

PSYCHOLOGY MISCELLANY

No.19 Supplement A - January
2011

Tutorial Essays on Psychology
and Learning Disabilities

Kevin Brewer

ISSN: 1754-2200

Orsett Psychological Services
PO Box 179
Grays
Essex
RM16 3EW
UK

orsettpsychologicalservices@phonecoop.coop

This document is produced under two principles:

1. All work is sourced to the original authors. The images are all available in the public domain (most from http://commons.wikimedia.org/wiki/Main_Page). You are free to use this document, but, please, quote the source (Kevin Brewer 2011) and do not claim it as you own work.

This work is licensed under the Creative Commons Attribution (by) 3.0 License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-nd/3.0/> or send a letter to Creative Commons, 171 2nd Street, Suite 300, San Francisco, California, 94105, USA.

2. Details of the author are included so that the level of expertise of the writer can be assessed. This compares to documents which are not named and it is not possible to tell if the writer has any knowledge about their subject.

Kevin Brewer BSocSc, MSc

An independent academic psychologist, based in England, who has written extensively on different areas of psychology with an emphasis on the critical stance towards traditional ideas.

A complete listing of his writings at <http://kmbpsychology.jottit.com>.

CONTENTS

| | Page Number |
|--|-------------|
| 1. DUAL DIAGNOSIS: LEARNING DISABILITIES AND OBSESSIVE-COMPULSIVE DISORDER | 4 |
| 2. OFFENDERS WITH LEARNING DISABILITIES | 8 |
| 3. MEDICAL PROBLEMS AND LEARNING DISABILITIES | 17 |
| 4. COMPARING CHILDREN'S UNDERSTANDING OF MONEY WITH ADULTS WITH LEARNING DISABILITIES | 19 |
| 5. PERCEPTIONS OF ADULTS WITH LEARNING DISABILITIES BY CAREGIVERS: TWO EXAMPLES | 22 |
| 6. QUALITY OF LIFE AND ADULTS WITH LEARNING DISABILITIES | 27 |
| 7. BURNOUT OF PROFESSIONAL CARERS OF ADULTS WITH LEARNING DISABILITIES | 30 |
| 8. APPLIED BEHAVIOUR ANALYSIS | 32 |
| 9. THREE LESS COMMON GENETIC CONDITIONS WITH LEARNING DISABILITIES | 34 |
| 10. CURING AUTISM? | 36 |
| 11. FACIAL EMOTION RECOGNITION AND WILLIAMS SYNDROME | 41 |
| 12. THREE DIFFERENT THEORIES OF AUTISM: CORRELATION OR CAUSATION? | 44 |

1. DUAL DIAGNOSIS: LEARNING DISABILITIES AND OBSESSIVE-COMPULSIVE DISORDER

- 1.1. Introduction
- 1.2. Obsessive-compulsive disorder (OCD)
- 1.3. References

1.1. INTRODUCTION

Dual diagnosis refers here to adults with learning disabilities (AWLD) who suffer from mental illness. Learning disability (or mental retardation in the USA) is defined as "substantial limitations in present functioning. It is characterised by significant sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work" (Luckassen et al 1992).

In the Welsh Health Survey 1995 (Welsh Office 1995) rates of psychiatric illness were calculated as 32.2% for AWLD and 11.2% for the general population¹. While in Australia, 31.7% of AWLD were rated as having a "life-to-date psychiatric illness" (Morgan et al 2008). Other studies have put the prevalence rate at nearer 40% for AWLD (Cooper and van der Speck 2009).

In terms of the use of psychiatric services, about half of AWLD over 19 had done so (Bhaumik et al 2008), which compares to about 2% of the general population (Cooper and van der Speck 2009).

The prevalence of mental disorders will also vary with the severity of the learning disability. For example, Holden and Gitlesen (2004) compared thirty-four individuals with moderate LD, 31 with severe, and 31 with profound LD. Despite diagnostic problems with non-verbal individuals, none of the latter group were rated as depressed, only one of the severe LD adults (3%), and seven of the moderate group (23%).

Studies of prevalence face a number of issues (Cooper and van der Speck 2009):

- i) How representative of the population of AWLD is the sample studied?

¹ Emerson and Hatton (2007) reported, using government figures, a rate of 36% for children and adolescents with LD in Britain compared to 8% of general population (odds ratio 6.5).

ii) The time period of the study (eg: prevalence in last month or last year).

iii) The techniques used to measure and diagnose mental disorders - eg: Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD) (Royal College of Psychiatrists 2001); Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson 1988). Intellectual and communication limitations make it difficult to use standard diagnostic criteria and interview techniques (Hurley 2006).

iv) Which mental disorders are included in the study.

v) Whether the study include challenging behaviour or not.

vi) Whether autism included in the study.

1.2. OBSESSIVE-COMPULSIVE DISORDER (OCD)

Russell et al (2005) compared forty adults with Asperger syndrome and high-functioning autism (AS) (attending the Maudsley Hospital, south London) with forty-five gender-matched adults with Obsessive-Compulsive Disorder (OCD) (at a specialist clinic in west London) on obsession and compulsion symptoms.

This was done using the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) (Goodman et al 1989) and the associated Symptom Checklist (Y-BOCS-SC) (table 1.1). The latter lists fifty examples of obsessions and compulsions which are simply rated as present or absent. The Y-BOCS rates the severity of obsessive and compulsive behaviours with ten items ².

- Checking that you will not/did not harm others.
- Concern with dirt and germs.
- Need for symmetry, exactness and order.
- Cleaning household objects and other items.
- Fear of blurting out obscenities or insults.

(Source: Feinstein et al 2003)

Table 1.1 - Examples from Y-BOCS-SC.

² For obsessions and compulsions separately, the respondent rates 0-4 for time spent on them, interference from them, distress caused by them, resistance to them, and control over them.

A quarter of the AS group were formally diagnosed with OCD as well as AS.

Both groups showed a similar frequency of individual obsessions and compulsions, except that the OCD group had significantly more somatic obsessions ³ (53.3% vs 15.0%), and repeating (68.9% vs 42.5%) and checking (82.2% vs 60.0%) compulsions. Overall, the OCD group had a higher total of symptoms (mean: 10.4 vs 6.7), and a higher severity score on the Y-BOCS (figure 1.1).

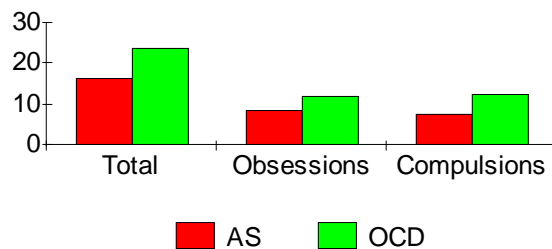


Figure 1.1 - Mean Y-BOCS scores for both groups.

Table 1.2 summarises the main strengths and weaknesses of the Russell et al (2005) study.

| STRENGTHS | WEAKNESSES |
|--|--|
| <p>1. Exclusion of AS sufferers with co-morbidity of psychosis and/or substance misuse, and IQ scores of lower than 70.</p> <p>2. Clear diagnosis of Asperger Syndrome or autism using ICD-10 criteria (WHO 1992).</p> <p>3. The use of standardised measures of obsessions and compulsions.</p> <p>4. The concepts of "obsession" and "compulsion" were checked with the AS group at the beginning of the essay to make sure they understood, and could distinguish them from stereotypic behaviours and interests.</p> | <p>1. Self-reported measures of obsessions and compulsions completed by the interviewer. No verification of information from other sources, like family members.</p> <p>2. Though the two groups were gender-matched, there was an age difference between them. The AS group had a mean age of 27.9 years compared to 36.6 years for the OCD group. Did that effect the results?</p> <p>3. The AS group were sampled from a specialist clinic that treats co-morbidity by using consecutive referrals over a certain period, and not from the community.</p> <p>4. Structured diagnostic interviews were not used.</p> |

Table 1.2 - Main strengths and weaknesses of Russell et al (2005) study.

³ eg: "Concern that you will get ill from contaminants".

1.3. REFERENCES

- Bhaumik, S et al (2008) Psychiatric service use and psychiatric disorders in adults with intellectual disability Journal of Intellectual Disability Research 52, 986-995
- Cooper, S-A & van der Speck, R (2009) Epidemiology of mental ill health in adults with intellectual disabilities Current Opinion in Psychiatry 22, 431-436
- Emerson, E & Hatton, C (2007) Mental health of children and adolescents with intellectual disabilities in Britain British Journal of Psychiatry 191, 493-499
- Feinstein, S.B et al (2003) Item-by-item factor analysis of the Yale-Brown Obsessive Compulsive Scale Symptom Checklist Journal of Neuropsychiatry and Clinical Neuroscience 15, 187-193
- Goodman, W.K et al (1989) The Yale-Brown Obsessive Compulsive Scale I: Development, use and reliability Archives of General Psychiatry 46, 1006-1011
- Holden, B & Gitlesen, J.P (2004) The association between severity of intellectual disability and psychiatric symptomatology Journal of Intellectual Disability Research 48, 556-562
- Hurley, A.D (2006) Mood disorders in intellectual disability Current Opinion in Psychiatry 19, 465-469
- Luckassen, R et al (1992) Mental Retardation: Definition, Classification and Systems of Support Washington DC: American Association for Mental Retardation
- Matson, J (1988) The Psychopathology Instrument for Mentally Retarded Adults Worthington, Ohio: IDS Publishing
- Morgan, V.A et al (2008) Intellectual disability co-occurring with schizophrenia and other psychiatric illness: Population-based study British Journal of Psychiatry 193, 364-372
- Royal College of Psychiatrists (2001) DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) London: Gaskell Press
- Russell, A.J et al (2005) Obsessions and compulsions in Asperger syndrome and high-functioning autism British Journal of Psychiatry 186, 525-528
- Welsh Office (1995) Welsh Health Survey 1995 Cardiff: Welsh Office
- WHO (1992) ICD-10 Classification of Mental and Behavioural Disorders Geneva: World Health Organisation

2. OFFENDERS WITH LEARNING DISABILITIES

- 2.1. Introduction
- 2.2. Sex offenders
- 2.3. Fire setters
- 2.4. Re-arrest
- 2.5. References

2.1. INTRODUCTION

Offenders with learning disabilities (LD) are a small part of the offending population. Cockram and Underwood (2000) found that AWLD were less likely to be arrested than the general population.

