"Autistic-friendly Practice: Striving for excellence in autistic healthcare (mental & physical)"

- **Dr. Ava Ruth Baker** (arbak@clear.net.nz / www.avaruthbaker.com)

"The health care needs of people with ASD can be complex … the appropriate management of their health care needs is complicated by the impact of the symptoms of ASD itself. …

Accounts by people with ASD suggest that there are barriers to good health care, which include lack of attention to health issues, anxiety, poor communication and confusion and avoidance of contact caused by dissatisfaction with previous contact."

- NZ ASD Guideline: 2.3a Health Needs (1, pp 74-5)

‘Autism Spectrum Consultancy’

(based Canterbury, Kapiti Coast & Bay of Plenty)

- **Diagnosis** – all ages
- **Post-diagnosis consultations**
  - supports & strategies
  - short-term counseling
- **Family member consultations**
  - understanding autism
  - ‘translating’ NT-AS
- **Talks & training** for professionals & community

(Background: GP with post-grad qualifications in mental health, autism (including accreditation in ASD diagnosis) and research methods)

Community-based participatory research
(autistic adults as equal partners)

"Autistic adults have a wealth of information to offer about their experiences …

Researchers have argued that obtaining input from individuals with developmental disabilities is critical to producing scientific information that is valid, ethical, and inclusive of their perspectives. …

[yet] autistic adults have rarely been included as partners in autism research" (10)

Autists: ‘zoo exhibits’ → ‘zoologists’?

“Their worth was becoming redefined …

Suddenly it wasn’t the experience of people on the spectrum that were of importance and insight,

it was also their *opinions.*

They were figuratively moving from existing as zoo exhibits, to becoming *talking* zoo exhibits, and then to themselves becoming the zoologists.”

-Michael John Carley (27, p40)

NZ ASD Guideline: 2.3a Health Needs (1, pp 74-5)

"Recommendations …

- **2.3.1 Medical and health care practitioners require knowledge of ASD and how it affects their clients to be able to provide optimum health care services.**

- **2.3.6 Healthcare providers have … been advised to**
  - work with the person and their family / supporters to ensure that their needs are understood
  - work with the interests and strengths of the person with ASD
  - alter … procedures to take the ASD needs into account …
  - communicate clearly
  - use photographs or pictures to explain procedures
  - provide visual and written information
  - remove stimuli that may distress the person
  - give feedback and encouragement"

Terminology

Terms used here for *whole* autism spectrum (including Asperger's Syndrome)

- **autism, autistic**
- **AS** (autism spectrum)
- **ASD** (autism spectrum **differences** / disorder)
- **'on the spectrum'**
- **'autist', 'aspie'**

NT (neurotypical) = not autistic (brain works more 'typically)

'Invisible end of the spectrum' (3)

'Autistic-friendly' practice

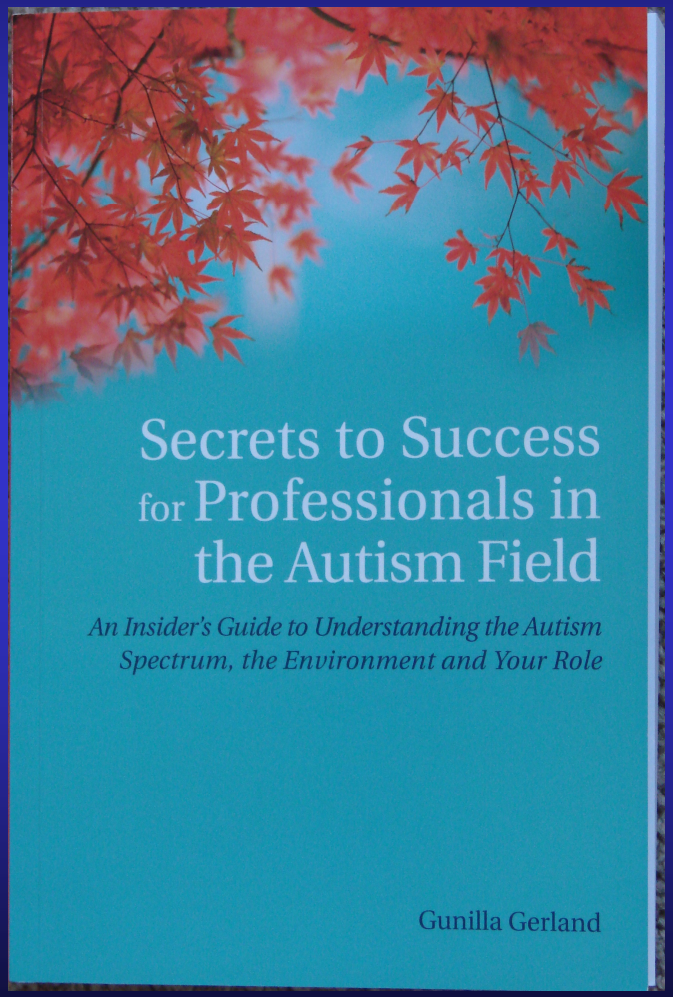
‘Invisible end of the spectrum’

