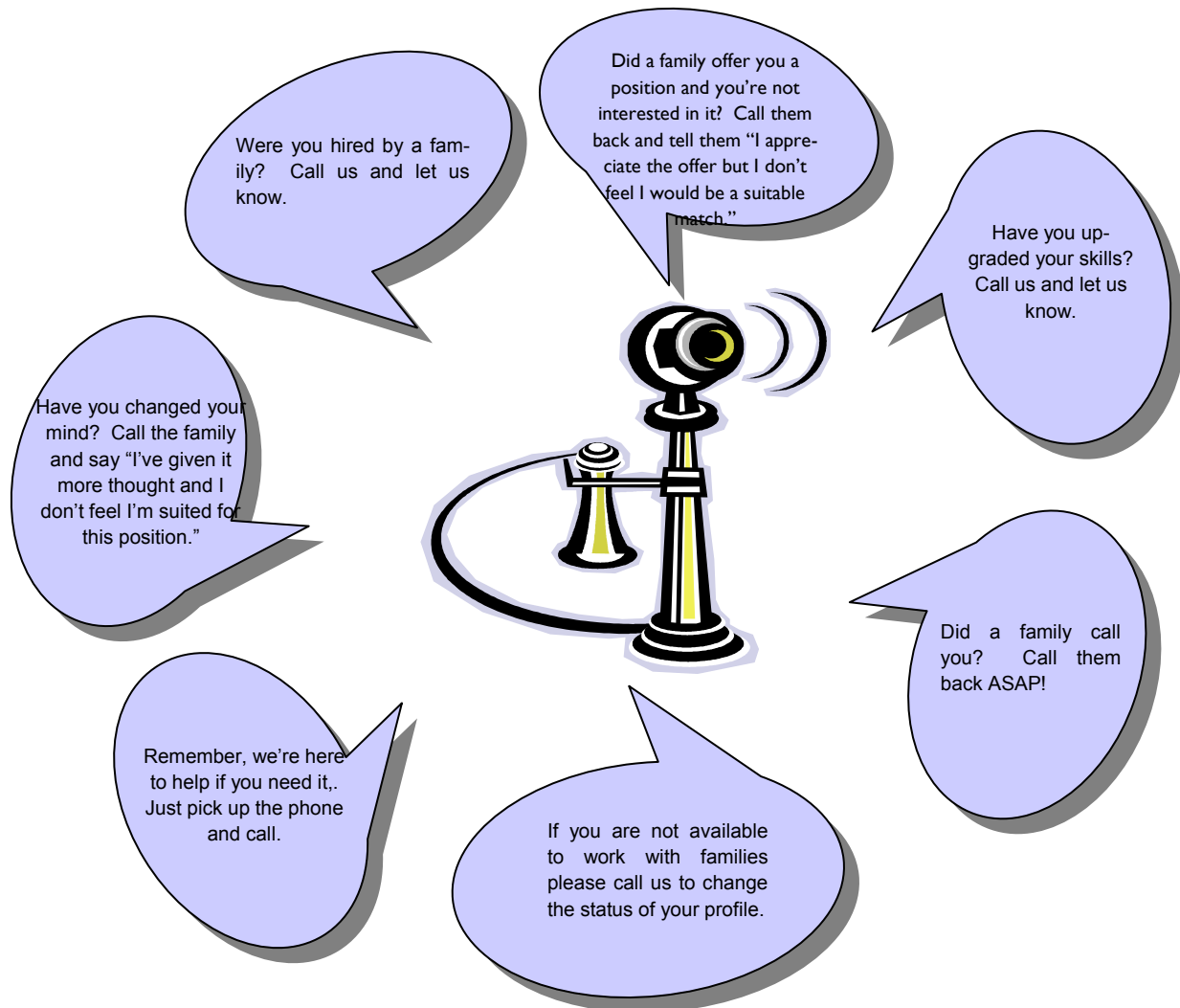
If you would like to attend an event or have further questions, please contact Natalie Blackwell at nblackwell@respiteservices.com or 416 322 6317 ext 7. Please check the website information for any cost associated with the workshop and make your cheque payable to the Geneva Centre for Autism.



Community Helpers for Active Participation

Telephone Etiquette

“The telephone is a great way to keep in touch and keep others informed.”



Communication is the key to a successful relationship!

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We would like to hear from you! Let us know what you think about the newsletter. Do you have information to share with other CHAP workers? Do you have any questions you would like answers to? Have you discovered a great resource that other workers may want to know about? How often would you like to receive the newsletter? Please forward your comments to a CHAP Coordinator to be included in the next issue.