"Studies of forensic issues in the field of intellectual disability are both complex and controversial. Behaviours that are considered criminal by the courts might be seen as reflecting behaviour problems by the welfare system, thus rendering the responsibility unclear" (Sondenaar et al 2008).

The exact amount of offending is difficult to measure generally, but it may be hindered (and so underestimated) by carers who hold views about what to report to the police. For example, McBrien and Murphy (2006) presented fictitious scenarios involving crimes or not to 65 police officers and 80 care staff from sixteen different residential homes in an English city. Half of the scenarios involved individuals with LD and half with non-LD individuals (table 2.1). Three crimes (assault, rape, and minor theft) were selected.

There was agreement as to what constituted a crime between the police and carers over the scenarios with non-LD individuals, but the carers were significantly less likely to perceive an event as a crime (assault and rape only) when an individual with LD was involved (table 2.2) ⁴.

- Perpetrator with LD

Jenny is a 25-year-old woman who has a learning disability. She lives in a residential home for people with learning disabilities and attends a local day centre. Although she has limited comprehension, she has been taught to use buses on familiar routes. One morning she is on her way to the day centre. Arriving at the bus stop she finds

⁴ McBrien and Murphy (2006) commented about their study: "Vignettes are commonly used in attribution research but responses to them only represent what respondents say they would - hypothetically - do in such a situation, which may differ from what they would do in reality. Many participants, particularly the police, commented that they would not make a judgement based on the limited information provided if it was a real-life situation" (p140).

she has missed her bus. She starts to mutter loudly, then to shout and swear, directing this at a pensioner at the bus stop. She becomes more agitated and pushes and kicks the pensioner, who is trying to calm her. The pensioner falls, and receives grazing and bruising to the leg.

- Perpetrator without LD

Jenny is a 25-year-old woman who works at the check-out in a local supermarket. One morning she is on her way to work. Arriving at the bus stop she finds she has missed her bus. She starts to mutter loudly, then to shout and swear, directing this at a pensioner at the bus stop. She becomes more agitated and pushes and kicks the pensioner, who is trying to calm her. The pensioner falls, and receives grazing and bruising to the leg.

(Source: Table I p131 McBrien and Murphy 2006)

Table 2.1 - Examples of scenarios used by McBrien and Murphy (2006).

| TYPE OF CRIME | CARERS | | POLICE | |
|---------------|-------------|--------|--------|--------|
| | LD scenario | Non-LD | LD | Non-LD |
| Assault | 67.5 | 95 | 100 | 100 |
| Rape | 82.5 | 100 | 100 | 100 |
| Theft | 47.5 | 45 | 71.9 | 81.8 |

Table 2.2 - Percentage advocating reporting crime to police.

Using the criteria of an IQ score of 70 or less, prevalence rates for AWLD have been found at 20% in custody samples (ie: convicted and non-convicted) (eg: Crocker et al 2007), and 7.1% in a UK prison sample (ie: convicted) (Hayes et al 2007). Other studies have found higher rates using other definitions of learning disability (Sondana et al 2008).

Offenders with LD show differences to non-LD offenders for comparable crimes. Wahlund and Kristiansson (2006) found that homicide offenders with autistic traits in Sweden were less often intoxicated at the time of the crime, and made less use of knives or guns than homicide offenders with anti-social traits.

2.2. SEX OFFENDERS

One assumption is that sex offenders with LD have a lower sexual knowledge than non-LD sex offenders, and this lack of knowledge is a risk factor (Chaplin 2006). But is this the case?

Lunsky et al (2007) found higher sexual knowledge among sex offenders with LD than non-offenders with LD.

Talbot and Langdon (2006) compared four groups of participants in eastern England using the General Sexual Knowledge Questionnaire (GSKQ):

a) 12 male adults with learning disabilities (AWLD) with a history of sexual offending who had received psychological treatment for it (Sex Offender Intellectual Disability - Treatment Group; SOID-T).

b) 13 male AWLD with a history of sexual offending waiting for treatment (Sex Offender Intellectual Disability Group; SOID).

c) 23 male and five female AWLD with no history of sexual offending (Intellectual Disability Group; ID).

d) Five men and five women without a LD (with no history of sexual offending) (No Intellectual Disability Group; no-ID).

The GSKQ contained 63 questions about knowledge of sexual issues divided into six sections: physiology, sexual intercourse, pregnancy, contraception, sexually transmitted diseases, and sexuality.

The no-ID group had a significantly higher total score than the other groups (figure 2.1), which signified a greater knowledge about sexual matters. Importantly, there was little difference between the three AWLD groups suggesting that lack of sexual knowledge is not involved in sexual offending. If this was the case, sex offenders without treatment (SOID group) should have scored significantly different (lower) to the non-offending AWLD (ID group).

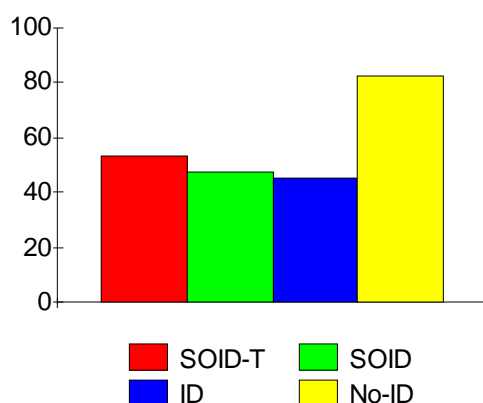


Figure 2.1 - Mean total scores on GSKQ for four groups.

Attitudes consistent with sexual offending (or cognitive distortions) not only facilitate sexual offending, but influence information processing and selective attention as well as providing justifications

for the behaviours. They are also a risk factor for re-offending (Lindsay et al 2006). Treatment programmes need to combat such cognitive distortions with, for example, consideration of the effects on the victim, identifying own motivations (rather than attributing cause to victim), and sex education (eg: Rose et al 2002).

The Questionnaire on Attitudes Consistent with Sexual Offences (QACSO) (Broxholme and Lindsay 2003) was designed to measure the distortions using 107 items divided into sections on rape and attitudes to women, voyeurism, exhibitionism, dating abuse, homosexual assault, offences against children, and stalking.

Lindsay et al (2006) compared AWLD convicted of sexual assaults on women, or on child, or an exhibitionist offence using QACSO. It was found that the offenders held different cognitive distortions depending on the type of offence. The mean scores for each section of the QACSO were higher than those of non-offender AWLD (table 2.3).

| | RELEVANT OFFENDERS | NON-OFFENDERS |
|---------------------------|--------------------|---------------|
| Rape and sexual assault | 7.7 | 2.7 |
| Exhibitionism | 4.7 | 1.8 |
| Offences against children | 8.4 | 2.2 |

(Source: Lindsay et al 2006)

Table 2.3 - Mean scores on sections of QACSO.

The prediction of potential re-offenders based on risk factors is classed as important, particularly for sex offenders. Static/historical predictors are aspects of the offender's history or personality (ie: factors that do not change), while dynamic/proximal predictors are variable factors like current substance abuse or acute psychotic symptoms (Lindsay et al 2004).

"In the field of mainstream criminality we now have a good idea of the relevant static variables, which predict violence and we are beginning to understand the proximal/dynamic variables, which might predict re-offending. However, in the field of intellectual disabilities, the picture is less clear" (Lindsay et al 2004 p300).

Thus, to try and rectify this problem, Lindsay et al (2004) analysed the data from fifty-two male sex offenders with mild to moderate learning disabilities in the UK. From the research literature, 17 static variables and 35 dynamic ones were coded as either present or absent (table 2.4).

Each variable was correlated with re-offending (ie:

conviction) or suspicion of re-offending (based on reliable reports - eg: "a known child molester frequenting a children's playpark or having children in his house, or, a known exhibitionist being seen in a park where he had previously offended"; Lindsay et al 2004 p301).

Static

- Age at first arrest
- Employment history
- Juvenile record

Dynamic

- Impulsivity
- Anti-social attitude
- Disorganised home life
- Deficits in empathy
- Length of most recent treatment

Table 2.4 - Examples of static and dynamic variables in sex offending.

A number of static and dynamic variables were found to be significantly correlated with re-offending and suspicion of re-offending (table 2.5). Having an anti-social attitude, low self-esteem, and lack of assertiveness were common to both along with allowances by staff and staff complacency. The first three factors are common predictors of non-LD sex offenders. However, this sample was different to non-LD offenders in that certain variables were not found to be predictive: "Employment history, deviant victim choice, diverse sexual crimes, prior non-sexual offences, criminal lifestyle, criminal companions, social and emotional isolation, and mental illness showed no significant relationship whatever with the dependent variables" (Lindsay et al 2004 p303).

2.3. FIRE SETTERS

Lindberg et al (2005) distinguished between "pure arsonists", who commit no other type of offence, and "non-pure arsonists", who have a history of other types of offences as well.

Lindberg et al (2005) collected details about ninety arson recidivists (43 "pure") in Finland between 1973 and 1993, of which sixteen (18%) had an IQ score of 70 or below ⁵. Fifteen of the sixteen offenders with LD were

⁵ The average IQ of the whole sample was 93 (low average).

| | RE-OFFENDING | SUSPICION OF RE-OFFENDING |
|---------|---|--|
| Static | (2) <ul style="list-style-type: none"> • Poor relationship with mother. • Prior offences involving violence. | (1) <ul style="list-style-type: none"> • Sexual abuse in childhood. |
| Dynamic | (7) <ul style="list-style-type: none"> • Anti-social attitude. • Low self-esteem. • Lack of assertiveness. • Allowances by staff. • Complacency in final months of probation. • Staff complacency. • Poor response to treatment. | (12) <ul style="list-style-type: none"> • Anti-social attitude. • Denial of crime. • Low self-esteem. • Lack of assertiveness. • Low treatment motivation. • Erratic attendance (at treatment). • Unexplained breaks from routine. • Deterioration in family relationships. • Allowances by staff. • Staff complacency. • Unplanned discharge. • Poor response to treatment. |

(Source: Lindsay et al 2004 table 1 p302)

Table 2.5 - Variables significantly correlated to sexual re-offending by AWLD.

"pure arsonists".