Autistic issues hidden beneath

- **Compensatory / coping strategies**
- **Other conditions e.g. anxiety**
- **Seemingly advanced skills in some areas**
  - mixed profiles ability & difficulty
  - may be copied or learnt by rote

  e.g. advanced vocab. hiding poor comprehension

‘Invisible end of the spectrum’



“The real paradox here is that the more [they] learn to ‘blend in’, to ‘behave’ or ‘seem’ like others …

the smaller the chance that [they] will be met with an understanding of their difficulties.”

– Gunilla Gerland: AS counselor, supervisor & educator (4, p154)

‘Invisible end of the spectrum’

“What is especially frustrating to hear
is the opinion that some of us,
rather than being autistic, merely have
a few ‘autistic-like traits’.

Well, suppose a wheelchair athlete came to a stairway and managed to get up it by dragging himself or herself with upper-body strength.

Would it be reasonable to say to the person,
‘You are not disabled; you only have a few
disabled-like traits’?
I think not.” – Dave Spicer (5)

‘Invisible end of the spectrum’

“Having a good interface means that the amount and scope of an individual's efforts … would go undetected

until they … led to the person breaking down under the accumulated stress.” - Dave Spicer (5)

Outside view: only top 1-2 layer(s) seen

Lack of achievement; overwhelmed by life; eccentric 'misfit'

Low self-esteem, anxiety etc. put down to character flaws or mental illness: e.g. atypical depression, personality disorder

Unseen: deeper layers

Own response to difference: confusion, anxiety, efforts to cope, compensatory strategies etc.

Core condition = Autism → Differences (social, sensory, executive function etc)

Inside experience: 4 layers

Lack of achievement; overwhelmed by life; eccentric 'misfit'

Others' response to difference (bullying; labels: stubborn, lazy, selfish) → worse self-esteem & anxiety; may trigger mental illness

Own response to difference: confusion, anxiety, efforts to cope, compensatory strategies etc.

Core condition = Autism → Differences (social, sensory, executive function etc)

(3) (with animation assistance from C Hearst)

‘Autistic-friendly’ practice

- **Awareness & understanding** of autism
  - in general (including post-diagnosis issues)
  - unique expression & needs in each individual
  - undiagnosed autistics with similar needs

- **Adapting practice** to all of above

→ **equal access to quality healthcare**

"When several unpredictable things
happen one after the other,
I feel like my …
world is collapsing...

as if I am trying to hold onto something
very important and
it is becoming
slippery in my hands.

[Or] imagine standing in the ocean,
with the water almost up to your mouth ..
[then] seeing waves coming at you …
[then] feeling the sand beneath your feet
shifting
[and not knowing how to swim]."

-Dave Spicer (6)

3 Key Differences often overlooked

(= ‘Ava Ruth’s Triad’: not to be confused with ‘triad of impairments’!)

- **Processing differences**
- **‘Executive function’ (EF) issues**
- **‘Social radar’**

Each autist has own unique profile of these

=keys to understanding autistic issues like anxiety and responding helpfully

Processing Differences in Autism: (3)

- **Slow, conscious, one channel at a time**
- **no 'filter'**

→ **tiring**

→ **overload** → **meltdowns** / **shutdowns** if more floods in than can be processed: e.g.

