

**“KNOWLEDGE INTO ACTION!” – Effective Practice for Child and Family Services  
CONFERENCE**

2<sup>nd</sup> – 4<sup>th</sup> August, 2004

Sydney Convention and Exhibition Centre, Darling Harbour

Session #12 Presenters:

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- **“Someone to turn to...”™** is a network of support for parents of children with Autism Spectrum Disorder – some form of autism.  
Lisa and I would like to describe the program to you, with a little about its beginnings and its development.
- It is a program which provides support for carers (or parents as they have all been to date), support for parents of children with autism, by parents of children with autism. It is an initiative of the Autism Association of NSW (Autism Association), based on perceived real needs of many of its parents – as Lisa, who has a son with autism, will explain.

**RATIONALE**

*\*Parent Requests / Needs*

**One of the beauties of this program is that the volunteers are all parents of a child with an Autism Spectrum Disorder. Not all of the parents have young children. Some of the volunteers have high school aged and adult children so the needs of the parent can be met regardless of what age or situation their child is at.**

**When our son was first diagnosed with autism, I sought out as much information as I could, but it was many months later before I actually came in contact with another parent of a child with autism. Until that time I felt isolated and alone. I looked at other children my son’s age and compared him to them. Obviously he wasn’t doing half the things they were doing and I couldn’t really talk to their mother’s about my concerns because they wouldn’t understand. I’m sure they would have been sympathetic, but it wasn’t reasonable to expect them to really understand what I was going through.**

**Quote from book – *Lessons from My Child* – “While medical information proved to voluminous, Bernadette was soon struck by the lack of material on the one subject that she desperately needed to know more about – what could she expect from life with a disabled child? Were the roller-coaster ride of emotions she suffered through normal? Was there anyone else who could relate to her feelings? Where were the voices of parents like herself...?”**

**While I personally have worked with parents coming to terms with a new diagnosis, the same types of questions and concerns apply when these children come up against a new challenge. Perhaps transitioning from a special school environment to mainstream schooling. From primary school to high school. Or dealing with puberty and the challenges that that represents.**

**The introduction of this program indicates how the Autism Association does not just deal directly with the person who has autism, but works to support the parents.**

*\*Empathy*

**Empathy is defined as an “Identification with and understanding of another's situation, feelings, and motives.”**

**In the role of volunteer, we don’t aim to solve issues that arise for parents; rather, we are there to listen. Having a child with an Autism Spectrum Disorder ourselves means that we are able to identify**

**with their feelings and situations. It means that when a parent is struggling with even the basics of their parenting role we can say that we understand.**

**It's not easy to go shopping when your child has a "melt-down" because of all the noise and lights. Helpful strangers give you advice about controlling your child while others give you a look that tells you that their child would never behave like that in public.**

**Or you go to the local park and while other children play happily on the equipment or play chasing games, your child sits in the sand pit and pours sand over his head, again and again and again...**

**The frustration and embarrassment for parents in these types of situations is common and often parents prefer to stay at home and become, as one of my parents says, "a prisoner in her own home". Because it's just too hard to go out with their child.**

**So often well meaning family and friends are only capable of offering sympathy and pity, when what you really need is understanding and support.**

**It's at these times that we can look to others that have "been there, done that". Someone who can validate your emotions, know that your battles are not hopeless and who can celebrate the triumphs not understood by the greater society, but by another parent.**

## ***SUPPORT PARENTS***

It is the common bond of having a child with autism between volunteers like Lisa, and carers they are supporting, which is the fundamental crux of this network.

(Whilst volunteers are themselves carers, we call these support parents volunteers, and those they support, carers or parents, for the purpose of distinguishing them.

This particular support program, "Someone to turn to..."™, complements other professional and family support available in the community. Each support avenue has, of course, its own benefits.

As support through "Someone to turn to..."™ is on a 1-1 basis so it is focused exclusively on the needs of the parent. It can be given in the relative ease of the parent's and volunteer's own home, at a time which is mutually convenient to both. This 1-1 linking also permits more frequent support where necessary and allows parents to reach out to their volunteers in times of need (although it is the volunteers' own decision as to whether they give out their phone number to their parent – most choose to do so).

\*\* Importantly, parents and volunteers are specifically matched according to diagnosis and age of the child with Autism Spectrum Disorder, the volunteer's child being approximately 2 years older than that of the parent they are supporting, to give the benefit of hindsight and allow for parallel thinking about diagnostic and intervention tools.

## ***NATURE OF SUPPORT***

### ***Emotional***

**No emotion exists in isolation, so it is quite usual to be chatting to a Mum whose emotions range from depression and despair to wry humor in the space of a phone call.**

**Many parents feel a sense of anger. At some stage almost all will go through the many stages of grief that comes to some sort of acceptance. The role of the volunteer is to support the ranges of emotion without judgment or criticism. Often you are the only one that they can 'vent' to. Some mothers are so used to putting on a 'brave face' for family and friends that they can feel safe in telling a volunteer what is really playing on their minds.**

### *Practical*

As an example of this type of support, I will tell you of a time when one of my parents was feeling overwhelmed with the new concept of including pictures into their everyday life to help her son to understand what was going to happen, to assist him in requesting things and to supplement his general communication needs.