Murphy and Clare (1996) reported that angry feelings, not being listened to/attended to, and feeling bad/depressed were the major pre-fire-setting emotions of arsonists with LD.

2.4. RE-ARREST

Cockram (2005) was able to investigate re-arrest rates among AWLD using data sources in Western Australia. The Disability Services Commission is a register of individuals with any disability and includes an IQ test score, while the Western Australian Police Service database records apprehension records. The period from 1st April 1984 to 31st December 1994 was used.

During this period 843 AWLD were arrested (index group), and they were compared with 2442 "general population offenders" (control group). Cases of re-arrest during the period were then ascertained. The average follow-up period was around six years.

Overall, the AWLD had a significantly higher rate of re-arrest than the general population offenders, and this was mostly the case with further analysis of sub-categories including:

- Ethnicity and gender - Male non-Aborigines, female non-Aborigines, and male Aborigines, but no difference for female Aborigines.
- Ethnicity and age - Male non-Aborigines under 30, but no difference for male Aborigines under 30. Male non-Aborigines over 30 had a higher re-arrest for the control group. There was not enough data for analysis of male Aborigines over 30.
- Offence type - For male non-Aborigines the only offence type where AWLD were not higher was drug-related, and this was because there was not enough cases of AWLD offenders here.

A key strength of this study was that the calculation of probabilities of re-arrest took into account the length of follow-up (which varied greatly), and the time spent in custody. Put simply, an individual may not have re-offended because there was not time (ie: study ended) or opportunity to do so (ie: in prison). However, it was not possible to record details of individuals who moved out of the state of Western Australia and re-offended or not. Cockram (2005) felt that this may have under-estimated the re-arrest rate of the control group.

Alexander et al (2006) followed two cohorts of AWLD released from a medium secure unit between 1st September 1987 - 31st December 1993 (n = 27), and 1st January 1994 - 31st December 2000 (n = 37) ⁶. The follow-up period ranged from 1-13 years.

Re-offending was the main outcome measure, but others were also (table 2.6).

- Re-offending: included any contact with the police (even if this did not lead to charges), cautions or convictions.
- Offending-like behaviour: behaviour, which could be classed as an offence but has not involved the police, ie: dealt with by the carers within the residence.
- Relapse: a relapse of mental illness or serious challenging behaviour that was not classed as offending behaviour, being seen as part of a mental health disorder, but did not lead to re-admission to hospital.

For analyses of frequency purposes offending-like behaviour and relapse have been separated into three groups, which are defined thus:

⁶ Overall, 11 individuals were rated as moderate LD (IQ score: 40-54), 35 as mild LD (IQ score: 55-69), 17 as borderline (IQ score: 70-80), and one person as "normal" intelligence (IQ score: 81-100).

- Regular offending-like behaviour/relapse: on-going, regular offending behaviour or relapses since discharge.
- Phasic offending-like behaviour/relapse: one period, or occasional infrequent periods of offending behaviour or relapses since discharge.
- No offending-like behaviour/relapse: No offending behaviour or relapses since discharge.

(Source: Alexander et al 2006 box 1 p306)

Table 2.6 - Definitions of terms used by Alexander et al (2006).

By the study definition, 30% of the sample re-offended, but only seven individuals (11% overall) were re-convicted⁷. Re-conviction was more likely for individuals with a history of theft or burglary, a personality disorder, and/or schizophrenia. But 58% showed "offending-like behaviour" and 37% "relapse".

2.5. REFERENCES

Alexander, R.T et al (2006) Long-term outcome from a medium secure service for people with intellectual disability Journal of Intellectual Disability Research 50, 4, 305-315

Broxholme, S & Lindsay, W.R (2003) Development and preliminary evaluation of a questionnaire on cognitions related to sex offending for use with individuals who have mild intellectual disabilities Journal of Intellectual Disability Research 47, 472-482

Chaplin, E.H (2006) Forensic aspects in people with intellectual disabilities Current Opinion in Psychiatry 19, 486-491

Cockram, J (2005) Careers of offenders with an intellectual disability: The probabilities of re-arrest Journal of Intellectual and Developmental Disabilities 49, 7, 525-536

Cockram, J & Underwood, R (2000) Offenders with an intellectual disability and the arrest process Law in Context 17, 101-109

Crocker, A.G et al (2007) Rate and characteristics of men with an intellectual disability in pre-trial detention Journal of Intellectual and Developmental Disabilities 32, 143-152

Hayes, S et al (2007) The prevalence of intellectual disability in a major UK prison British Journal of Learning Disabilities 35, 162-167

Lindberg, N et al (2005) Looking for pyromania: Characteristics of a consecutive sample of Finnish male criminals with histories of recidivist fire-setting between 1973 and 1993 BMC Psychiatry 5, 47

Lindsay, W.R et al (2004) Predictors of sexual offence recidivism in offenders with intellectual disabilities Journal of Applied Research in Intellectual Disabilities 17, 299-305

⁷ This compares to about one-quarter of individuals without LD discharged from medium secure units (eg: Madden et al 1999).

Lindsay, W.R et al (2006) Response patterns on the Questionnaire on Attitudes Consistent with Sexual Offending in groups of sex offenders with intellectual disabilities Journal of Applied Research in Intellectual Disabilities 39, 47-53

Lunsky, Y et al (2007) Sexual knowledge and attitudes of men with intellectual disability who sexually offend Journal of Intellectual and Developmental Disabilities 32, 74-81

Madden, A et al (1999) Outcome of admission to a medium secure psychiatric unit British Journal of Psychiatry 173, 313-317

McBrien, J & Murphy, G (2006) Police and carers' views on reporting alleged offences by people with intellectual disabilities Psychology, Crime and Law 12, 127-144

Murphy, G.H & Clare, I.C.H (1996) Analysis of motivation in people with mild learning disabilities (mental handicap) who set fires Psychology, Crime and Law 2, 153-164

Rose, J et al (2002) A group treatment for men with intellectual disabilities who sexually offend or abuse Journal of Applied Research in Intellectual Disabilities 15, 138-150

Sondenaa, E; Rasmussen, K & Nottestad, J.A (2008) Forensic issues in intellectual disability Current Opinion in Psychiatry 21, 449-453

Talbot, T.J & Langdon, P.E (2006) A revised sexual knowledge assessment tool for people with intellectual disabilities: Is sexual knowledge related to sexual offending behaviour? Journal of Intellectual Disability Research 50, 7, 523-531

Wahlund, K & Kristiansson, M (2006) Offender characteristics in lethal violence with special reference to anti-social and autistic personality traits Journal of Interpersonal Violence 21, 1081-1091

3. MEDICAL PROBLEMS AND LEARNING DISABILITIES

Adults with learning disabilities (AWLD) suffer from disproportionately more medical problems than the general population. For example, 94% of AWLD compared to 63% of the general population in the 1995 Welsh Health Survey (Welsh Office 1995). While the Second Dutch National Survey of General Practice (Straetmans et al 2007) found that AWLD visited a GP nearly twice as much as the average.

There could be a number of possible reasons for this increase in medical problems (Kwok and Cheung 2007):

i) The cause of the learning disability also caused the medical problems (eg: genetics).

ii) The medical problems are side effects of the medication prescribed for challenging behaviour, say. Psychotropic medications, like anti-psychotics are commonly used with AWLD to combat challenging behaviour rather than to deal with psychiatric illness (eg: 22% of AWLD prescribed anti-psychotics in Oklahoma; Spreat et al 1997). Disturbingly, multiple drugs are often used (known as polypharmacy) (Kwok and Cheung 2007).

Powerful psychotropic medications have severe side effects, which, in the case of anti-psychotics include tardive dyskinesia ⁸, diabetes, and weight gain.

iii) Social causes for the medical problems, like poverty, poor living conditions, or unhealthy lifestyle.

The most common medical problems include:

a) Vision problems - eg: 92% of 76 individuals with severe and profound multiple disabilities in a Dutch study (Van den Broek et al 2006).

b) Epilepsy - eg: 26% of AWLD in a UK study (McGrother et al 2006). There is some concern that such sufferers are more resistant to anti-epileptic drugs than the non-AWLD epilepsy sufferers (eg: over two-thirds continued to experience seizures while on medication; McGrother et al 2006).

A number of new anti-epileptic drugs have been introduced in recent years (approximately ten since 1990; Huber and Seidel 2006). For example, topiramate was reported in early studies as reducing seizures in AWLD,

⁸ This has up to 25 different symptoms including movements and grimaces of the mouth, and tics and mannerisms

but having side effects like sedation and cognitive deterioration (eg: Kelly et al 2002). Similarly with levetiracetam (eg: Huber et al 2004).

c) Dementia - Individuals with Down's syndrome have a higher risk of Alzheimer's disease after fifty years old than the general population with nearly four times more at 65 and above (Strydom et al 2009).

REFERENCES

Huber, B & Seidel, M (2006) Update on treatment of epilepsy in people with intellectual disabilities Current Opinion in Psychiatry 19, 492-496

Huber, B et al (2004) Efficacy and tolerability of levetiracetam in patients with therapy-resistant epilepsy and learning disabilities Seizure 13, 168-175

Kelly, K et al (2002) Topiramate in patients with learning disability and refractory epilepsy Epilepsia 43, 399-402

Kwok, H & Cheung, P.W.H (2007) Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities Current Opinion in Psychiatry 20, 443-449

McGrother, C.W et al (2006) Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications Seizure 15, 376-386

Spreat, S et al (1997) Use of psychotropic medication in Oklahoma: A state-wide survey American Journal of Mental Retardation 102, 80-85

Straetmans, J.M.J.A.A et al (2007) Health problems of people with intellectual disabilities: The impact for general practice British Journal of General Practice 57, 64-66

Strydom, A et al (2009) The relationship of dementia prevalence in older adults with intellectual disabilities (ID) to age and severity of ID Psychological Medicine 39, 13-21

Van den Broek, E.G et al (2006) Visual impairments in people with severe and profound multiple disabilities: An inventory of visual functioning Journal of Intellectual Disabilities Research 50, 6, 470-475

Welsh Office (1995) Welsh Health Survey 1995 Cardiff: Welsh Office

4. COMPARING CHILDREN'S UNDERSTANDING OF MONEY WITH ADULTS WITH LEARNING DISABILITIES

Children's understanding of money and finances develops in stages, as with so many behaviours, in relation to their understanding of numbers (Berti and Bombi 1988). There are different concepts involved.

