

ASSID Conference

Hobart

November 2009

Down Syndrome WA – Workshops for Fun and the Future

Today I'm going to tell you how Down Syndrome WA (DSWA) has involved people with Down syndrome in developing its strategic plan through a number of workshops called Fun and the Future.

But first of all I want to give you a little information about Down Syndrome WA, so you can understand the background to this. Down Syndrome WA began 23 years ago as a small parent support group. Our first project was to produce an information kit for parents of new babies with Down syndrome, as there was no other positive and up to date information available.

Over the years, the Association grew and is now the main group in WA representing people with Down syndrome, their families and carers. We have hundreds of members all over WA, and run a range of programs including family support, the Aim High program and Aim High club for young people with Down syndrome and training workshops for teachers, support workers and child care workers.

Down Syndrome WA doesn't get ongoing government funding so we have to work very hard at fundraising and putting in for grants.

Down Syndrome WA has four part-time staff members as well as project officers depending on what programs we are running, and what funding grants we get! We also have a Board to govern the Association. Most Board members have someone in their family who has Down syndrome, but we also have some Board members who don't, but bring some great skills to the Board. We don't have any people with Down syndrome on the Board – this is something we want to happen.

Down Syndrome WA has had a strategic plan for quite a few years, but in the past it has always focused on supporting families. When we began working on a new strategic plan in 2008, things took a new direction.

The Board and staff of DSWA got together in mid 2008 to work on a new strategic plan. We had a workshop and then we worked on finishing off the draft strategic plan by email.

The new draft plan had a very different focus – people with Down syndrome themselves. The new vision statement is “People with Down syndrome live a life of their choice and make their contribution to the community”.

This doesn't mean that family support isn't important any more, but that it is just one of the ways that we plan to achieve our vision focussing on people with Down syndrome themselves.

Once we had the draft plan, we needed to make sure that it reflected the views of our members and other people and groups that Down Syndrome WA has contact with. Most importantly, we needed to make sure people with Down syndrome had a say.

We employed two different consultants to do the work:

- E-QUAL disability consultants to do the more 'traditional' consultation with families, other organisations and other community people; and
- Leah Ciancio to do the consultation with people with Down syndrome.

It's the consultation run by Leah that I want to tell you more about today:

- WHY we chose a different way of consulting with the people with Down syndrome;
- HOW the consultation was run;
- WHAT people said – what came out of the workshops;
- WHAT we learned from them; and
- HOW this will guide Down Syndrome WA in planning what it does

So first of all, WHY did we want a different way of consulting people with Down syndrome?

We wanted to make sure that people with Down syndrome could really have their say, and we knew that the usual ways of consulting (surveys, one off interviews, focus groups etc) just wouldn't work for lots of people, especially those who don't use words to communicate. We also had concerns that consultations can sometimes cause problems for people when they aren't done carefully eg sometimes people will open up about things that cause them grief, and often the people consulting don't have the skills to support them.

We knew that to really hear their true opinions we had to have a way of consulting that:

- Gave people time to get to know the person asking them questions, so they feel comfortable, safe and supported in saying what they think.

- Gave the consultant time to get to know the people taking part; to understand each individual, their concerns and how they communicate;
- Gave enough time for people to understand what the consultation was about and to understand the strategic plan;
- Offered a range of creative ways for people to express their views; and
- Was FUN! (This was REALLY important! We wanted to be sure people enjoyed the experience and kept coming back for the workshops.)

So, Leah created “Workshops for Fun and the Future”.

These consisted of two lots of workshops – people could attend either Series 1 in December 2008 or Series 2 in January/Feb 2009. Each series consisted of three workshops.

Down Syndrome WA advertised the workshops not only to its members but to all adults with Down syndrome in WA (the WA Disability Services Commission helped with this). 25 people contacted DSWA to find out more information. 19 people then decided to take part in the workshops – about half in each series. Most but not all people taking part lived in Perth, either at home with their families or in the community but still with help from their family. There were 12 female and 7 male participants. Most, but not all, people were of Australian/Anglo Saxon background. There was a big variation in the communication skills of people taking part, though most used at least a few words.

Leah gathered together some of her creative colleagues to help her and together they created and ran workshops designed to gather feedback on the strategic plan in a fun way.

Each workshop session followed this routine:

1. 10 minutes to settle in, sometimes with ‘circle time’ on the floor
2. A 1 hour inclusive arts activity
3. A 15 minute break for refreshments
4. A 15 minute presentation by some of the people taking part
5. A half hour focus group on the strategic plan – covering one main question each time

Having the same basic routine each session helped the participants feel more comfortable and relaxed.

The ‘circle time’ is often used at our Aim High club, as it often is in other youth groups as a way to bring everyone together in a relaxed way. Circle time lends

itself to games or taking turns with an activity or just chilling out with friends. It was sometimes used in these workshops to begin the session.

I'll now talk about the other activities in each workshop.

The aim of the arts activity each week was to have fun together and encourage people to express themselves in a sensory way and open them up to giving feedback.

