



# The Changing Pattern of Childhood Disability

## Implications for Practice and Early Intervention

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***The history of man for the nine months preceding his birth would, probably, be far more interesting and contain events of greater moment than for all the three score and ten years that follow it.***

***Samuel Taylor Coleridge (1803)***

***Miscellanies, Aesthetic and Literary To Which is Added The Theory of Life***

**Worldwide, 780 million young children are affected by biological, environmental and psychosocial conditions that can limit their cognitive development.**

***(Guralnick, 2004)***

**Iodine deficiency is the  
greatest cause of intellectual disability  
in the developing world.**

**(Fujaira, 2004)**

**‘Poverty can increase the risk of a child having an impairment... Having a disabled child can also mean that parents find it harder to maintain full-time employment, their housing can be inadequate for their child’s needs, and expenditure on basic needs is increased.’**

*(Prime Minister’s Strategy Unit, 2005, p. 86)*

**55% of families with a disabled child are living in poverty or on the margins of poverty.**

*(General Household Survey, 2002)*

***‘Families of children with severe disabilities are less likely to be car or telephone owners, even though they are more dependent on these services.’***

*(Family Fund Data, 1998)*

# Impact of poverty:

## Children living below the poverty line

- 19.8% children in the UK
- 22.4% children in the USA
- 10.7% children in Germany
- 7.9% children in France
- 2.6% children in Sweden

*(UNICEF, 2000)*



**‘The challenge to our society is to loosen and break the stranglehold of poverty on the development of our children.’**

***(Mittler, 2000)***

At birth...

**Society makes a Social  
Contract with its families.**

*(Conliffe)*

# Trends in society

- From group to individual
- From 'we' to 'I'

*(Mombaerts, 2004)*

'375,000 newborn babies per year exposed in the womb to cocaine, heroin, marijuana, methadone, amphetamines.'

*The Times* (June 1995) reporting on an American study

## PRESS MONITORING

'Smoking by pregnant mothers consistently causing low-birth weight or long term damage to unborn babies, or their death in 50% of cases.'

*The Guardian* (June 1998)  
reporting a study by Dr  
Slotkin at Duke University,  
North Carolina, USA

# Programmes for children with intra-uterine drug exposure in the USA

- Project Strive
- The Early Infant Transition Center
- Home-U-Go Safely

*(Belcher et al., 2005)*

# The Perils of Alcohol in Pregnancy

**“.... Even moderate consumption of alcohol had a serious effect on the formation of the body’s central nervous system. This indicates that the nerve pathways in the brain have been damaged”.**

*Lecture given by Professor Peter Hepper, University of Belfast,  
Foetal Behaviour Research Unit to the Royal Society of Medicine*

*16 November 2005*

**Hepper's study appears to corroborate US research, conducted after birth, which shows that drinking during pregnancy lowers a child's IQ and increases hyperactivity.**

*Hepper, P. G., Dornan, J. C. & Little, J. F. (2005)*

**Maternal alcohol consumption during pregnancy may delay the development of spontaneous foetal startle behaviour**

*Physiology & Behaviour, 83, 711-714*

# Foetal Alcohol Syndrome

## How is it caused?

- Alcohol is a teratogen.
- It crosses the placenta within 10–15 minutes of an alcoholic drink being consumed. Umbilicus goes white and flaccid.
- One unit of alcohol remains in the mother's system for approx. 1 hour (longer in a baby's).
- Results in reduction of brain cells and migration of cells to the wrong place.



**‘Social levels of drinking can have lifelong impacts on offspring health and development’.**

*Ann Streissguth, 2005*

***Her recent research has shown that ...***

**“abnormalities in the corpus collosum, which transmits signals between the brain’s left and right hemispheres, can affect executive functioning and motor skill development”**

*(CHDD, 2005)*

# Foetal Alcohol Spectrum Disorder (FASD)

- FASD is the single biggest cause of non-genetic learning disability.
- 1 in 300 children are affected (1 in 666 children with Down's syndrome).
- In the UK, this amounts to 600–1,200 occurrences per annum.
- England has the biggest binge-drinking, female population in the world. A quarter of women aged 16–24 years drink more than 21 units of alcohol per week. (14 units is the recommended maximum.) (*Health Survey for England, 2003*)

***Continued.../***

- Excess drinking lowers babies' birth weights – more than 20 units of alcohol causes intellectual impairment. Babies with FASD have substantially smaller brains than average.
- In France, legislation demands that health warnings are displayed on alcohol bottles.
- In the US, the warning on alcohol bottles states:
- 'Drinking while pregnant is overly risky for the foetus: it is the major cause of mental retardation.'