- i) Concept of quantity - eg: difference in number of items in two groups (0-3 years old).
- ii) Basics of counting (3-5 years old).
- iii) Basic arithmetic.
- iv) Understanding of money (approximately 4 years old).
- v) Economic concepts like buying and selling, and monetary exchange (6-7 years old) ⁹.

The understanding of money and of number overlaps.

How do these stages compare with the abilities of adults with mild learning disabilities?

Suto et al (2006) recruited thirty volunteers with mild learning disabilities (average IQ 61.80 ¹⁰) in the Cambridge area of England. Five sets of tasks were developed (increasing in difficulty) (figure 4.1).

a) Ordering quantities (OQ) - Three tasks involving placing five cards containing different numbers of spots in order of quantity.

b) Number familiarity (NF) - Three tasks involving five cards with different numbers written on them, and the participants had to identify the number.

c) Money familiarity (MF) - Two tasks of identifying coins and notes of different values, and one task of identifying a simple combination of coins and notes (eg: £1.02 = £1 coin and 2p coin).

⁹ Six year-olds know that money related to buying, but see it as "ritual" (like "thank you"). Seven to eight year-olds think shopkeeper passes on goods from wholesaler, but, by 11 years old, children understand "mark up" by shopkeepers to cover costs (without necessarily understanding "profit") (Berti and Bombi 1988).

¹⁰ An IQ score of 70 is usually taken as the cut-off point for learning disabilities, where a score of 100 is the norm (and 70-80 classed as borderline). Below 70 is divided into categories - 55-69 mild, 40-54 moderate, 25-39 severe, and less than 24 profound learning disability (AAMR 2002). In terms of the LD population, 85% have mild LD, 10% moderate, 4% severe, and the remainder (1%) profound LD (Rosenhan and Seligman 1995).

d) Ordering numbers (ON) - As task (a) but using cards with numbers on them.

e) Ordering money (OM) - Two tasks of placing coins and notes in order of value.

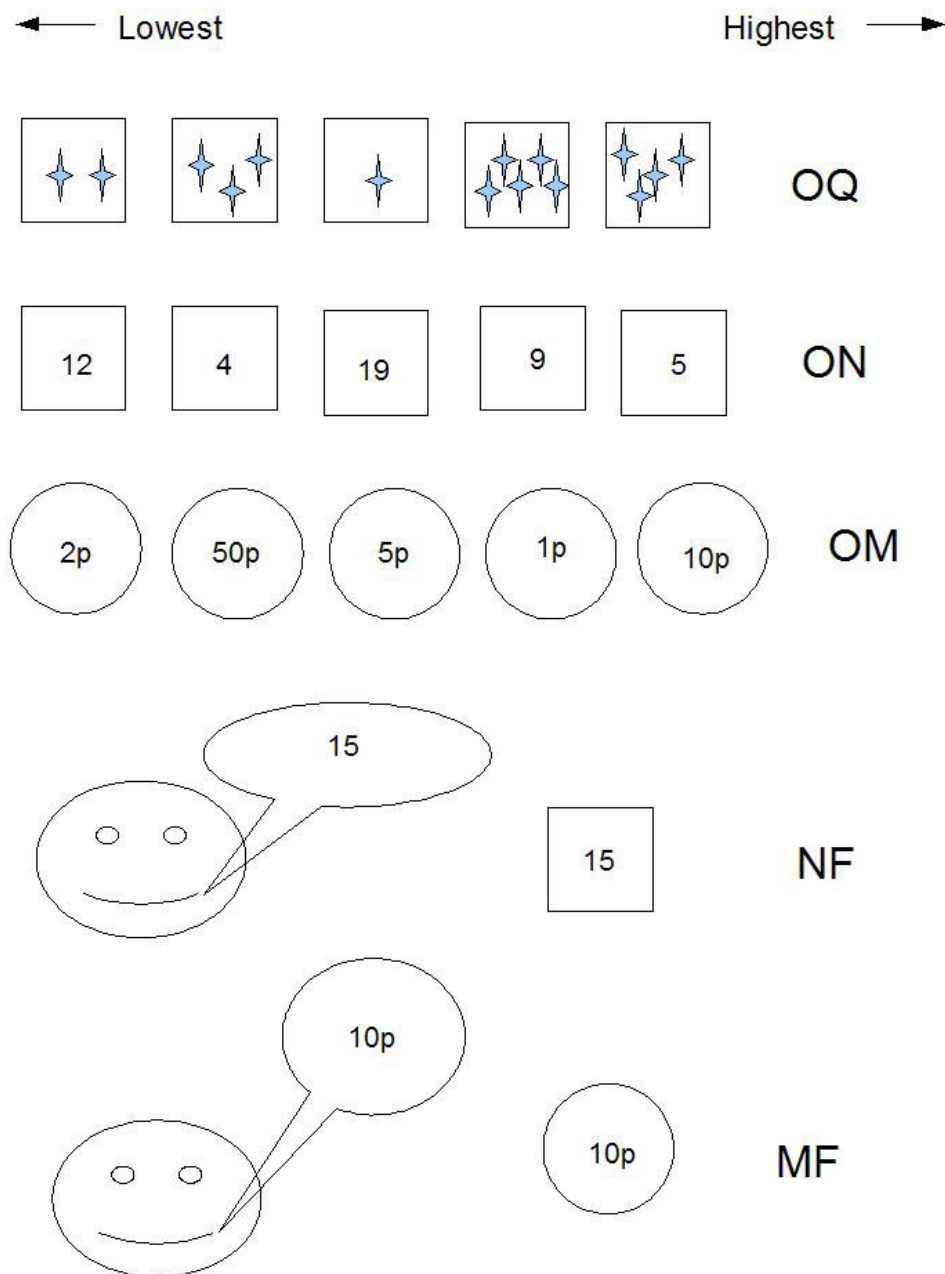


Figure 4.1 - Tasks developed by Suto et al (2006).

Participants were tested individually on all the tasks.

More participants were able to complete the earlier tasks (eg: 90% on OQ) than the later ones (eg: 46.7% on ON) (figure 4.2). So some tasks were significantly easier for the participants than others (table 4.1).

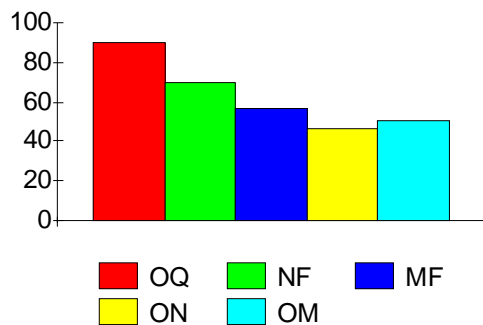


Figure 4.2 - Proportion of participants completing every task of each type.

| TASK | SIGNIFICANTLY EASIER THAN: | SIGNIFICANTLY HARDER THAN: |
|------|----------------------------|----------------------------|
| OQ | All others | - |
| NF | ON | OQ |
| MF | - | OQ |
| ON | - | OQ/NF |
| OM | - | OQ |

Table 4.1 - Tasks that were significantly easier or harder than others.

REFERENCES

AAMR (2002) Mental Retardation: Definition, Classification and System of Supports Washington DC: American Association on Mental Retardation

Berti, A.E & Bombi, A.S (1988) The Child's Construction of Economics Cambridge: Cambridge University Press

Rosenhan, D.L & Seligman, M.E.P (1995) Abnormal Psychology (3rd ed) New York: Norton

Suto, W.M.I et al (2006) Understanding of basic financial concepts among adults with mild learning disabilities British Journal of Clinical Psychology 45, 261-266

5. PERCEPTIONS OF ADULTS WITH LEARNING DISABILITIES BY CAREGIVERS: TWO EXAMPLES

- 5.1. Attributions about challenging behaviour
 - 5.1.1. Evaluation of Weigel et al (2006)
- 5.2. Sexuality
- 5.3. References

5.1. ATTRIBUTIONS ABOUT CHALLENGING BEHAVIOUR

Individuals make sense of other people's behaviour through a process called attribution. They attribute the cause of a behaviour as internal (eg: personality trait) or external (eg: environmental trigger). The attribution made also links to assumptions like whether the behaviour is deliberate or accidental, controllable by the individual or not, and enduring or temporary. However, the process of attribution is prone to errors like the fundamental attribution error. This is the tendency to over-estimate the cause of the behaviour as internal (Heider 1958).

Weigel et al (2006) found that care staff made the fundamental attribution error by attributing the challenging behaviour of a client with learning disabilities (LD) as internal. Consequently the behaviour was seen as controllable, and less help was offered. Where the challenging behaviour is attributed as external, staff were more willing to offer help (Sharrock et al 1990).

Weigel et al (2006) investigated the attributions of fifteen staff members in relation to a client with challenging behaviour (CB client) and one without (non-CB client). The challenging behaviour included screaming, and throwing objects and items of furniture. Attributions of recent negative events were measured by five Likert scales. The negative events of the CB client were attributed as significantly more internal, and controllable by the client (figure 5.1).

| | | | |
|--------------------------|---------------|---------------|------------------------|
| INTERNAL TO CLIENT | | | EXTERNAL TO CLIENT |
| | 2.60 | 4.71 | |
| | CB client | non-CB client | |
| UNCONTROLLABLE BY CLIENT | | | CONTROLLABLE BY CLIENT |
| | 2.64 | 5.33 | |
| | non-CB client | CB client | |

Figure 5.1 - Significant differences in mean scores of attributions by staff.

5.1.1. Evaluation of Weigel et al (2006)

1. Problems in finding comparable recent negative events by clients for staff to attribute. Obviously, challenging behaviour could not be used because one individual showed it and the other did not. This raises an issue about internal validity of the study (Weigel et al 2006).

2. This study has high ecological validity in that real clients were used rather than hypothetical scenarios as in other studies. However, real events may produce more negative emotions for the staff than hypothetical examples (Wanless and Jahoda 2002).

3. Though the sample of staff was small, it was a good number considering the requirement was a staff member familiar with the two clients.

4. Attribution is the individual's perception of the cause, and not necessarily the actual cause of the behaviour. The attributors may be causing another's behaviour without noticing it.