The three activities for each series of workshops were:

- A walkabout in the area around the workshop venue, then back to the venue for drawing and painting inspired by the walk. Leah ran this with Art tutor David Mitchell.
- Dance artists and tutors in the Perth culture and the arts scene Sete and Rachel ran a dance class including stretching, individual and partnered free form dance. This was enjoyed by everyone.
- Ken Allen, a leading community arts director and professional cartoonist taught the participants the basics of cartooning and how to draw caricatures.

The professional arts facilitators were paid professional rates and also received DSWA calendars in thanks.

A very successful part of each session was a presentation by an adult with Down syndrome about achieving their goals. Originally the consultant had planned to find presenters from outside the group but it soon became clear there was plenty of talent and potential leadership in the group of people registered for the workshops.

Having members of their own group presenting helped to inspire the participants, showing them that everyday people with Down syndrome, people sitting next to them, are doing wonderful things. It also showed that these people are not living perfect lives; they are still working towards their goals and are having to get past stumbling blocks along the way.

The other participants asked the presenters lots of questions and said how much they enjoyed the talks and wanted to learn more.

While most of the peer presenters were able to write and present their stories, one of the presenters, Dave, gave a visual presentation about his work. Dave speaks through his wonderful artworks – he has had a solo exhibition and has an exhibition later this month in partnership with two other artists.

Yolanda talked about her life 'The life I love' – her job and her role as a member of the WA Ministerial Advisory Council on Disability.

Justin talked about his family, his sporting achievements, his work and how he feels about having Down syndrome. Justin is a very experienced public speaker.

Julia spoke about being an actress and gave some very good advice for parents of new babies with Down syndrome.

Anna talked about independence, the loss of her Mum to cancer, her spiritual life through yoga, massage and meditation and how she wants to be involved with Down Syndrome WA

Three friends, Alana, Elena and Caroline spoke about their wonderful friendship since they were young girls.

The peer presenters received certificates of appreciation and gifts of DSWA merchandise. There were spot gifts of merchandise to the other participants as well for taking part.

The half hour focus group asked one key question each time:

Week 1. "What do you like to do?"

Week 2. "What do you think of the goals of DSWA?"

Week 3. "How do you find talking about Down syndrome?" series 1 only.

Participants brainstormed and discussed each of these while Leah and her colleagues wrote and drew the comments and ideas in bright coloured markers on a long piece of butcher's paper. Some people added their own comments to the paper. Leah skilfully made sure to draw out comments from even the quietest person. She sometimes clarified her understanding with parents after the sessions to make sure the meaning was correct.

Week 1. "What do you like to do?"

This question aimed to find out the range of things that interest (and what is important to) adults with Down syndrome.

What was clear is that this group of young adults enjoys the same things as everyone else: buff bodies, sports and thrills, going out, TV and DVDs, music and musicals, Facebook; gossip and celebrities; sleeping in; sleepovers and holidays; acting and dancing; being creative and so on. The two main themes coming out of this activity were PEOPLE and EXPERIENCE; or "giving it a go".

Leah followed up with a number of parents about the goals and dreams their sons and daughters talked about. It became clear that the individuals and their families need more support and mentoring to develop their goals and that this could be an area DSWA develops as part of its services.

Week 2. "What do you think of the goals of DSWA?"

This was done in two different ways:

Series 1. This was done by asking 'this is goal 1. What do you think of this?' While people gave some interesting comments, it was clear that most people didn't understand the strategic plan as it was written.

In Series 2, this was approached in a different way, by asking simpler questions about each goal area. For example under the heading "Advocating for and enriching the lives of people with Down syndrome", the following questions were asked:

- How would you like to have your say and help other people with DS too?
- What stops you from talking about what you want?
- How might someone else help you, from the association for example?

This approach worked very well. Some issues that came up that people were worried about were bullying and personal safety. One person also talked about a sibling with personal issues showing that people with Down syndrome may need help in dealing with a range of family issues and not just their own personal challenges.

Week 3. "How do you find talking about Down syndrome?"

This question was included because a parent said that while her daughter enjoyed the workshops, she said she was uncomfortable talking about Down syndrome. She wondered if it could be discussed in the group.

Some, though not all, of the answers to the last question showed that some people, in different ways, are struggling mentally to deal with the way they are labelled and treated. Because the consultant could not provide counselling as part of the workshops, the issues weren't explored in depth within the workshops.

In addition to getting feedback on the strategic plan, a range of issues came out of these focus groups including that what Mums and Dads want is sometimes not the same as what adults with Down syndrome want for their future or personal growth.

Individuals taking part were very keen to have person to person contact and Leah spent quite a lot of time doing this, especially with one participant.

Some of the recommendations from the workshop are that DSWA look at developing more individual and systemic advocacy and also should make sure a plan is in place to refer any people taking part in any DSWA to a counselling service if needed.

During the course of the workshops, people also explored the question "What makes a person feel welcome?"

