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The experience of daily stress in  
individuals with Asperger's syndrome: a  
grounded theory exploration

# The “Problem”

- Ghaziuddin (1999) found 65% of their sample of people with AS presented with some symptom of psychiatric disorder
- Soderstromet (2000) report people with AS have higher levels of obsessional personality traits
- Gillot (2001) found children with HFA were significantly more anxious than normal controls
- Tonge (1999) report heightened levels of anxiety in people with AS
- Bolton (1998) report heightened levels of depression in people with AS
- Blackshaw (2001) report people with AS have significantly higher levels of paranoia than normal controls
- Attwood (2004) reports that 65% adolescents experience anxiety and depression

# The “Problem”

- Simonoff et al., (2008)

70% participants (n=114) presented with one co-morbid disorder

42% presented with two or more

- Most common

Social anxiety disorder 29%

ADHD 28%

ODD 28%

# Autobiographical Accounts

- Life **Behind Glass**
- A **Real** Person
- **Pretending** to be Normal
- An **Anthropologist** on **Mars**
- **Martian** in the Playground
- **Nobody** Nowhere

# My Perspective

- What can I do about this as a practitioner?
- What tools do I have?
- Do they work?

# Cognitive Behaviour Therapy

- Effective intervention working with anxiety
- Growing evidence that it is effective in addressing anxiety in ASD e.g. Reaven et al., (2003)
- Attwood 2001, 2005
- Still much work to do on this as there are potential difficulties around communication, understanding of language, Theory of Mind

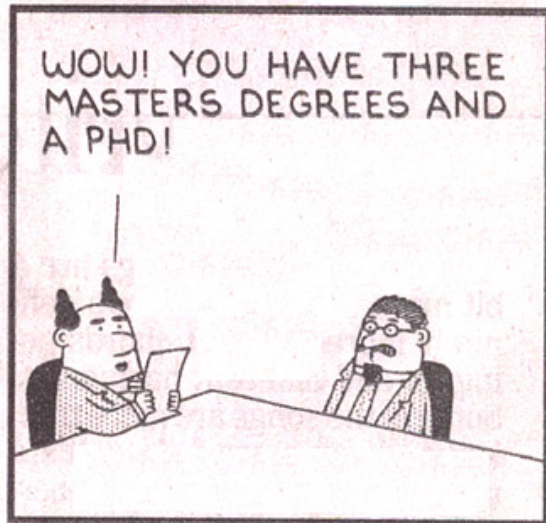
# Question Persisted

- Why is anxiety such a problem?
- Conversations with young people with ASD suggested to me that its the seemingly innocuous business of everyday life that challenges and causes anxiety

# Functioning in the “real world”

**Dilbert**

By Scott Adams



www.dilbert.com  
scottadams@aol.com



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# What is the Experience of Stress?

- Use data collection creatively to allow me to accommodate the differing communicative abilities
- Use a method that allows the use of a range of data collection and also allows me to create or develop a model or explanation rather than give a description

# Method (lets not get too technical)

- Phenomenology

(much deliberation)



- Grounded theory



# Data Collection / Sample

- Interview
- Journaling (hard copy / “e” journal)

## Sample

- All diagnosed with Asperger’s syndrome
- Recruited through local Autism Charity

# The Sample

Participant	Age	Gender	Employment	Home
Participant 1	26	M	Some voluntary work	Lives with mother
Participant 2	21	M	Full-time catering	Lives with parents
Participant 3	28	M	Unemployed	Lives with parents
Participant 4	21	F	Student	Lives with parents
Participant 5	21	F	Voluntary Work	Lives with parents
Participant 6	23	F	Student	Lives with parents
Participant 7	26	M	Full time employment	Lives with parents
Participant 8	18	M	Work placement	Lives with parents
Participant 9	35	M	Working	Lives with parents
Participant 10	22	M	Working	Lives with parents

# The Paradigm Model

Categories:

- Context
- Conditions
- Actions / Interactions / Emotions
- Consequences
- Core Category

# The Paradigm Model

Levels:

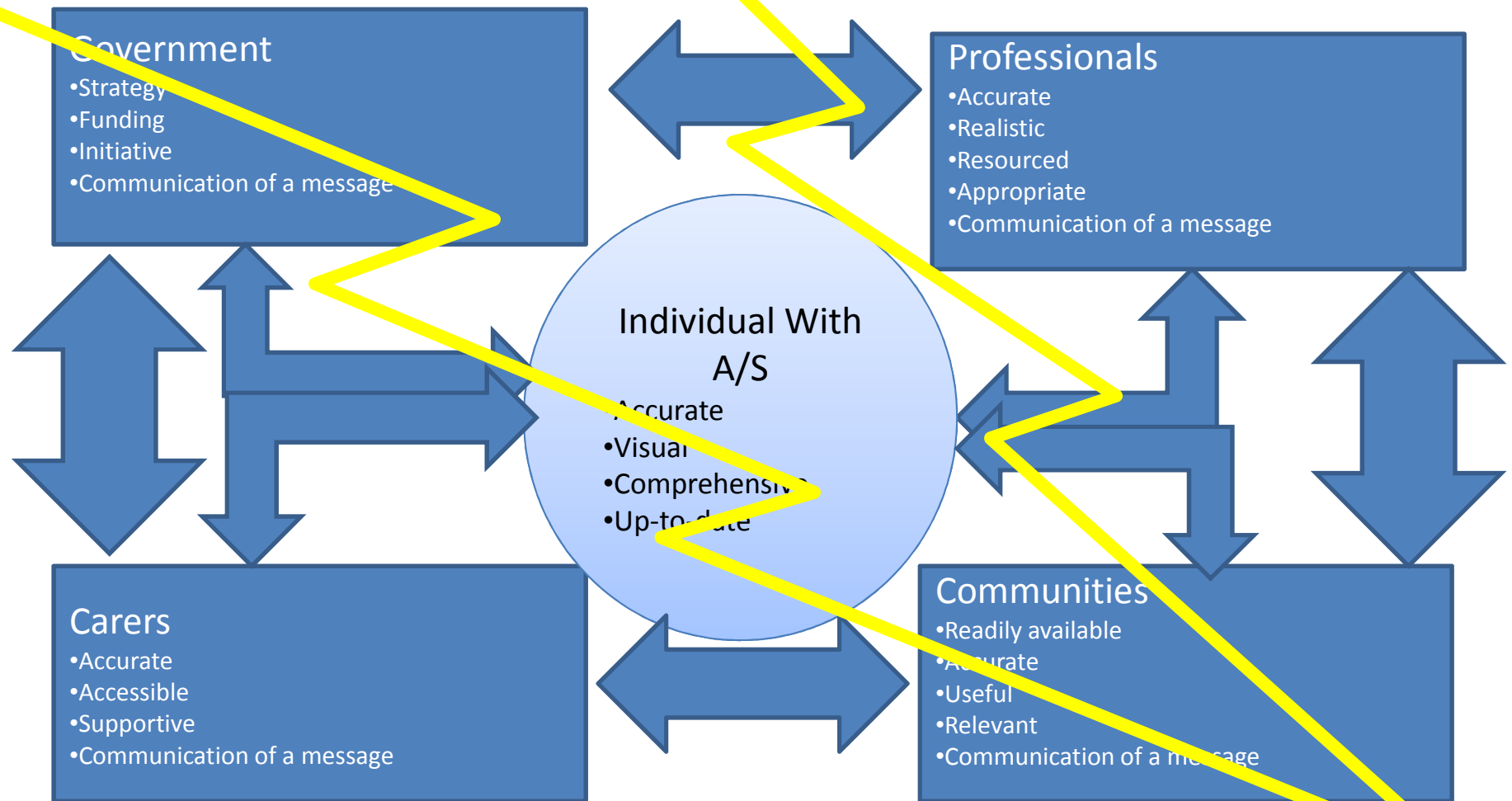
- Concept
- Sub categories
- Categories
- Core category