Weigel et al (2006) found some evidence that the behaviour of the care staff may be producing the challenging behaviour of the client through "expressed emotion" (EE) (Vaughn and Leff 1976)¹¹. This is the degree of expression of positive or negative comments/emotions about a child, say, by its mother. Parents who make a number of critical comments about their child behave differently towards that child which can lead to anti-social behaviour by that child (McCarty et al 2004).

Weigel et al (2006) found that care staff made significantly more critical comments when talking about the CB client (figure 5.2). These were retrospective comments, so it is not possible to establish that the negative comments caused the client's challenging behaviour. This study was not a true experiment, so such causality could not be established.

¹¹ High EE includes critical comments about the individual, hostility towards them, and emotional over-involvement (eg: over-concern) (Vaughn and Leff 1976).

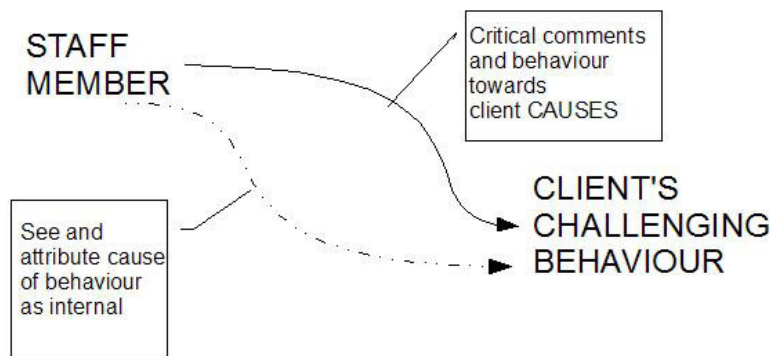


Figure 5.2 - Possible cause of challenging behaviour.

5.2. SEXUALITY

The sexuality of adults with learning disabilities (AWLD) is problematic for many caregivers because of the concerns about vulnerability to sexual abuse and exploitation, and the mistaken belief that AWLD are "child-like and incapable of sexual feelings" (Swango-Wilson 2008).

Swango-Wilson (2008) investigated the caregivers' perceptions about the sexuality of AWLD in Anchorage, Alaska, USA. Eighty-five completed surveys based on the Perception of Sexuality (POS) scale (Scotti et al 1996) were returned. The POS scale has 28 statements about seven areas of sexual behaviour: private display of affection, public display of affection, safe sex, same sex partners, prolonged public kissing, anal sex, and risky sex. Each statement is rated between 1 ("absolutely inappropriate behaviour") to 5 ("absolutely appropriate behaviour") with 3 for "uncertainty of behaviour acceptance".

Half of the respondents completed the POS scale for AWLD first, and then for themselves/their peer group, and half the other way around.

The majority of the respondents were paid caregivers (93%), and were female (75.8%). The overall POS scale mean was 3.8 for AWLD. This mean was based on different views about the seven areas of behaviour (figure 5.3).

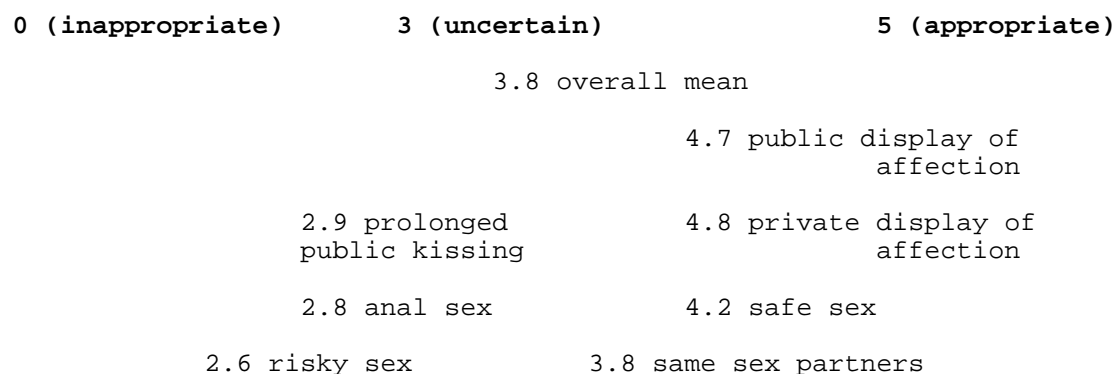
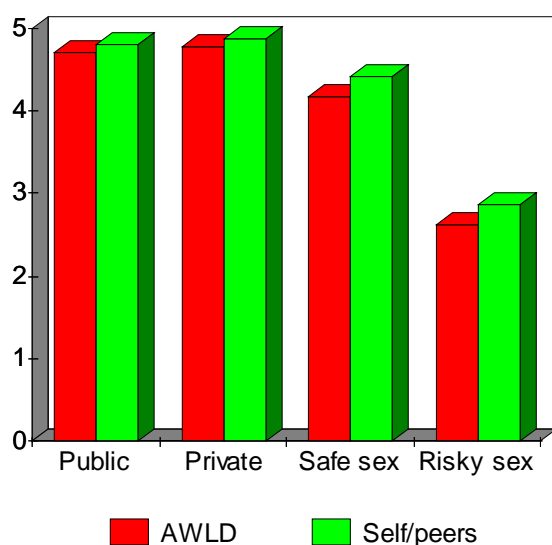


Figure 5.3 - Mean scores for sections of POS scale for AWLD.

There was no significant difference between the overall mean of the POS scale for AWLD and for themselves/their peer group, but there were significant differences for four sections of the scale. All these areas were perceived as more acceptable for the self/peer group than for AWLD: public/private display of affection, and safe/risky sex (figure 5.4).



Public = public display of affection
 Private = private display of affection
 Higher score = perceived as more acceptable

Figure 5.4 - Mean scores for significant differences on POS scale for AWLD and self/peer group.

5.3. REFERENCES

Heider, F (1958) The Psychology of Interpersonal Relation New York: Wiley

McCarty, C.A et al (2004) Parent-child interactions in relation to critical and emotionally over-involved expressed emotion (EE): Is EE a proxy for behaviour? Journal of Abnormal Child Psychology 32, 83-93

Scotti, J et al (1996) College student attitudes concerning the sexuality of persons with mental retardation: Development of the perceptions of sexuality scale Sexuality and Disability 14, 249-263

Sharrock, R et al (1990) Explanations by professional care staff, optimism and helping behaviour: An application of attribution theory Psychological Bulletin 20, 849-855

Swango-Wilson, A (2008) Caregiver perception of sexual behaviours of individuals with intellectual disabilities Sexuality and Disability 26, 75-81

Vaughn, C.E & Leff, J.P (1976) The influence of family and social factors on the course of psychiatric illness: A comparison of schizophrenic and depressed neurotic patients British Journal of Psychiatry 129, 125-137

Wanless, L.K & Jahoda, A (2003) Responses of staff towards people with mild or moderate intellectual disability who behave aggressively: A cognitive emotional analysis Journal of Intellectual Disability Research 46, 507-516

Weigel, L et al (2006) Challenging behaviour and learning disabilities: The relationship between expressed emotion and staff attributions British Journal of Clinical Psychology 45, 205-216

6. QUALITY OF LIFE AND ADULTS WITH LEARNING DISABILITIES

Quality of life (QOL) is not easy to define, but it is best measured using objective and subjective criteria. Though there is overlap between the objective and subjective, there are also differences (Bertelli and Brown 2006). For example, Perry and Felce (2005) found that for adults with learning disabilities (AWLD) who were residents of community housing services in Britain, subjective satisfaction with choice did not correlate with an objective measure of it.

QOL is also multi-dimensional. For example, the measures used by the "Ask Me! Project" in the USA have eight dimensions (Keith and Bonham 2005):

- Physical well-being.
- Emotional well-being.
- Material well-being.
- Interpersonal relations.
- Personal development.
- Social inclusion.
- Self-determination.
- Rights.

It is usually the individual themselves who rate their QOL (table 6.1). However, it has been asserted by some researchers that individuals lacking cognitive skills cannot attribute value to aspects of their life. "This assertion is just a prejudicial belief", argued Bertelli and Brown (2006). Saying that, individuals close to the respondent can help, especially for those with profound LD. For example, the Lyons' Life Satisfaction Matrix (LSM) (Lyons 2005) measures the satisfaction of individuals with profound LD by using the observation of consistent behavioural repertoires by carers.

Choice is seen as a key element of quality of life. Two main definitions of choice exist:

- "The act of an individual's selection of a preferred alternative from among several familiar options" (Shevin and Klein 1984).
- "A response to a situation, where the response is one of a number which is possible in that situation" (Rawlings et al 1995) (quoted in Smyth and Bell 2006 p228).

Each question begins with: "How happy or sad do you feel about"

- the things you have? Like the money you have, and the things you own?
- how healthy you are?
- the things you make or the things you learn?
- your friends or family?
- how safe you feel?
- doing things with people outside your home?
- your own happiness?

Response options - drawings of faces showing different expressions like happy or sad.

Table 6.1 - Example of items from Comprehensive Quality of Life Scale (ComQol-I5) (Cummins 1997) ¹².

Smyth and Bell (2006) observed:

Articles about choice often make the assumption that some choices are easy, such as choice of a biscuit, and that some are hard, such as choosing a sexual partner. In isolation, choosing a biscuit may seem clear and simple. There are conditions however in which even this choice may be more complex than has been previously assumed. It may depend on knowledge of dietary needs, what other options are available or presented, past experience of choice, the general quality of life of the person with learning disabilities and the expectations or lifestyle and dietary knowledge of care-staff (p228) (table 6.2).

The choice of food consumed is actually an important decision in the context of health issues. Smyth and Bell's argument is that the promotion of choice for AWLD, particularly in reference to food, has inadvertently promoted unhealthy food choices and contributed to the high level of obesity among AWLD ¹³.

Jingree and Finlay (2008) found that fifteen support staff used two main discourses when talking about choice for AWLD:

- "Increasing autonomy" which emphasised the rights of the individual and freedom of choice.
- "Practicalities talk" to explain why choices were limited in certain situations.

¹² Available at <http://www.deakin.edu.au/research/acqol/instruments/comqol-scale/comqol-i5.pdf>.

