

## Being Heard

By Wendy Lawson BSc, BSW(Hons)  
GDip(Psych) GDip(PsychStud)  
June 08

### What to expect from this talk

- A description of the key factors in a successful journey as an AS adult and a few suggestions about how friends and family can best assist their adult member with an Autism Spectrum Disorder.
- I'll use examples from my life and from others' lives.

### Autism: My Gender

My gender and I are a package.  
We come as part of the deal.  
"But autism shows far more damage".  
"Look at the things that you feel".

### Autism My Gender

I cannot account for these feelings.  
Emotions intense and extreme.  
But my issues with everyday dealings,  
Can cause me to rant, shout and scream.

### Autism My Gender

I don't desire the 'make-up'.  
Fashion and high-heels don't appeal.  
I don't like perfume or my hair cut,  
But my need for 'understanding', is real.

The expectations placed upon me,  
Being female and all,  
Push me further into pain and grief,  
With my back against the wall.

### Autism My Gender

"I cannot multi-task", I say.  
"But you must, You're a woman. You can".  
You must cook, clean, organise and play  
The role that supports your man.

Your children and men depend on you,  
You must be strong, in control and sure.  
"What if these things I cannot do?"  
"What if my timing is poor?"

### Autism My Gender

"You must work harder, try harder to be,  
What society says and dictates".  
"But both my autism and gender are  
me, you see'  
They both influence my states".

As a woman I function differently.  
As a woman I think, see and feel.  
As a woman I value all that is me.  
My autism is part of the deal.

### ACCEPTANCE

- Being accepted for who I am is the very best thing and sends me a message that I am valued.
- Part of that acceptance is understanding that I have interests that take over my attention.
- Using those interests constructively keeps me motivated and gives me a starting place to share with others in our every day lives.

### Recognising strengths

- Profiling and observation; great ways to recognise strengths.
- Often, strengths come from interests. Interests don't have to be a distraction. They might be an asset.
- I'm only too aware of my difficulties and yes, I do accept that I need help with lots of things.
- But, I don't need others to focus on these, as much as I need them to focus upon my strengths.

### Valuing my disability/diffability

- Appreciating strengths and using them; a good way to assist me in the outside world.
- Some individuals are good with maps. Mapping can help us de-stress.
- Some are good with numbers; counting, ordering, calendars, dates and figures; these might help build a structure that we hang our day on.
- Some of us are good at noticing, we could be your best asset!

### Being Valued

- In being and feeling valued four key principles are a must: rights, independence, choice and inclusion (Valuing People, White Paper, UK Department of Health, 2001). This involves listening to the person and making sure they are always at the centre of planning and delivery of services plus offering support that meets the individual's needs, wishes, goals, abilities and personalised requirements...

### Whilst moving towards TLV

- TLV (typical Life Values) ordinary daily living means:
- Coping with disappointment
- Coping with change
- Coping with transition
- Respecting self & others
- Building confidence
- Person Centered Planning (PCP)

### Obsession?

Willey, (2001) "At the base, I have to wonder, are we so very different from marathon athletes, corporate presidents, bird watchers, or new parents counting every breath their newborn takes? It seems lots of people, NT or otherwise, have an obsession of sorts. In my mind, that reality rests as a good one, for obsessions, in and out of themselves are not bad habits.

### Obsession?

There is much good about them. Obsessions take focus and tenacious study. They are the stuff greatness needs. I have to believe the best of the remarkable – the artists, musicians, philosophers, scientists, writers, researchers and athletes—had to obsess on their chosen fields or they would never have become great. In some respects, then, it must be said that obsessions do not have to be considered handicaps. (p. 122)

### Putting it all together

- rights, independence, choice and inclusion
- I have a right to a positive future
- But I need to learn how to 'do' interdependence
- Choice might mean choosing not to choose
- Inclusion might mean accepting who I am then building our lives separately & together

### What is my understanding?

- Some AS individuals are able to articulate their desire very clearly, whereas others need a great deal of support to express their basic needs.
- Some AS individuals may not understand abstract concepts such as feelings, dreams or desires.
- They may find it difficult to imagine or visualise a life other than the one they are already living.

### Finding ways to build concepts

- Power Point
- Video
- Photos
- Role play
- Video games
- Interacting with individual's interests as rewards, motivators and places to share
- Projects
- Ongoing reviews etc.

### Choice: Age Appropriate?

- choice making can be improved by restructuring the environment to emphasise the options available whilst highlighting the functional relationship between a choice and its consequences.
- For example, Jack likes looking at car magazines and likes carrying a load of magazines when he goes out. He finds it difficult to put down his magazines even in bed and the bath.