"A patterned carpet or wallpaper …
floods my senses & shuts down a lot of the ability
to understand what I hear…"

-Donna Williams (7, p97)

Executive function (EF) issues in autism (8)

- Organising & planning (time & space), prioritizing
- Flexibility (thinking of alternatives, adapting to new etc)
- ‘Inertia’ (starting, stopping, transitioning)
- Controlling impulses and emotions
- Alertness, attention, working memory
- Self-awareness & self-monitoring etc

Effects of EF & Processing Differences: (8)

struggle with

- **quick decision-making**
- **multi-tasking & 'busy' situations**

(= much of modern daily life!)

good at

- **planned practised routines:** low-stress
- **tasks needing singular focus**: brilliant at!

‘Social radar’ vs. ‘scripts’ (8,9)

‘Social radar’ = ability to detect & interpret nonverbal signals and ‘read between the lines’ of verbal messages

NTs use ‘social radar’ & EF: unconsciously

to continuously monitor environment, predict & adapt

vs. autists depend on navigating life using

- predictable environment (including social environment)
- conscious ‘scripts’ & explicit info
- logic

→ **lost & anxious if** ‘what, when, how’ are unclear or change without warning

(→ need concrete info not ‘slippery’ responses)

AASPIRE Healthcare Study (10,11)

(AASPIRE = Academic Autistic Spectrum Partnership in Research & Education)

Principal Investigators: Christina Nicolaidis, MD, MPH, Oregon Health & Science University; Dora Raymaker, MS, Autistic Self Advocacy Network

- used a community-based participatory research approach
  (autistic people equal partners in research etc)
- looked at **healthcare experience of adults on autism spectrum adults, and ways of improving it.**
- compared with
  - non-autistic adults with other disabilities
  - non-autistic adults without disabilities
- surveyed & interviewed autistic adults, their support people & providers

AASPIRE Healthcare Study (10,11)

(AASPIRE = Academic Autistic Spectrum Partnership in Research & Education)

Results: "a significant problem in how healthcare is delivered to autistic adults"

Adjusting for such factors as socioeconomic & health status, **autistic adults experienced**:

- ***more* unmet physical & mental health needs**
- ***poorer* communication** between provider & patient
- ***lower* healthcare self-efficacy** e.g. ability to
  - access health information
  - judge *when to see* a healthcare provider (HCP).
  - *discuss issues* (with their HCP)
  - *carry out* advice given
  - access practical or emotional support - etc

Factors with greatest impact

on quality healthcare for autistics - AASPIRE (10, 11)

- **Communication issues**
- **Need for more time**
  - for communication & decision-making
  - to get use to premises, providers & procedures
- **Sensory processing issues**
  - coping with waiting-room, examinations & procedures
  - identifying symptoms
- **Issues around staying calm & knowing what to expect**
- **Assumptions & misconceptions among providers**
  - autism myths & stereotypes
  - intelligence & ability to understand (under- or over-estimated)
- Navigating healthcare as a whole (fm choosing provider thru to treatment)
- Role of supporters (positive or negative)

AASPIRE Healthcare Study (10)

(AASPIRE = Academic Autistic Spectrum Partnership in Research & Education)

"Not having a diagnosis may deprive patients and their providers
of possible insights, strategies,
and accommodations
to try to improve healthcare experiences …

Efforts are needed to improve the healthcare of autistic individuals,
including individuals who may be
potentially perceived as having fewer disability-related needs." (10)

AASPIRE Healthcare Toolkit Project (11)

Toolkit includes

- **AHAT** (Autism Healthcare Accommodations Tool)
  - autistic patient completes survey on interactive website

  →computer generates a personalised accommodations report to give healthcare provider

- **Printable healthcare resources**
  - **For providers** (not available yet: forms, templates, autism info, tips for successful office visits)
  - **For autistic patients & support persons "to help … understand, access and use the healthcare system"**

AASPIRE Healthcare Toolkit Project (11)

Healthcare Visit Worksheets & Checklists

- Preparing for a healthcare visit
  - tips for finding a provider
  - making an appointment worksheet
  - what to bring to an appointment checklist
  - symptoms worksheet
  - understanding types of visits
  - preparing what topics to cover
  - what your provider may want to know about your symptoms
- During the visit
  - general workflow
  - risks & benefits of disclosing an autism diagnosis
  - asking for accommodations
  - communication tips
  - personal info
  - questions to ask your doctor
  - things to know before you leave worksheet

Tools to help autistic healthcare visits go smoothly

General strategies

- AHAT & Information sheets (11)
- Alert on file
- Autism assessment forms (12) – profile & needs
- Booking: ?beginning or end of day / longer slot / time that fits with autistic's routines
- Minimising transitions – changes of room & staff
- Taking all communication attempts seriously e.g. memos

Meltdown strategies

Sensory processing strategies

Communication strategies

Overload in healthcare settings

"[People] on the spectrum can be extremely sensitive to tensions in the atmosphere,

and the general 'busyness' of care settings,

or staff bustling about,

is likely to increase their 'edginess' ...