¹³ For example, 16% of male and 25% of female AWLD obese compared to 6% of men and 8% of women in the general population in Great Britain (Smyth and Bell 2006).

| INDIVIDUAL FACTORS | CARER/STAFF/MANAGEMENT FACTORS |
|--|--|
| 1. Cognitive ability. 2. Lifestyle. 3. Socio-economic status. 4. Past experience of choice. 5. Lack of knowledge. 6. Degree of dependency. 7. Physical ability. 8. Genetic and physiological factors. 9. Oral and dental health. | 1. Beliefs, attitudes and opportunities. 2. Ability to teach AWLD how to make choices. 3. Management support. 4. Duty of care. 5. Stigma of disability and choice as a "cloak of competence" (Edgerton 1967) to allow AWLD "to pass as normal in society". |

Table 6.2 - Factors that affect choice-making in relation to food for AWLD (Smyth and Bell 2006).

The two discourses were combined in a third ("mixing increased autonomy and practicalities talk") to explain the "realities" of life for AWLD.

REFERENCES

- Bertelli, M & Brown, I (2006) Quality of life for people with intellectual disabilities Current Opinion in Psychiatry 19, 508-513
- Cummins, R.A (1997) Manual for Comprehensive Quality of Life Scale (5th ed - ComQol-I5) School of Psychology, Deakin University, Melbourne, Australia
- Edgerton, R.B (1967) The Cloak of Competence USA: University of California
- Jingree, T & Finlay, W.M.L (2008) "You can't do it.. it's theory rather than practice": Staff use of the practice/principle rhetorical device in talk on empowering people with learning disabilities Discourse and Society 19, 6, 705-726
- Keith, K.D & Bonham, G.S (2005) The use of quality of life data at the organisational and system level Journal of Intellectual Disability Research 49, 799-805
- Lyons, G (2005) The Life Satisfaction Matrix: An instrument and procedure for assessing the subjective well being quality of life of individuals with profound multiple disabilities Journal of Intellectual Disability Research 49, 766-769
- Perry, J & Felce, D (2005) Correlation between subjective and objective measures of outcome in staffed community housing Journal of Intellectual Disability Research 49, 278-287
- Smyth, C.M & Bell, D (2006) From biscuits to boyfriends: The ramifications of choice for people with learning disabilities British Journal of Learning Disabilities 34, 227-236

7. BURNOUT OF PROFESSIONAL CARERS OF ADULTS WITH LEARNING DISABILITIES

"Professional" (paid) carers of adults with learning disabilities (AWLD) can suffer from stress and burnout. Burnout is seen as a specific type of prolonged occupational stress in the "human services" caused by (Schaufeli and Enzmann 1998):

- i) Individual factors, like over-commitment, or unrealistic job expectations.
- ii) Interpersonal factors, like the imbalance between the demands of the clients and the employee's resources.
- iii) Nature of the work (ie: caring).
- iv) Organisational factors, like lack of support, or lack of control.

The role of these factors in occupational stress have been confirmed by studies, like Hatton et al (1999) of 450 professional carers of AWLD. There are many similarities to professional carers in other fields and with other client groups, but also differences. AWLD can require a greater level or intensity of support than other client groups, as well as increased levels of challenging behaviour (White et al 2006). For example, staff who have to use restraint techniques on their clients found it a negative experience (as did the clients) (eg: Hawkins et al 2005).

Other stressors have developed in recent years with the growth of care in the community. Practically, professional carers often have "to straddle many government departments who provide services and more models of service delivery (some of which may be conflicting)" (White et al 2006 p505).

Innstrang et al (2004) reported the benefits of a stress-reduction programme for staff in Norway that included exercise, educational seminars, and changes in shift patterns.

REFERENCES

Hatton, C et al (1999) Organisational culture and staff outcomes in services for people with intellectual disabilities Journal of Intellectual Disability Research 43, 206-218

Hawkins, S; Allen, D.D & Jenkins, R (2005) The use of physical intervention with people with intellectual disabilities and challenging

behaviour: The experiences of service users and staff members Journal of Applied Research on Intellectual Disability 18, 19-34

Innstrang, S et al (2004) Job stress, burnout and job satisfaction: An intervention study for staff working with people with intellectual disabilities Journal of Applied Research in Intellectual Disabilities 17, 119-126

Schaufeli, W & Enzmann, D (1998) The Burnout Companion to Study and Practice: A Critical Analysis London: Taylor & Francis

White, P et al (2006) Stress and burnout among professional carers of people with intellectual disability: Another health inequity Current Opinion in Psychiatry 19, 502-517

8. APPLIED BEHAVIOUR ANALYSIS

Individuals with learning disabilities (LD) show behaviour problems more often than the general population (Tassé 2006).

Historically, the main non-pharmacological treatment for such problems has been Behaviour Modification (BM) programmes based on the principles of operant conditioning. The focus is upon rewarding desired behaviour and punishing negative behaviour. BM tends not to explore the cause (or function) of the problem behaviour, whereas Applied Behaviour Analysis (ABA) is interested in this (Baer et al 1968).

So, individuals with learning disabilities do not engage in problem behaviour because they have LD, rather that the problem behaviour serves a function or purpose.

ABA has three aims (Iwata and Worsdell 2005):

- i) To identify the triggers for the behaviour.
- ii) To identify the reinforcements/consequences maintaining the behaviour.
- iii) To generate alternatives that serve the same function.

Practically, the following steps are involved in ABA (O'Neill et al 1997):

1. Clear operational definition of problem behaviour (eg: head banging, hair pulling, hitting staff) (ie: measurable and observable definition).
2. Identification of situations where problem behaviour occurs and does not occur.
3. Identification of factors preceding problem behaviour (ie: antecedents).
4. Identification of factors following problem behaviour (ie: consequences).
5. Experimental testing of antecedents and consequences to establish causal relationships with problem behaviour.
6. Development of hypotheses about the function of problem behaviour.
7. Development of intervention strategy to replace problem behaviour.

REFERENCES

Baer, D.M; Wolf, M.M & Risley, T.R (1968) Some current dimensions of applied behaviour analysis Journal of Applied Behaviour Analysis 1, 91-97

Iwata, B.A & Worsdell, A.S (2005) Implications for functional analysis methodology for the design of intervention programmes Exceptionality 13, 24-34

O'Neill, R.E et al (1997) Functional Analysis pf Problem Behaviour: A Practical Assessment Guide (2nd ed) Pacific Grove, CA: Brooks/Cole

Tassé, M.J (2006) Functional behaviour assessment in people with intellectual disabilities Current Opinion in Psychiatry 19, 475-480

9. THREE LESS COMMON GENETIC CONDITIONS WITH LEARNING DISABILITIES

Prader-Willi Syndrome (PWS)

In PWS, individuals suffer primarily from hyperphagia (ie: a failure to stop eating), which means if food is available they will continue eating. The cause has been linked to a gene that controls satiety (Einfeld 2004). As well as obsessive thoughts about food, many sufferers show non-food-related compulsions, like hoarding, needs to know, tell, or ask, and excessive concerns with ordering (Dykens 1998). Other symptoms include short stature, small hands and feet, as well as LD.

PWS affects 1 in 15 000 births (Dyken 1998), and is linked to chromosome 15 abnormalities (eg: deletions).

There is often co-morbidity with affective disorders, and obsessive-compulsive disorder (Dykens 1998).

Fragile X Syndrome

Affecting 1 in 1000 persons (Dykens 1998), this is the result of inheriting certain mutations on the X chromosome (eg: FMR-1 gene). There are a wide number of learning and behaviour problems.

There is often co-morbidity with attention deficit hyperactivity disorder, anxiety, and pervasive developmental disorder (Dykens 1998).

Velocardiofacial Syndrome (VCFS)

VCFS is caused by a deletion on chromosome 22 which produces characteristics like cleft palates, long faces, prominent noses, and slender hands as well as LD (Einfeld 2004).

Not only do the genes that cause these conditions produce the overall learning disabilities, they lead to changes in brain functioning, which is now being observed by neuroimaging. For example, Van Amelsvoort et al (2006) found, in a functional magnetic resonance imaging (fMRI) scanner, less activation in the right insula and frontal regions, and more activation in the occipital regions of the brain of adults with VCFS when processing pictures of facial emotions. Eight individuals with VCFS and nine controls were shown pictures of happy, angry or neutral faces, and asked them to judge the gender of the face.

REFERENCES

Dykens, E.M (1998) Maladaptive behaviour and dual diagnosis in persons with genetic syndromes. In Burack, J et al (eds) Handbook of Retardation and Development Cambridge: Cambridge University Press

Einfeld, S.L (2004) Behaviour phenotypes of genetic disorders Current Opinion in Psychiatry 17, 343-348

Van Amelsvoort, T et al (2006) Processing facial emotions in adults with velo-cardio-facial syndrome: Functional magnetic resonance imaging British Journal of Psychiatry 189, 560-561

10. CURING AUTISM?

- 10.1. Introduction
- 10.2. "Alternative" treatments
- 10.3. An alternative view
- 10.4. References

10.1. INTRODUCTION

The idea that autism can be cured is a belief or goal of many parents of children with the condition. For those so inclined it is fuelled by studies like Guy et al (2007), who reported the ability to reverse ("cure") the effects of Rett syndrome-like ¹⁴ symptoms in mice by genetic engineering. Technically, it was the restoration of functions in the brain that had ceased with Rett syndrome. Such research, though with a small number of animals, rises the hopes of parents with children with such conditions that a cure is possible.

10.2. "ALTERNATIVE" TREATMENTS

Shute (2010) suggested that as many as three-quarters of children with autism are undergoing "alternative" treatments that have no scientific basis. Many are bogus: "They have not been tested for safety or effectiveness, they can be expensive, and some of them may actually do harm" (p64). The Internet is the marketplace for these "treatments".

Because scientific knowledge about the cause of autism is limited, there are many different ideas proposed (many of them from observations by parents of children with autism). Each treatment will be based upon an explanation for the cause of autism.

Shute (2010) listed some treatments that do not have studies showing efficacy:

1. Immunoglobulin.

The injection of anti-bodies used to combat leukaemia and AIDS. It is proposed that either a virus of some type has caused autism (eg: "stealth virus") and/or the immune system of autistic individuals is compromised. The anti-bodies will help the immune system fight the

¹⁴ Rett syndrome is a severe autistic-spectrum disorder that affects girls, and is caused by mutations in a gene on the X chromosome (Guy et al 2007).

virus. Studies have shown no benefits (eg: Handen et al 2009).