### Keeping Jack & his stuff safe

- Through information gathering, it was concluded that in Jack's experience, magazines would be removed from him as a punishment. Often, Jack's magazines would fall into the hands of other unruly residents who tor or lost them.
- We found various colour coded cases to keep Jack's magazines safe. Eventually, Jack learnt that he could safely put down his magazines in these zones, continue with his activity and could get his magazines back. Jack still walks with magazines when he goes out. Only not a dozen as he used to, but three magazines in a carrier bag.

### Examples:

- At College, Jim's teachers complained about Jim's constant activity. One sighed, "He never sits down..". Another remarked, "He gets up in the middle of my lessons to sharpen his pencils and he twists around in his seat so much that it distracts the other students".

### On the Go; strength or weakness?

Jim's teachers mostly agreed. But two of them seemed confused. The phys. Ed. teacher claimed that she didn't have "any problems" with Jim and that he was one of her strongest students. She saw him as active and athletic, a leader, and as an asset to her class. He participated fully in all activities and tried hard to acquire new skills. The science teacher also described Jim as an active learner and called him "cooperative and inquisitive".

Some saw Jim's energy and activity as an asset while others saw it as a problem.

### Examples: Drawing? Doodling?

- At Uni, allowing students to draw can be an effective "stay-put" strategy. Unfortunately, doodling is often seen as off-task behavior. Some students, with and without identified needs, however, are better able to concentrate on a lecture or activity when they are given the opportunity to draw on a notepad, write on their folders or sketch in a notebook.

### Examples in every day life

- Interests connect:
- E.g. an individual who loves talking about the weather, so join this interest by talking about the daily weather in the newspaper. Then introduce the other sections of the newspaper. Over time, the person might become interested in the sports section, for example. Eventually, they might show interest in sports biographies, joining a sports club or being confident to share in conversation with others.

### Think better on the move?

One lecturer noted frequent movement and interaction assisted learning. He offered "ambulatory opportunities" to all. Giving students a prompt to discuss (e.g., What do you know about the stock market?; What is a statistic?) and then directing them to "talk and walk" with a partner. After ten minutes, he brought the students back together and asked them to discuss their conversations.

### Making a record or sharing ideas

- **Projects & Interests**
  - Having a project increases motivation
  - Areas: health, diet, exercise, sport, hobbies etc.
- **Using camera**
  - To get images onto the computer
  - To get images for printing
  - For daily use, objects of interest, food etc
  - For specific events

### What fuels motivation?

- **Confidence**
  - Belief one's efforts are worthwhile
  - OR frustration and anger: belief that one's efforts are NOT worthwhile
- **Evidence: what are we showing evidence of?**
- **Interest in an outcome:**
  - Strongest interests may be avoidance, of people, of confusion and fear..
  - If we don't facilitate the opposite.

### When individuals feel valued, at ease to listen?

- **What environments are there?**
  - Physical, emotional, social
- **Which ones are predictable?**
- **What environments put us at ease?**
- **What environment offers the most structure?**
- **Technology can be part of the answer**

### The tool of Technology

- **Environment: including other people**
  - Structured,
  - predictable,
  - stimuli-reduced
  - Maximise the individual's control of controllable things and those that are not.
- **Is in keeping with the way the rest of the world is going, so, it's fashionable!**

### Common interest - Shared fun

- **Around the computer**



### Developing in confidence and skill

- **Through the medium of technology (i.e. Sims; Second Life, email):**
- **listening**
- **Observing**
- **Sharing**
- **Valuing**
- **Appreciation of self and of other**

### Developing confidence

- If we feel confident and valued we are less likely to need to be stubborn, difficult and unfriendly.
- Treat us the way you would want others to treat you.
- We have interests too

### What are my strengths?

- Appreciate me and my abilities



### Support: Things to consider

- Individualisation
- Readiness
- Person centred planning
- Using connections
- Flexible supports

### Practice

- Needs assessment, risk management strategies and skilled staff will enable a collaborative effort between staff, families and health professionals.
- For example, Jane expressed in her review that she would like a boyfriend.
- Instead of being dismissive of her expression of choice all stakeholders involved in her support had action groups, with participation from Jane, to develop a support plan in this area.

### Practice

- Listening and consulting with Jane, (using social stories on relationships), we discovered Jane would like friends and 'boy friend' was a term that she had picked up from college.
- So a support network was put in place to enable Jane to be safe (risk managements) whilst the focus was on shadowing Jane on her initial outings and fading away the level of prompts to allow greater independence and a sense of achievement.
- we should be aware of the risk of overstepping the boundary between supporting Jane to make decisions and acting as decision makers.

### Language

- As family, friends or support workers, we can support to enable choice.
- In its most practical and attainable circumstances.
- If this is not possible, it's likely because the right information and options are not made accessible to AS individuals in a language they can understand.

### Programs & Care Plans

- Must consider NV communication.
- A good PCP might assist to “balance between freedom and control; supporting autonomy and providing protection and encouragement and coercion” (Smull M, Sanderson H, 2005. Essential Lifestyle Planning for Everyone. H.S.A: Manchester. Smull, Burke & Harrison, 1992).