[and signs of agitation] such as pacing or shouting."

– Alison Morton-Cooper (2, p39)

‘Low arousal’ environment (2, p42-3)

- **limited access area**
- **minimal number of people present**
- **quiet**: no radio, no chatter, no sudden or loud noises (or pre-warn when unavoidable)
- **softly lit** (non-fluorescent)
- **uncluttered; restful décor**
- **scent-free** (perfumes, cleaning products, air fresheners etc)
- **sensory items available** to help keep nervous system in optimum state of arousal (e.g. weighted blankets, beanbags, spinners, soft cloths, play-dough, squishy ball)
- **visual supports** for auditory processing issues

Example of Written Meltdown Plan:

"I HAVE AUTISM –

Open & read in an emergency"

[& inside it reads:]

- **Emergency contacts =**
- **Warning signs of escalation =**
- **What those present could do to help =**
  - **reduce overload** (sensory, emotions, people, words)
  - **don't touch** me
  - "**never try** to reason, give lengthy explanations, teach new coping skills, or ask me open-ended questions **while I am in an agitated state"** (13, p74)

Tone down staff emotions & gestures

"A teacher's attempt to 'reach' a child with great kindness, usually appears, to the Asperger's' child, as the teacher mysteriously talking in a strange 'syrupy' voice and insisting on patting them on the arm or shoulder.

When people behaved like this to me, my only thought was how to escape as quickly as possible from this baffling and therefore perhaps dangerous behaviour (it wasn't until the end of my teens that I worked out what the intention behind it was)." (14, p96-7)

"Even the reassuring handshake or hand on the shoulder can be misinterpreted" (2, p43)

Aspie / Autist Body-language

"The atypical body language of Aspies can be misinterpreted as lack of attention, disrespect or malingering.

Some Aspies may avoid eye contact, speak in monotone, or have a meltdown when over - stimulated or frustrated. Alternatively, some may become calmly analytical when in extreme pain or distress.

Rely more on literal interpretations of verbal or written communication. For example, if we tell you that we are in extreme pain, believe us even if we don't jerk and wince."

-from "What I Wish My Doctor Knew About Me as a Person on the Autism Spectrum" (11)

Answering Questions: may need prompts

"I couldn't think of anything I'd done at the weekend,
although I know that if someone had prompted me
with specific question like 'Did you…?'
I would have been able to answer accurately.

I just couldn't access my memories on demand."
(14, p63)

Difficulty with Open-ended Questions

e.g. "What do you want to do?"

→ "first … make a mental list of all the possible things that can be done in that moment (which of course is virtually endless)

→ then evaluate each possibility as realistic or not as a choice in the moment - trying to consider at the same time any rules or expectations

→ [only] then … begin to consider which of the possibilities might be appealing

and this whole time, the person who asked the question is standing there, looking at you, impatiently waiting for an answer!" (15, p42)

Alternative ways of presenting information

e.g. to outline what to expect / give answers or advice

Demonstration (12) - e.g. model, role-play (puppets, play-people)

Visual supports

- collages, drawings, felt-board / story-board (12)
- visual timetables, flow-diagrams, work-reward systems (11, 12, 17)