2. Vitamin supplements.

The cause here is that autistic children are deficient in vitamins or minerals in some way. The Cochrane Collaboration, which reviews all research on health matters, felt the evidence was inconclusive about vitamin B6 supplements, for example ¹⁵.

3. Stem cell-based interventions (SCBI).

For example, the cause of autism is linked to a failure in the immune system of sufferers, and stem cells from embryonic, or umbilical cord blood or adult stem cells would indirectly improve the efficiency of the immune system.

Regenberg et al (2009) questioned the use of stem cells generally where there is little scientific evidence. They analysed the websites of twenty-three commercial providers of SCBI. The authors were sceptical of the claims of the providers because help was offered for "an implausibly wide range of conditions", and without explanation of how the stem cells would help these conditions.

The authors concluded: "It is possible, although unlikely, that these providers have completed their own independent science in support of their SCBIs. It is also possible that this work is legitimate despite having not been reported or shared with the broader scientific community. These possibilities aside, the reviewed material offers scant evidence of provider efforts to accrue scientific evidence through carefully planned clinical trials. Without evidence from high-quality clinical trials, providers (as scientists) should be very cautious in making claims about the benefits and risks of their SCBIs. The benefit and risk picture, in the absence of scientific evidence, should primarily be a story about unknowns" (pp2317-2318). They felt that some of the advertising on the websites had a "disturbingly similar note to the copy from these old snake oil ads" in the 1890s (eg: Clark Stanley's Snake Oil Liniment treats "rheumatism, neuralgia, sciatica, lame back, lumbago, contracted muscles, toothache, sprains, swellings, etc"; quoted in Regenberg et al 2009).

¹⁵ Latest update at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.cd003497>.

4. Lupron.

This is a drug developed for use with prostate cancer which limits the production of testosterone in men and oestrogen in women as excessive androgens (eg: testosterone) is viewed as the cause of autism here.

5. Sensory integration therapy.

A substantial sub-group of individuals with autism have abnormal responses to sensory stimuli (over- or under-sensitive) (Dawson and Watling 2000). Sensory integration therapy attempts to rectify this with various techniques with excess stimulation, for example (eg: the child is tightly wrapped in a blanket).

Dawson and Watling (2000) reported four studies on the effectiveness of sensory integration therapy using objective measures. The studies had 1, 2, 5, and 18 participants respectively with no comparison group (ie: non-autism). No firm conclusions were possible from the studies.

6. Hyperbolic oxygen chamber.

Normally used to overcome compression sickness in divers, it temporarily increases blood oxygen levels, which could help reduce inflammation if that was the cause of autism.

7. Chelation.

A drug used to remove lead and mercury from the body. This is recommended because the cause of autism is believed to be methylmercury (a preservative in vaccines). However, this was removed from most vaccines in 2001, and autism rates have risen since then (Shute 2010).

There are serious side effects to the drug including kidney failure, and a five-year-old boy with autism in Pennsylvania died in 2005 after receiving intravenous chelation (Shute 2010).

8. Secretin.

A deficiency in this gastro-intestinal hormone is the proposed cause of autism. Clinical trials of increased secretin failed to find any benefits (Shute 2010).

For example, Chez et al (2000) arranged for 56

children with autism to receive one injection of secretin, and then to be assessed 3-6 weeks later. Significant improvements as rated by parents on the Childhood Autism Rating Scales (CARS) were not found. This was an open-label trial as all parties knew what had been injected. Expectations could have influenced the results, and so a placebo group is needed ideally.

In their second study Chez et al (2000) enrolled 25 children with autism in a double-blind crossover trial. Group A received an injection of secretin followed by a saline solution one (placebo) four weeks later, and group B the opposite. Parents completed the CARS at four weeks and eight weeks without knowing which group their children were allocated to. At this stage, the researchers did not know either. Though there were some changes, no significant improvements were observed from baseline, nor significant differences between the secretin and the placebo.

9. Gluten- and casein-free diets.

It is believed that casein (a milk protein) and/or gluten (a wheat protein) interfere with receptors in the brain. Three small clinical trials have found little benefits (Shute 2010) ¹⁶.

10.3. AN ALTERNATIVE VIEW

Some individuals with autism spectrum disorders ¹⁷ are challenging the ideas about curing autism. Concepts like "Autism Pride Day" are based on the belief that it is about autism as human variation or neurodiversity, not as a disability (Saner 2007).

Simon Baron Cohen talks of a cure for autism as "a sledgehammer approach" which can lead to the loss of its special qualities like attention to detail and the ability to concentrate for long periods on a small topic in depth (Saner 2007).

10.4. REFERENCES

Chez, M.G et al (2000) Secretin and autism: A two-part clinical investigation Journal of Autism and Developmental Disorders 30, 2, 87-94

Dawson, G & Watling, R (2000) Interventions to facilitate auditory,

¹⁶ Latest update of Cochrane Collaboration at <http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD003498/frame.html>.

¹⁷ Autistic-spectrum disorders include "typical" autism, high functioning autism, and Asperger syndrome (Toal et al 2005).

visual, and motor integration in autism: A review of the evidence Journal of Autism and Developmental Disorders 30, 5, 415-421

Guy, J et al (2007) Reversal of neurological defects in a mouse model of Rett syndrome Science 315, 1143-1147

Handen, B.L et al (2009) A double-blind, placebo-controlled trial of oral human immunoglobulin for gastrointestinal dysfunction in children with autistic disorder Journal of Autism and Developmental Disorders 39, 796-805

Regenberg, A.C et al (2009) Medicine on the fringe: Stem cell-based interventions in advance of evidence Stem Cells 27, 9, 2312-2319

Saner, E (2007) "It is not a disease, it is a way of life" Guardian 7/8, II 12-15

Toal, F et al (2005) Autistic-spectrum disorders: Lessons from neuroimaging British Journal of Psychiatry 187, 395-397

Shute, N (2010) Desperate for an autism cure Scientific American October, 62-67

11. FACIAL EMOTION RECOGNITION AND WILLIAMS SYNDROME

Individuals with different learning disabilities are poorer at facial emotion recognition than typically developing individuals. However, recognition of positive emotions, like happiness, is less affected than for negative emotions, like sadness (Zaja and Rojahn 2008).

Facial emotion recognition has been particularly studied in individuals with Williams Syndrome (WS)¹⁸. This condition is a rare genetic condition, occurring in 1 in 25 000 births, due to a deletion of genes on chromosome 7 (Karmiloff-Smith 2002). It includes high sociality, high empathy, impulsivity, and high social anxiety with an IQ ranging from 50-65 usually (Karmiloff-Smith 2002). WS sufferers are highly proficient at recognising and remembering faces (Karmiloff-Smith 2002).

It has been proposed that WS individuals are, thus, more sensitive to social emotions. However, this is not supported by studies of facial emotion recognition.

For example, Plesa-Skwerer et al (2006) compared a group of WS sufferers with a group of individuals with general learning disabilities (LD) and a typically developing group for accuracy of emotion recognition. The WS group were no better than the general LD group at identifying the emotions in pictures of faces, and they were both significantly poorer than the typically developing group (figure 11.1).

Individuals with WS may actually be poorer at face processing (ie: whether individual features or the whole face is used to infer information from the face, including emotional cues). Karmiloff-Smith et al (2004) designed facial stimuli where elements could be changed as well as the whole face. The WS group were as accurate as typical developing individuals in spotting if individual features had changed between two quickly presented faces, though the WS individuals were slower to answer. But they were poorer at detecting if the whole face had changed. This suggested that WS sufferers use individual features to process faces including to recognise facial emotions which can lead to misinterpretation of emotions (Zaja and Rojahn 2008).

WS sufferers process faces using different brain areas than controls in studies of electrical activity in the brain - left hemisphere or both hemispheres compared

¹⁸ Also called Williams-Beuren Syndrome.

to right hemisphere predominance in controls (Karmiloff-Smith 2002).

While Meyer-Lindenberg et al (2005) found differences in amygdala activity in a brain scanner between thirteen WS individuals with a normal IQ range (around 100) and thirteen matched controls. The participants had to match two faces showing anger or fear, or to match a fearful or threatening scene. The WS group showed increased amygdala activation in the latter task and the controls in the former task.



Figure 11.1 - Examples of types of stimuli used in face emotion recognition studies.

REFERENCES

Karmiloff-Smith, A (2002) Elementary, my dear Watson, the clue is in the genes.. Or is it? Psychologist December, 608-611

Karmiloff-Smith, A et al (2004) Exploring the Williams Syndrome face processing debate: The importance of building developmental trajectories Journal of Child Psychology and Psychiatry 45, 1258-1274

Meyer-Lindenberg, A et al (2005) Neural correlates of genetically

abnormal social cognition in Williams Syndrome Nature Neuroscience 8, 8, 991-993

Plesa-Skwerer, D et al (2006) Perceiving facial and vocal expressions of emotion in individuals with Williams Syndrome American Journal of Mental Retardation 111, 15-26

Zaja, R.H & Rojahn, J (2008) Facial emotion recognition in intellectual disabilities Current Opinion in Psychiatry 21, 441-444

12. THREE DIFFERENT THEORIES OF AUTISM: CORRELATION OR CAUSATION?

- 12.1. Introduction
- 12.2. Androgen theory
- 12.3. Age of father
- 12.4. Excessive rainfall
- 12.5. References

12.1. INTRODUCTION

It is generally accepted that the underlying cause of autism is genetic mutation (spontaneous deletions or duplications) (Eichler and Zimmerman 2008).

Neuroimaging has led to the discovery of differences in the brain of autists as compared to the general population, like (Toal et al 2005):

- Differences in the volume of the whole brain - eg: due to early over-growth and pre-mature cessation of growth; Courchesne 2004).
- Differences in specific areas - both in structure and function.
- Differences in brain development of individuals with autism and savant abilities (eg: Boddaert et al 2005).

Autism is "neither simple nor uniform", and at least sixty different genetic, metabolic, and neurological disorders are associated with it (Eichler and Zimmerman 2008). Such diversity has led to many and varied theories about the cause of autism. This article has selected three different ones to consider.

