

## **COMMUNICATING OPENLY, HONESTLY & GENEROUSLY**

### **A Presentation by Adrian Ford, CEO of the Autism Association of NSW & Roger West, Consultant, WestWood Spice**

#### Introduction

- The paper examines communication processes in the Autism Association of NSW and follows a project which began more than two years ago.
- The Association is the largest provider of autism-specific services in Australia.
- Last year it was in contact with 5000 people with Autism Spectrum Disorders and their families. The vast majority of these clients were children or young people.
- The latest estimates are that there may be as many as 12,000 children and young people with an Autism Spectrum Disorder living in NSW alone.
- Association services include an information line, a number of early intervention programs, a range of services for school aged children and family support. There are also a small number of services for adults with autism.
- Services stretch from Newcastle in the north to Pambula in the south on the Victorian border.
- There are many definitions of autism. It is a life long developmental disability. Its cause or causes are unknown but it is probable that a complex genetic explanation will be found in years to come.
- In the meantime we rely on behavioural indicators to identify autism.
- Rita Jordan, in *Autistic Spectrum Disorders*, published by David Fulton Publishers, London 1999 and one of the international educationalists in this field, has provided a very practical definition around behaviour, accepting that there is a huge range in each of these factors. Even so the three factors she has identified are in all people on the spectrum to some degree.
  1. There are difficulties interacting with others – aloof, detached, and odd.
  2. There are difficulties in all aspects of communication – verbal and non-verbal.
  3. There are difficulties with flexible thinking and behaviour - rather it is repetitive and stereotyped behaviour.
- So when a person is diagnosed with autism, families are faced with the reality that communication and social connection in their family with this person is going to be very challenging for the rest of their lives.
- It is not surprising therefore when so much, both practically and emotionally, has to become invested by a family in trying to sort out communication with their person with autism that an organisation that has been set up specifically to support people with autism and their families will have very high expectations placed on it to be an effective communicator with the family and the client.

- And of course from time to time we at the Association fail to meet these expectations about communication.
- This project began after one such crisis. It provided the impetus for the Association to learn more about this particular process in this organisation and to search for ways that it could communicate more clearly.
- Roger will introduce what turned out to be a very large project which he facilitated with the Association and then I will report on some of the outcomes so far.

### The Communications Project

*“Communication usually fails - except by chance”* Osmo Wiio, Finnish researcher

#### **Aims**

- A Communication Strategy
- A Communication Policy
- A Communication Protocol (or best practice guidelines for organisational communications)

#### **A Three Pronged Strategy**

- Parents and Staff Survey
- Case Study
- Consultations/conversations including parent/family groups, staff consultative committee, staff groups, management group and Board.

In this presentation we focus on the survey.

#### **Parents and Staff Survey**

There were 3 kinds of communication content...

- about autism (the subject)
- about the Autism Association (the organisation)
- about a particular client or family (the relationship)

There were 3 purposes for communication (for example from the Association's perspective)

- to give information (to tell)
- to request/seek information (to ask)
- to receive information (to listen)

By combining the purpose of communication, that is, (a) to give information (to tell), (b) to request/seek information (to ask) and (c) to receive information (to listen) with the content of communication, that is (a) about autism (the subject), (b) about the Autism Association (the organisation) and (c) about a particular client or family (the relationship) a matrix was created with nine possible combinations of communication.

For each of these nine combinations we asked parents and staff:

- How well does the Autism Association perform in this area?
- How important is this area to you?

We used a 5 point scale: 5 = very high and 1 = very low.

### **Some Findings**

- Staff responses and parent responses were very consistent.
- Both considered communication generally to be VERY IMPORTANT (4.5)
- Both said the most important kind of communication for the Association was giving/telling – first about particular clients/families, then about Autism, then about the Association.
- The Association tended to perform best in the areas that were seen as the most important.
- The average performance was 3.4 i.e. above average, but room for improvement.
- Answers were supplemented by comments, and these were often very useful: eg *“The newsletter is great...(but) we need more info about therapies and therapists...and groups our child can attend”*
- Parents rated the Association as performing best in the area of giving/telling i.e. the area they saw as the most important.
- They said the Association was best at giving info about Autism, then about particular clients/families and then about the Association itself.
- They said the Association was least good at receiving/listening – first (worst) about particular clients/families, then about autism and then about the Association itself.
- Staff also rated the Association as performing best in the area of giving/telling, but their focus was on clients/families.
- So they said the Association was best at giving info about particular clients/families, then about receiving information about clients/families and then requesting information about clients/families.
- They said the Association was least good at giving info about itself, then at requesting information about itself, and then at listening to information about Autism.

### The Outcomes So Far

- Roger’s report was completed in December 2003. An action plan was developed to be implemented from 2004 to 2006. These are some of the outcomes so far.

- Outcomes have focused on both families and staff. By ensuring better processes were in place for both groups it is expected that this should lead to better outcomes for people with autism.
- The entire report including the survey was placed on the Association's web site [www.autismnsw.com.au](http://www.autismnsw.com.au) – an uncensored “warts and all” document. It could be nothing less.
- A communications protocol was developed and endorsed as a policy to be implemented across the Association.
- The Association's magazine/newsletter which was previously tied to being a financial member is now freely available to anyone on the Association's web site or in hard copy form at a minimal cost.
- Every staff member receives a fortnightly newsletter attached to their pay sheet.
- A successful induction program has been implemented for all new staff. It is held on a quarterly basis.
- Our school staff have completely revised the way and the frequency they give feedback to parents about how the students are progressing. It is being recognized now as a model process.
- A staff advisory group on communication has been formed. It will meet for a whole day twice a year and workshop communication in the organisation.
- We are piloting a workshop for staff and a workshop for parents on communication to be held later this year. Following feedback on these workshops they will progressively be made available to all staff throughout the Association over the next two years and offered to all parents whose children are receiving services from the Association
- The Association has developed a number of cross divisional work groups to work on Association-wide tasks. Along with some good work being done through these task groups, people are finding out about the strengths across the Association outside of their own particular division.
- Currently, the Association is investigating the possibility of developing services in a number of regions. One of these is the Far North Coast. The first step in this was to undertake a community consultation regarding the needs of people with autism and their families living in that area.
- Previously the Association had responded by setting up whatever service or services it could in remote locations without a more complete process such as we undertook on the Far North Coast.
- It was conducted over five weeks by an independent facilitator. She met with over 200 people.
- Some weeks after it was completed we received some interesting feedback from one of the key people with whom we consulted. She said that regardless what services the Association may be able to start, things were

better already – so much had been opened by the consultation process itself. People knew each other better. They had found they had more resources.

- This is one example of the Association listening more. It is an invaluable lesson we have clearly learnt through this process but we have much to do as we work towards completing all recommendations by the end of 2006.