	Category	Sub category	Concept
<b>Context</b>	Lack of governmental accountability for A/S	<ul style="list-style-type: none"> <li>Professional knowledge and understanding</li> <li>General poor understanding of A/S</li> <li>Information and support for the individual</li> </ul>	<ul style="list-style-type: none"> <li>Poor information provided at diagnosis</li> <li>Poor post diagnostic support</li> <li>Poor understanding of Asperger's syndrome in the community</li> <li>Difficulties with employers</li> <li>Poor understanding of what Asperger's syndrome is and its impact</li> </ul>
<b>Conditions</b>	Living with A/S	<ul style="list-style-type: none"> <li>Relationships</li> <li>communication</li> <li>General impairments related to A/S</li> </ul>	<ul style="list-style-type: none"> <li>Friendships</li> <li>Bullying</li> <li>Understanding what others are saying</li> <li>Expressing oneself and being understood</li> <li>Literal understanding of language</li> <li>Sensory difficulties</li> </ul>
<b>Actions / Interactions/ Emotions</b>	Emotional Impact of living with A/S	<ul style="list-style-type: none"> <li>Vulnerability</li> <li>Need for Acceptance</li> </ul>	<ul style="list-style-type: none"> <li>Isolation</li> <li>Sense of danger</li> <li>Fear of being picked on</li> <li>Sense of vulnerability</li> <li>Fear of rejection</li> <li>Disassociation from autism</li> <li>"Normality"</li> </ul>
<b>Consequences</b>	<ul style="list-style-type: none"> <li><b>High incidence of anxiety</b></li> <li><b>Low self esteem</b></li> </ul>		
<b>Core Category</b>	<b>Individuals with A/S victims of a breakdown in communication</b>		

# Core-Category

**Individuals with ASD  
Victims of a  
Communication  
Breakdown**

# Networks of Communication



# Communication Breakdown

Professionals communicate an inconsistent and inaccurate message about the impact of Asperger's syndrome

Individuals with Asperger's syndrome have a poor understanding of their needs and a communication disorder

# Findings

- Poor understanding of autism in communities
- Employers and workplaces have a poor understanding of autism
- Misconceptions around Asperger's syndrome: in the current research participants were convinced of its "mildness"
- Participants experiencing exacerbated daily stress as a result of bullying and negative perceptions of autism
- Lack of structured and consistent services for adults with autism

# Congruent with Other Reports

- National Audit Office UK (2009), *Supporting People with Autism Through Adulthood*, London: National Audit Office UK.
- National Autistic Society (2001), *Ignored or Ineligible*. London National Autistic Society.
- — (2002), *Taking Responsibility Good Practice Guidelines for Adults with Asperger's syndrome*, London: National Autistic Society.
- — (2006), *Make School Make Sense*, London: National Autistic Society.
- — (2007), *Think Differently Act Positively*, London: National Autistic Society.
- — (2008a), *I Exist*, London: National Autistic Society.
- — (2008b), *I Exist: The Message From Adults With Autism in Scotland*, London: National Autistic Society.
- — (2009a). *If I Tell Them How I Feel, Then they'll Understand*, London: National Autistic Society.

# Recommendation

Information post diagnosis has been shown to be highly effective in improving efficacy and emotional management (Street et al. 2008)

# Information

- What is Asperger's syndrome: e.g. not "mild" autism;
- How will Asperger's syndrome affect me; socially, flexibility in thinking, communication;
- The nature of social skills, flexibility in thinking and communication difficulties for individuals with Asperger's syndrome;
- Sensory difficulties;
- Friends and friendships;
- How to explain to others that you have Asperger's syndrome;
- Bullying and victimisation and the right way to avoid it and deal with it;
- Coping strategies for living in the real world;
- Strengths and abilities;
- Positive role models.