Here are some ways the workshops themselves were made more welcoming:

- People were invited to bring something from home to share with the group. (This gave participants something to show or talk about during introductions. Also, we played participants' CDs, put up posters of their favourite stars, displayed people's artwork, sporting trophies, treasured photos and so on).
- Peer presenters were given support leading up to their presentation moment.
- The workshop space was brightened and softened using wall art and cushions.
- Afternoon tea was supplied, including homemade muffins on two occasions!
- One participant in the second series, who had no one to assist her with getting to the venue, was picked up and dropped off by the consultant each week.

One parent said "Your workshops stood out. It was a forum where they felt safe to explore different things and where they could develop personally"

To the question "What can Down Syndrome WA do to make people feel more welcome?" one participant replied:

"OPEN THE DOOR AND LET THEM IN OUR HEARTS"

Some worksheets were also given to the group members to complete at home:

- What's important to me
- A bit about me
and
- About Down Syndrome WA

The worksheets used simple text and Compic.

The aim of this was to collect more information to support the information gathered in the worksheets. Not many worksheets were returned, probably because:

- Written surveys aren't ideal for people with intellectual disability (which is why the workshops were held to give people face to face chances and activities to help them give feedback;
- The timing of the worksheets wasn't good as people were in 'holiday mode' especially parents/carers who help to complete forms all year round; and
- Surveys don't usually get many replies anyway.

These workshops delivered a lot more than we had expected. Not only did we get to hear what people with Down syndrome thought about the draft strategic plan, they actually developed their own version of the Vision, the Values and the Mission. The people who took part in the workshops also put together their own set of goal areas for the plan. These show how people with DS want to be involved in the work of Down Syndrome WA. They called it "Our Version"

OUR VERSION

WHAT WE SEE FOR THE FUTURE

I am happy - living the life that I want.

I am important and have stuff to offer people around me.

WHAT WE BELIEVE

I have the same rights as everyone else.

The right to choose/vote; the right to be treated fairly; the right to a good home, education and work; and so on.

I am important and have stuff to offer.

I have things that I can do that make a difference to those around me.

WHAT DSWA DOES

Down Syndrome WA helps people like me to achieve their goals

This plan will be achieved by ensuring people like me:

Help with the job of supporting families

This plan will be achieved by ensuring people like me:

- Help with the job of supporting families (For example, by talking to new Mums and Dads about my life)
- Have their say (with and without the help of others) and live happily
- Help with the job of teaching people in the community about Down syndrome and other things that will help people be more welcoming. (For example, by talking to new support workers about my life)

- Are involved in the good running of the organisation. (For example, by participating in a Reference Group that reports to the Board)
- Help to market DSWA in a way that sticks in people's minds like Eagle's and Docker's branding. (For example, by taking opportunities to be in TV ads that promote good images of people with disability or by displaying my different talents wherever I can – drawing, acting, dancing, motor cross biking etc.)

As well as the development of "Our Version", a number of other recommendations were made as a result of the workshops:

- That the Board consider refining and releasing a short Plain English version of the Strategic Plan based on the version entitled "Our Version". Some photos and designs from the workshops could be used as visuals in such a publication.
- That the workshop footage be put to good use by way of a film project, possibly including follow-up interviews.
- That DSWA continues to offer personal and creative development workshops.
- That DSWA continues to offer opportunities for peer mentoring and presentation.
- That DSWA acknowledges the self-determination and leadership capacity of some of the participants in the consultation by convening a Reference Group to inform the Board.
- That DSWA considers the need for goal pursuit support as well as individual and independent (i.e. non-parent-led) advocacy amongst this target group.

DSWA is now updating its business plan and its operational plan with these recommendations in mind.

Recently, at the Annual General Meeting in September, two people who took part in the workshops co-presented along with one of the DSWA staff to tell members about the Strategic Plan and the Fun and the Future workshops.

Justin prepared and presented a talk, and Maddie prepared and showed a Powerpoint presentation. I wish they could also have been here today to present these to you.

In conclusion, the workshops were a way of giving this group of people a chance to take part in an experience and were a way for us to gather and interpret their opinions, their concerns and their dreams – to really get to know them so that DSWA can better meet its vision.

This was a very ambitious exercise – the concepts of an organisation and planning for the future were difficult for the group to grasp. The material had to be stripped right back to core questions of what people like doing and how they would like to be more involved with the association.

However, we gained so much more than we could have dreamed of and the workshops have told us that adults with Down Syndrome want to access creative and personal development programs, speak about their lives and take part in the running and activities of Down Syndrome WA.

DSWA would like to thank all the people who were involved in the project:

- Leah especially for giving so much of herself to the project
- Her arts colleagues David, Rachel, Sete and Ken
- LotteryWest for funding the strategic plan consultation
- And of course the wonderful individuals who took part and helped DSWA plan for its future.

I am glad to take questions and also to discuss afterwards if people would like to do that. If you would like more information about Down Syndrome WA please visit our new website at www.dsawa.asn.au

Jackie Softly