### In Practice

- In order to make meaningful change and valuable contribution to the individual's life, the White Paper indicated that all persons with LD & ASDs should have a 'personal life plan'. The plan should enable the person, professionals involved in care and parents to work together in order to assist in achieving full potential for the individual's life, and live as comfortable and independently as possible (NAS, 2008).

### Practice

- Tom is a 26 year old man with severe Autism, LD and PICA. Tom is non verbal.
- he was damaging property, ripping clothes and beddings and eating them, picking walls and breaking windows .
- He was attending to his personal care supported by three or four people as he appeared to be aggressive towards others. He did not have any community access. He was also known to be self harming.

### Practice

- For the first few days he allowed us to stay in his room for few minutes only. He did not want to make any eye contact or communicate. He gradually allowed us to step into his personal space for a few minutes at a time.
- After several months, Tom was able to interact with us by using simple communication board with symbols (PECS).

### Practice

- Gradually, Tom became more open and familiar to people. He also became more comfortable being surrounded by outsiders. Supported by two staff, he was going out to the local town and parks for short walks and meals.
- He picked up basic communication skills within a few months and was able to decide what he wanted to do, eat or where he wanted to go.

### Practice

- There are a number of structured processes or 'tools' designed to support PCP. Similarly, there are a number of formats for recording someone's plan
- Tom learned through TEACCH that beside clothes he can also rip the 'ripping material', which was much cheaper, put his ripped clothes in the green rubbish bin in the corner of his patio and not run naked in the garden.

### Practice

- We also involved Tom in refurnishing his flat and removing all unnecessary furniture. He also took part in designing his activity room considering his sensitivity to the strong lights and too many objects around. The flat redecoration, new guidelines in place and limits presented through TEACCH resulted in Tom becoming much calmer and happier.

### Practice

- Tom uses mainly PECS to communicate; however, from time to time he says single words to request for a thing. There are times when Tom has difficulties to communicate as his attention span is limited and he easily gets distracted. The most we can get from Tom is a few minutes of interaction with staff each day.

### Practice

- Tom has a board with symbols/pictures on it and is asked to choose the most appropriate one. The exercise includes topics like; 'What I like to Eat', 'Where I like to Go', 'What I like to Do'. The outcome of each session is recorded and summarised during staff meetings. The action plan is made and carried out as far as possible.

### Considerations

- There are serious risks in focussing on achieving plans rather than changing people lives. The guidance stressed strongly that PCP on its own, however well done, could not deliver White Paper objectives; rights, choice, independence and inclusion

### Considerations

- It is important that all involved in support work together and be capable of responding to the individual's needs and aspirations accordingly.
- The service providers should engage with each other as well as with the family of the person involved so that the individual receives co-ordinated support.

### Considerations

- The support staff should be trained on PCP and supervised on a regular basis in order to maintain a consistent approach to agreed strategies.
- Each individual with ASDs should have access to an independent advocate and that should be built into the planning process (NAS, 2003).

### To summarise

- Telling us what to do or not do might not work (literal; thinking is in closed concepts etc)
- Joining us at our point of interest might motivate us
- Finding appropriate medium that also acts as teaching tool (Photos, social stories, IT) can equip us for both present and future
- Walk beside us as we learn; not in front or behind.

### Resources

Web pages: [www.mugsy.org/wendy](http://www.mugsy.org/wendy)  
– [www.autismandcomputing.com](http://www.autismandcomputing.com)

- [www.autistics.org](http://www.autistics.org)
- Getting The Truth Out
- <http://www.youtube.com/watch?v=JnylM1h12jc> (In my language)
- [www.youtube.com](http://www.youtube.com) (Posautive)
- Wendy's BOOKS & other resources:
- [http://www.bookinhand.com.au/catalogue.php?sort\\_by=title](http://www.bookinhand.com.au/catalogue.php?sort_by=title)

### References

- Dowell E., 2007. *Autism and Independence. A guide for local authorities: enabling adults with an autism spectrum disorder to achieve greater independence.* London: National Autistic Society.

### References

- Holliday Willey, L. (2001) *Asperger Syndrome in the Family: Redefining Normal* London: JKP
- National Autistic Society, 2004. *A place in society. The importance of planning for life for people with autistic spectrum disorders.* London: Crowes Complete Print

### References

- Powell, A., 2002. *Taking Responsibility : Good Practice Guidelines – Adults with Asperger syndrome.* London: National Autistic Society.
- Sanderson H, 2000. *Person-centred planning: key features and approaches.* Available to download from: [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

### References

- Sanderson H, 2002. Person Centred Teams in Implementing Person Centred Planning (eds) O'Brien, J and Lyle O'Brien Inclusion Press: Toronto. Available to download from: [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)
- Sanderson H, 2008. *The Emergence of Person Centred Planning as Evidence Based Practice.* Available to download from: [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)