One time when I met with this Mum at her home over lunch, I brought with me some materials that I use, some handouts that I had picked up from talks that I had gone to and some web site addresses for her to try. Being able to go through these together and show her how I had started made the implementation of this system clearer for her.

### *Phone*

Ideally it would be great if we could all meet face-to-face, but practically that is not the case.

Most contact between volunteers and parents is done over the phone. As an initial contact I set aside time and then check with the parent if it is a good time to chat. If not, I make a time and we catch up then.

For some, it is late at night when the children are in bed. For others, it's when the children are at school and they have some time to themselves. Whenever it is, it is important for the volunteers to make sure that they have set aside time to chat and not just squeeze in a quick call.

I also find it helpful to take notes while I chat so I can make sure that anything I can do practically to help I can follow up on. It is also helpful to read through any notes prior to making the next call.

### *Face to Face*

I have had the opportunity to meet a few of the parents I have been linked with face to face. It is lovely to put a face to a name. Unfortunately, it is not often practical for most volunteers.

Distance and time -constraints, plus the demands of family life for the volunteer usually require support to be offered over the phone.

Face to face contact can also be a little confronting for some parents and they feel more comfortable with the anonymity of the phone.

## **THE VOLUNTEER**

- The Autism Association values its volunteers as full staff members. (The only difference from other staff – they're not paid!) The Autism Association's Code of Conduct applies to volunteers as to all staff, and is particularly relevant in matters such as confidentiality and insurance.
- Essentially the role of the volunteer is to build a supportive relationship with the parent with whom they are linked, making contact about every two weeks. As Lisa said, volunteers not only provide an empathic listening ear, although this is very important and most appropriate in some cases, but, by building one conversation on the last, help the parent progress through current concerns. This encourages a carer to feel the volunteer is really interested in them, fostering a closer, more trusting relationship.
- The Autism Association is very protective of its volunteers.
- They only work with one parent at a time, unless volunteers themselves ask for another match, and,

- are encouraged to take time out from volunteering if they need it for any reason.
- Moreover, in appreciation of their work, the Autism Association keeps volunteers abreast of services, workshops and courses available. This, together with the support they gain from other volunteers, ensures that the volunteers are gaining something for themselves and their families.
- To assist volunteers to do their work in the most effective way possible, the Association provides training for them. Before they are linked with their 1<sup>st</sup> parent, volunteers participate in a full weekend of training – a big time commitment, especially with a child with a disability, but everyone who has done this training has been very positive about it. The weekend, using a workshop approach, examines the role of the volunteer in detail, with its specific aims and profile; fine-tuning skills and sensitivities. We discuss the need to encourage parents to seek professional advice from professionals. There is time for volunteers to share their own experiences – it's important that they have the opportunity to do so, whilst serving to emphasise that every situation, parent and reaction is individual, something to bear in mind when supporting others. Issues such as grief and loss, and coping strategies, are discussed through the volunteers' own eyes, as these are the kind of concerns which will arise for the carers they are working with. So, too, there is an afternoon on communication skills, in part specifically telephone skills – speakers from the Spastic Centre, including Paul Mavromatis, have taken these sessions.
- Every 8-10 weeks there is an evening of ongoing training, with a guest speaker and the opportunity for volunteers to discuss their work with colleagues. As in the first training weekend, guest speakers come both from; within the Autism Association, and have to date included Anthony Warren, Director of Outreach and Consultancy, (directly in charge of "Someone to turn to..."<sup>TM</sup>), one of our Family Counsellors, and our Behaviour Intervention team; as well as from Carers NSW and The Benevolent Society. Volunteers pass on new information to other parents, and can benefit themselves.
- The Autism Association soundly supports its volunteers. As the Coordinator of the network, I am there for them to discuss their work, to toss around ideas and where necessary, to debrief. I also source information for volunteers on behalf of their parents, such as respite in the carer's area, a strategy for bedwetting or information on services in another state for a family who was moving.

### *COORDINATOR'S ROLE*

- Essentially, then, the role of the coordinator is to link volunteers with all the other resources of the Autism Association and, through its volunteers, to link carers to these. The Coordinator is also the lynch pin between carers and volunteers.

Last March the Autism Association appointed me, as Coordinator, to help develop its 1-1 parent support program. Discussion about their volunteer programs with organisations such as The Benevolent Society and The Cancer Council helped to formulate the policies, procedures and practice of "Someone to turn to..."<sup>TM</sup>. So, too, the early months saw the spread of information about the forthcoming program to professionals and parents – so that once the first volunteers were trained in August, parents could begin to benefit.

For the program's effectiveness to be ongoing, this spread of information must continue, so that those in need of support can receive it, and other parents with children with autism have the opportunity to make a difference to these carers' lives. We use brochures, newsletters and presentations to inform the community. Organising the training workshops, participants, content and trainers, is part of the Coordinator's role.