# Findings

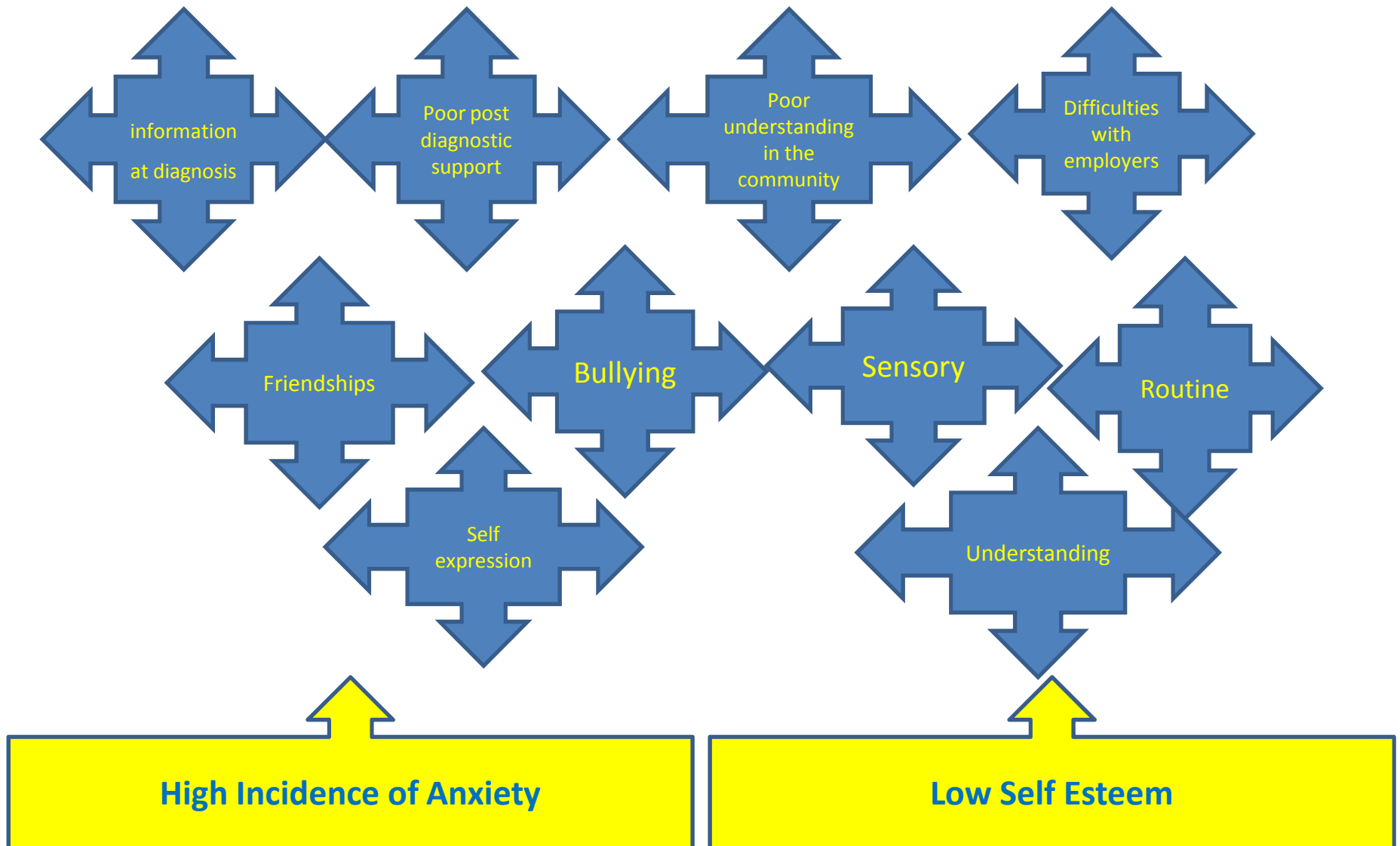
- Connectivity everything is relative
- Aspects of living with A/S impacts on other areas of life, functioning and stress

# Connectivity

- Research by White and Roberson-Nay (2009) indicates a relationship between anxiety and the feeling of social disability in highly functioning individuals with ASD. In their sample they noted that there is a lack of research highlighting relationships between aspects of anxiety, loneliness and social impairment, however, they tentatively suggest that anxiety may have an impact on loneliness and call for more research in the area
- Research by Whitehouse et al. (2010) identifies relationships between friendships, perceptions of friendships, loneliness and depression; all of these issues were identified in the current research

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# Connectivity



Poor Understanding in  
the Community

Bullying

Difficulties with  
Employers

Friendships

# Communication Can Address

- Misconceptions about ASD *“mild” / “Forest Gump”*
- Shame and avoidance of ASD *“I’ll pretend I don’t have it”*
- Vulnerability *“sometimes I don’t get peace to walk from A to B”*
- Loneliness *“I’m trying very hard to connect with people but I never seem to give them what they want”*

# DSM-5

- Asperger's syndrome merged with autism into an Autism Spectrum Disorder

# Communication?



THE ONE MILLION  
PEOPLE I SHOULD  
HAVE E-MAILED  
STANDING IN A  
LONG LINE WANTING  
TO KNOW WHAT  
IS GOING ON

Thank you