Tools combining strategies

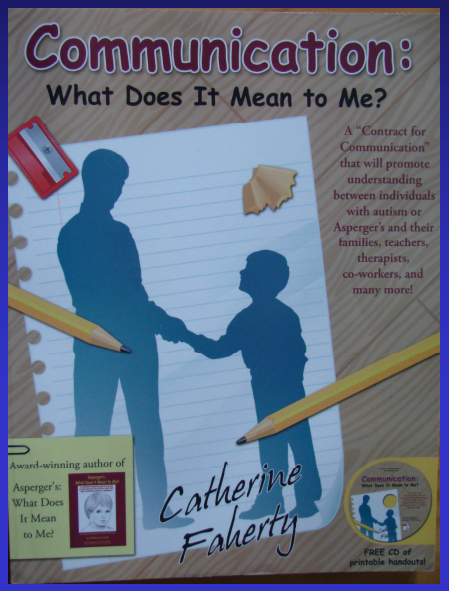
- 'social stories TM' (18), 'power cards' (12)
- games eg I-spy, bingo, puzzles, matching / memory (12)

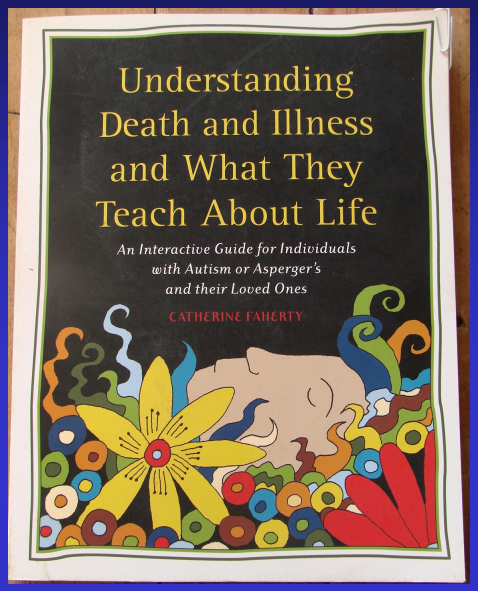
'Systematic interaction'

- 5-scale approaches (19, 20) : help communicate social/emotional concepts & learn self-management
- 'communication forms' (15, 21)
- systematic use of language (spoken & written)

Systematic interaction: Communication Forms

(15, 21)





1. detailed concrete information on topic
2. systematic format for responses to topic
   - numbered scales
   - tick-boxes
   - multiple choice options
   - Prompts
   - 'I have questions or something else to say'_____

Systematic interaction: Communication Forms

Examples of Health topics (21):

'What should I do when I am sick or injured?'

'What is an emergency?' / 'What is a difficult situation?'

'What helps people recuperate and heal?'

'After recuperating, are people the same as they were before they were sick or injured?

Bear in mind, autists may

- experience illness & injury atypically due to sensory processing differences
- have extraordinary knowledge on obscure topics but little know-how on everyday issues like health, hygiene, safety
- lack the words, or people, to discuss these

Systematic interaction: Language use 'clear, concise & informative'

Imprecise language increases confusion & anxiety

→ instead use a %, range or definition e.g.

- instead of 'probably' → 'it's 90% likely'
- instead of 'soon' → 'in 10 to 20minutes' time'
- instead of 'recently' → 'within the past month'

offer choices like

- 'more details available if you want'
- 'would you prefer a short simple or long technical answer?'
  (preference may vary from one occasion or topic, to another)

from “What I Wish My Doctor Knew About Me as a Person on the Autism Spectrum” (16)

“Language needs to be unambiguous,
but not necessarily simple.
It is not necessary to avoid technical language
as long as it is defined.
In fact, technical language can be helpful
because it is precise. …

Don’t make small talk.
Conversations take a lot of concentration —
like talking in a non-native language.
They don't put me at ease.
Save talking for
getting a history and negotiating a plan.”

from “What I Wish My Doctor Knew About Me as a Person on the Autism Spectrum” (16)

“Minimize distractions.
Work silently when not interviewing me.
Don't make jokes or use sarcasm,
unless you clearly identify it. …

Silent pauses … give me time to think.
If I need more time, consider leaving the room
and returning. …

Even if very verbal, many Aspies find it easier to
communicate in writing. Offer options.”