When a parent initially asks for some support through the "Someone to turn to..."<sup>TM</sup> program, I discuss their family with them for appropriate matching. A listening ear and the promise of some empathic support can be vital for carers at this time. It's important to note, though, that a parent

doesn't need to be in crisis to want to become involved with the support network – many of them aren't, but just want, and need, to share ideas and benefit from someone who's been there, and is there.

#### NOW

- There are currently 24 volunteers, with more to be trained in October.
- They are working with 34 families.
- Parents' children with autism Spectrum Disorder range in age from 2-16, those of volunteers from 5-36.
- So, too, we have volunteers who speak Japanese, Arabic and Filipino – and have our first match in another language – Japanese.

#### **EVALUATION**

##### *By volunteers*

**We are often given opportunity to give feed-back on how we, the volunteers, believe the program is going. We are also able to make suggestions as to areas that we would like some on-going training in as the needs arise.**

**I personally, enjoy my role and find the system and coordination to be supportive and empowering.**

##### *By Parents*

After about their sixth contact, or when the volunteer feels the parent may no longer need her support, I talk with the parent. If they wish the support link to it continue, and the volunteer is happy about this, it carries on as needed. Whilst the level of support perceived by parents must vary, all parents to date have reported their involvement with “Someone to turn to...”™ positively. Perhaps I could give you a few typical quotes:

“My volunteer ‘makes you feel like you know what you’re doing’.”

“This is the unknown for me but she’s been there.”

“ ‘It’s great’ when you speak to somebody and they can finish your sentence for you.”

“I’ve been too tired to call her but ‘it was really nice to know that I could reach out if I needed to and someone would be there’.”

#### **CONCERNS?**

**Some of the difficulties that volunteers have come up with since we started the program are;**

**Making contact – it’s sometimes difficult to make that initial contact and get the relationship started.**

**Playing phone -tag – you leave messages, you miss their call, they leave a message, you miss them etc. etc. One of the best ways to avoid this is to make a time to call and adhere to it. If something comes up, still make a call to let them know and re-schedule. It is important to the parents to know that they are not inconveniencing you!**

**Personal lives – we all have them. Volunteers are still parents, some of them work out of the home, and others are at home still raising a young family. We choose to fit the role of volunteer into our lives, but often things come up that make it difficult to fulfil that role for a time.**

**With consultation with the coordinator, it may be necessary to take a break while we deal with our own lives without having to feel guilt at not meeting our expectations as volunteer. Once that ‘crisis’ is passed, then we are able to re-commit to our role as volunteer.**

**High-maintenance parents – sometimes the needs of the parent can become quite overwhelming for the volunteer and the reliance on the volunteer too demanding. It is then that the coordinator is able to support the volunteer in making the break if required or offer advice in how to set and maintain the boundaries.**

Lisa mentioned “high-maintenance” carers who can indeed be very stressful for volunteers, although I am glad to say that there have not been too many ongoing cases of this nature. “Someone to turn to...”<sup>TM</sup> is anchored in the volunteer/carer shared experience of a child with Autism Spectrum Disorder, but it has been seen to have its own ramifications. It can also make it difficult for volunteers to maintain regular contact with their parents - a major concern.

Some volunteers choose to be in frequent contact with me, but for those who don't, striking a balance between their own privacy, and independence in their work, together with broadly monitoring contact with their parents, can be “tricky”.

Family commitments, particularly difficulties with child-minding, may preclude participation in ongoing training sessions, although motivation to attend seems to be high.

There have been a couple of inevitable personality clashes resulting in a change of match.

Of obvious concern is the waiting-list – there are 27 families waiting at present; it is heart-breaking to have to tell a stressed parent that they need to go on yet another waiting-list; waiting-time is dependent on an appropriate match becoming available; this may be a couple of weeks or some months.

## ***SUCSESSES***

We've talked a lot about concerns, and it's essential to identify them to move forward, but the overall success of STTT really speaks for itself – since the first volunteer-carer match in August last year, 41 families have benefited from the emotional, and practical, support offered by the Autism Association's network of trained volunteers. There is every reason for the program to continue to develop and grow, and is encouraged by the community at large to do so.

## ***THE FUTURE***

Much of the emphasis to date has been on setting up the program. Now it is time for more consistent in depth evaluation from both volunteers and parents for future planning.

It's important to promote greater professional and carer awareness of the “Someone to turn to...”<sup>TM</sup> parent-to-parent support network, and would appreciate any help you may be able to give us.

To meet greater demand and to keep the waiting-list down, we must source and train more volunteers.

We currently have two male volunteers, with another two to three to be trained in October; we want to build on this and develop more support for fathers. It is, of course, not necessarily the case that fathers need not only work with fathers.

We would very much like to expand into country areas and are hoping to get some funding to allow this; meanwhile there are a couple of rural communities interested in organising a similar 1-1 program in their area themselves, probably with some initial help from us. That would be a very exciting development for carer welfare.

We aim, too, to be able to offer support in more languages.

- WHO KNOWS - grandparents, siblings, you name it – “Someone to turn to...”<sup>TM</sup> can go anywhere

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