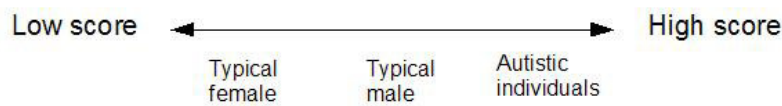
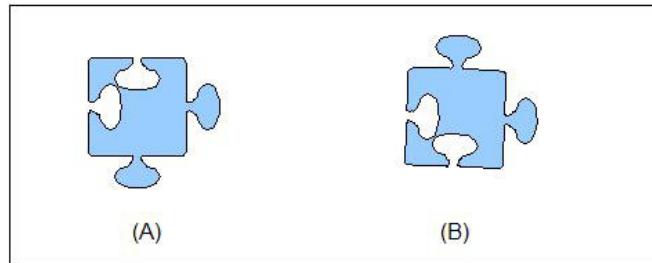
12.2. ANDROGEN THEORY

The androgen theory of autism explains the condition as due to increased levels of testosterone (androgen) in the womb. This excess of testosterone produces an "extreme" of the "typical male brain" (Baron-Cohen 2002). For example, typical males show more autistic traits on average than typical females.

Typical males perform better than typical females on tests of visuo-spatial ability (or "intuitive physics"), and autistic individuals are even better than typical males. On the other hand, typical males perform worse than typical females on tests of empathy (or "intuitive psychology", and autists perform even worse (figure 12.1) (Ingudomnukul et al 2007).

VISUO-SPATIAL TASK

Is shape B the same as shape A?



EMPATHY TASK

What emotion is face showing?

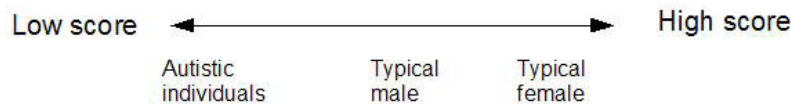


Figure 12.1 - Typical males and females and autistic individuals on two types of tasks.

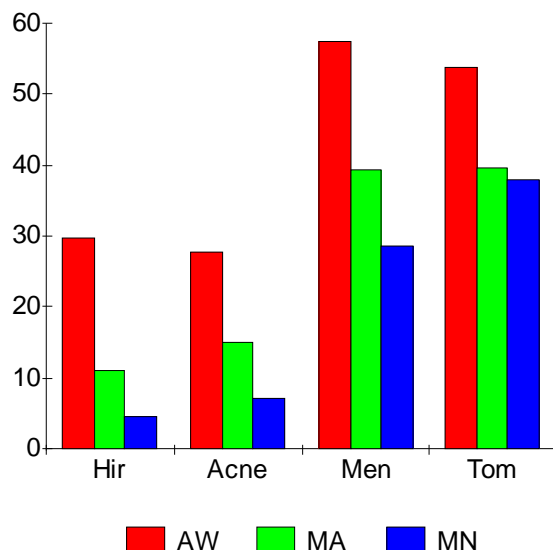
One prediction from the androgen theory is that women with autism will show physical masculinisation, and problems associated with increased levels of testosterone. These include hirsutism (excess bodily or facial hair), severe acne, menstruation problems, and gender identity issues (eg: "tomboy"). Ingudomnukul et al (2007) investigated this prediction with the Testosterone-related Medical Questionnaire (TMQ) ¹⁹.

This was given to 54 adult women with autism and

¹⁹ The TMQ has seven questions about medical conditions and problems related to excess testosterone.

seventy-four mothers of children with autism on the research database at the Autism Research Centre, Cambridge University, England, and 185 mothers of children without autism from the general population.

A number of problems related to increased testosterone were found. The women with autism had significantly higher rates of hirsutism, menstruation problems, severe acne in the past, and being considered a "tomboy" as a child, for example (figure 12.2).



AW = autistic women
MA = mothers of children with autism
MN = mothers of children without autism
Hir = hirsutism
Acne = severe acne in past
Men = irregular menstrual cycle in adulthood
Tom = considered tomboy as child

Figure 12.2 - Percentage of groups reporting symptoms of excess testosterone.

12.3. AGE OF FATHER

Recently, it has been reported that children with fathers over forty years old are nearly six times more likely to suffer from an autism-spectrum disorder than with father under thirty.

Advancing maternal age increases the risk of some learning disabilities, like Down Syndrome, but the research is divided over the effect on autism (Reichenberg et al 2006). Paternal age at birth of offspring is associated with congenital disorders, like cleft palate or hydrocephalus (Reichenberg et al 2006).

Reichenberg et al (2006) investigated the relationship between parental age at birth and autism spectrum disorders (ASD) among Jewish children in Israel

born during six years in the 1980s, and assessed at age 17 by the military draft board. The researchers made use of the Israeli Bureau of Statistics' records held on Israeli citizens based on a unique identification number given at birth.

ASD was over five times more likely for children whose father was aged 40-49 at birth as compared to 15-29 year-old fathers. The risk was seventeen times higher for female offspring of older fathers (table 12.1).

| AGE OF FATHER: | 30-39 years | 40-49 years |
|----------------|-------------|-------------|
| All children | 1.62 | 5.75 |
| Males | 1.62 | 5.35 |
| Females | 3.28 | 17.25 |

Table 12.1 - Adjusted odds ratios for ASD based on age of father at birth with 15-29 year-olds as base (ie: 1).

Maternal age had no effect after adjustment for paternal age.

One explanation for the findings about father's age is the greater risk of spontaneous genetic mutations in the sperm of older men ("copy error" hypothesis; Penrose 1955).

Alternatively, Reichenberg et al (2006) hypothesised that changes in genetic imprinting could occur with age-advanced sperm. Imprinting is the process by which the same gene can behave differently depending upon whether it is inherited from the mother or the father. For example, a maternal version may be "turned on" in development, and a paternal version "turned off". This is also called the "parent-of-origin effect".

Reichenberg et al (2006) admitted to eight limitations to their study that could influence or confound the relationship between paternal age and ASD in offspring:

i) A relatively small number of individuals with ASD for statistical analysis - 110 in cohort of 132 271.

ii) Incomplete data at age 17 for some individuals.

iii) Use of ASD as a general category might hide whether paternal age was linked to specific conditions like autism or Asperger syndrome.

iv) Diagnosis of ASD based on information held by the military draft board.

v) No information about ASD among parents. The behaviour of parent(s) with ASD could be a social cause of ASD in the child.

vi) No information about birth order. Birth order may be linked to autism.

vii) No information on pre-natal and childhood environments, which could be causes of ASD.

viii) Advancing paternal age is association with various genetic mutations.

There is enough uncertainty that it is not possible to say, from this study, that having an older father causes ASD.

12.4. EXCESSIVE RAINFALL

One way of viewing autism is as a biological predisposition to the condition that requires an environmental trigger. The question then becomes, what is such a trigger?

Waldman et al (2008) felt that the trigger could be bad weather, or specifically, rainfall which forces a young child to stay indoors. The researchers noted large variations in rates of autism in different US states, according to official figures. Waldman et al then focused on three states - Oregon and Washington (which have more rainfall in the western than the eastern parts), and California (which has variable rainfall in different areas of the state).

The mean annual rainfall between 1987 and 2001 was correlated with official rates of autism for children aged 6-18 years old in 2005. In Oregon and Washington autism rates were higher in the western counties, which received four times more rainfall than the eastern counties. There was no clear pattern in counties of California. Autism rates also varied in the states based on the amount of rainfall in a particular year between 1987 and 2001.

The data were correlational. How would increased rainfall in a particular area in a particular year trigger autism? Waldman et al (2008) suggested some possibilities:

a) Being indoors due to the rain leads to increased television viewing for young children, and it is this that triggers the development of autism.

b) Another trigger may be vitamin D deficiency in

young children through lack of direct sunlight on the skin.

c) Other aspects of the indoor environment could be the trigger, like the chemicals in household cleaners.

d) The rainfall itself could be the trigger for autism by, for example, transporting chemicals from the upper atmosphere to the ground.

e) Rainfall leads to increased plant growth and insect populations, which leads to increased use of pesticides, and these chemicals trigger autism.

The authors concluded: "Because we do not provide direct clinical evidence of an environmental trigger for autism among genetically vulnerable children that is positively associated with precipitation, our results are clearly not definitive evidence" (Waldman et al 2008 p1033).

Weiss (2008) argued that the study provided little insight into the cause of autism, but "the authors' analysis and the editor's decision to publish it are to be lauded, despite the uncertain ultimate contribution of this work and the possibility (likelihood?) that non-professionals are going to misinterpret and misuse it" (p1095).

Weiss suggested that other explanations may account for the findings, like variations in the collection of data and diagnosis of autism in different states in the USA, or bias in the methodology and analysis by Waldman et al. While Braun and Kalkbrenner (2009) argued that Waldman et al should have controlled for urbanicity in a state because autism is more reported in urban districts.

12.5. REFERENCES

Baron-Cohen, S (2002) The extreme male brain theory of autism Trends in Cognitive Science 6, 248-254

Boddaert, N et al (2005) Autism: functional brain mapping of exceptional calendar capacity British Journal of Psychiatry 187, 83-86

Braun, J.M & Kalkbrenner, A (2009) Autism prevalence and precipitation: The potential for cross-level bias Archives of Pediatrics and Adolescent Medicine 163, 5, 492

Courchesne, E (2004) Brain development in autism: Early overgrowth followed by pre-mature arrest of growth Mental Retardation and Developmental Disorders Research Reviews 10, 106-111

Eichler, E.E & Zimmerman, A.W (2008) A hot spot of genetic instability in autism New England Journal of Medicine 358, 737-739

Ingudomnukul, E et al (2007) Elevated rates of testosterone-related disorders in women with autism spectrum conditions Hormones and Behaviour 51, 597-604

- Penrose, L.S (1955) Parental age and mutation Lancet 2, 312-313
- Reichenberg, A et al (2006) Advancing paternal age and autism Archives of General Psychiatry 63, 1026-1032
- Toal, F et al (2005) Autistic-spectrum disorders: Lessons from neuroimaging British Journal of Psychiatry 187, 395-397
- Waldman, M et al (2008) Autism prevalence and precipitation rates in California, Oregon and Washington counties Archives of Pediatrics and Adolescent Medicine 162, 11, 1026-1034
- Weiss, N.S (2008) Precipitation and autism: Do these results warrant publication? Archives of Pediatrics and Adolescent Medicine 162, 11, 1095-1096