Knowing how to implement advice

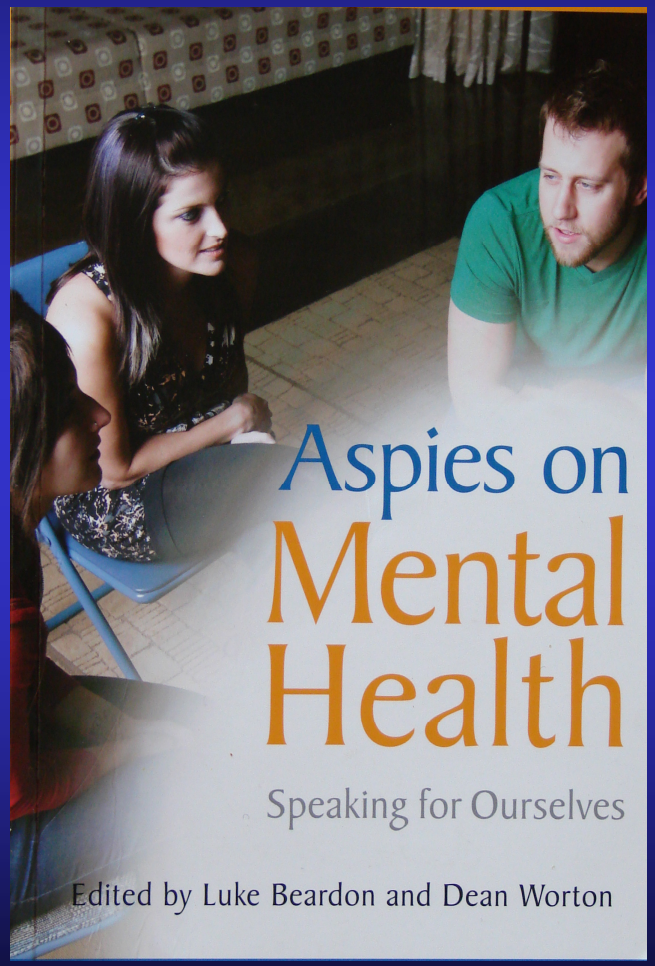
"I have a high IQ, yet am quite unable to manage ordinary things that other people can,

and this lack of social understanding … caused [mental health staff] intense frustration …

They'd listen to me talking academically and think they'd handed me a solution. But often I need VERY VERY explicit instructions on how to implement ideas

and lots of repetition …" (3)

Mental healthcare and autism (22)



For AS individuals, clear links between

- *how* assessment, counseling & support are approached
- *mis*diagnosis
- AS mental health

Mental healthcare and autism

"Until there is a far greater understanding of
AS [Asperger's Syndrome]
and how the [mental health] environment
(especially the people within it)
can and does influence people with AS,

and until there are changes made in
light of this,

people with AS will continue to be vulnerable to
mental ill health."

-Dr. Luke Beardon, senior lecturer in autism (22, p14)

Mental healthcare and autism

"If the [mental health] worker is not familiar with the AS person's need for clear expectations, literal language use, sameness etc.,

these are more likely to be seen as symptoms of illness rather than differences in mental processes.

People with AS get labels of 'difficult', 'resistant to change', 'unable to form a relationship', 'unable to benefit from therapy' and so on because the way they use language is different from the 'norm.' …

It seems lots of mentally healthy people with AS get unnecessarily labeled as mentally unhealthy due to a lack of understanding from the mental health worker."

-Veronica Bliss, psychologist (23, p50)

Mental healthcare and autism

It's crucial that psychotherapy …
"focuses on autistic-friendly strategies
for the issues and dilemmas
the individual is [actually] *seeking help* for,

not on trying to challenge or change the autistic's
innate way of being." (24)

Conclusion: Awareness & Attitude

Approaches outlined in this session –

- ways to implement NZ ASD Guideline recommendations
- address acknowledged barriers in autistic healthcare
- not expensive - **awareness and attitude!**
- harm nobody; benefit other patients & staff besides autists?

→ equal access to quality healthcare for

- those formally diagnosed AS
- 'invisible end of the spectrum'
- those with subtle autistic traits but no formal diagnosis
- anyone with similar needs re communication, processing, sensory issues etc (dyspraxia, dyslexia etc)

Conclusion: Accommodations that benefit all & harm none

"Like with everyone else, clear and direct communication makes for better understanding all around"
–Stephen Shore (25, p183)

"There really isn't anything in the ASD curriculum that would hurt anyone. Which makes me wonder, why don't we add more ASD friendly supports in every school and system we have?"
-Liane Holliday Willey (26, p 147)

"We don't need ramps or expensive equipment to make a difference for us: All we need is understanding."
-Clare Sainsubry (14, p9)

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