Sources:

*Dr Moira Plant, Alcohol Research Group, Tommy's Charity, London*

*Dr Raya Mukherjee, St George's Medical School, London*

**FURTHER INFORMATION:** [www.fasaware.co.uk](http://www.fasaware.co.uk) / [www.nofas.org](http://www.nofas.org)

# How common is FAS?

- Sweden – 1 in 600 live births
- France – 1 in 1,000
- Seattle – 1 in 700
- New York State – 1–5 per 1,000 live births
- Russia – 15 per 1,000 live births
- Native American reservation – 1 in 97
- Highest reported – 1 in 8 (Native Canadian village)

'Data from the Births Defects Register and Rural Paediatric Service Database in Western Australia indicate a prevalence of 0.02 per 1000 for non-Indigenous West Australians and 2.76 per 1000 for Indigenous West Australians'

**Australian National Council on Drugs/National Expert  
Advisory Committee on Alcohol (2003) *Fetal Alcohol  
Syndrome: National Workshop 2002*  
Canberra, Australia: Australian National Council on Drugs**

The prevalence of FAS/FAE amongst children born in New Zealand is not well known. One report estimates that each year in New Zealand there are up to 360 births of children whose development has been affected by their mother's drinking during pregnancy (Curtis 1994). This is more than the combined annual total of all children born with cystic fibrosis, cerebral palsy and Down's Syndrome

**Alcohol Advisory Council of New Zealand/New Zealand  
Ministry of Health (2001) *National Alcohol Strategy 2000-2003*.  
Wellington: Alcohol Advisory Council of New Zealand / New  
Zealand Ministry of Health**

In New Zealand,  
recently reported  
figures suggest a 90%  
survival rate for pre-  
term infants  
less than 1,500 grams,  
with a  
63% disability factor.

*(Woodward et al., 2003)*

# EPIcure UK Study

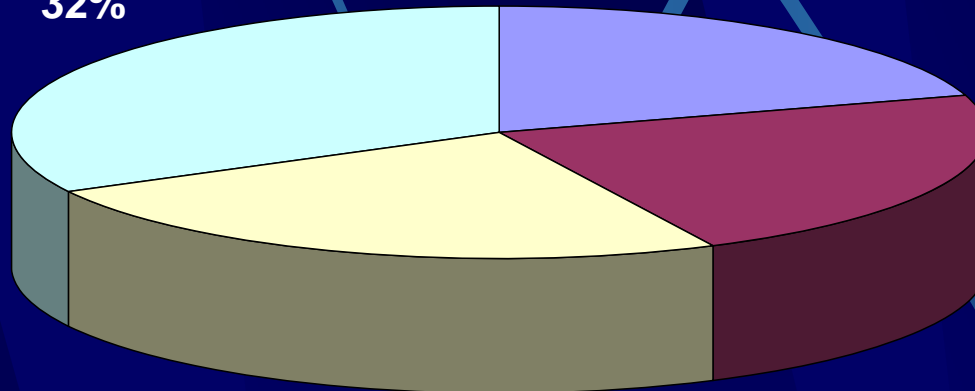
- Established 1995
- 80% survival of children born at less than 26 weeks
- Longitudinal study
- <http://www.nottingham.ac.uk/human-development/EPIcure/>

*(Marlow et al., 2005)*



**Low normal  
scores/ mild  
impairments  
32%**

**No problems  
22%**



**Severe  
disability  
22%**

**Moderate disability  
24%**

**Proportion of children with disability out of  
241 children seen at 6 years  
by comparison with their classmates (Marlow et al., 2005)**

'The first year of life  
gives you the  
organisational pattern  
of how you cope with  
external stimuli.'

*Patricia Champion (New Zealand) (2005)*  
*In B. Carpenter and J. Egerton*  
*Early Childhood Intervention*  
*Worcs: Sunfield Publications*

**A newborn infant that is not touched for two weeks will be severely traumatised, while this very same experience will have little impact on an adolescent.**

*Greenspan and Shanker, (2004)  
Brisch, (2002); Champion, (2005)*

'early repeated and prolonged pain exposure may contribute to altered development of pain systems, behaviour, cognition and learning in former pre-term infants in later childhood'

Grunau, R., Weinberg, J., Whitfield, M.F. (2005)  
*Paediatrics*, 114, (1), 77-84

# Emotions experienced by both parents of pre-term infant

- **Terror**
- **Guilt**
- **Depression**
- **Grief**
- **Impotence**
- **Intense fatigue**
- **Anger**
- **Jealousy**
- **Frustration**

'70% of multiple births as a  
result of *in vitro* fertilisation  
result in some form of  
disability.'

(Russell, 1998)

42% of eggs from all women  
have genetic defects that  
could prevent embryos being  
carried to term.

American Society  
for Reproductive Medicine – October  
2005

*reported in 'The Guardian' 19 October 2005*

**‘25 years after the birth of the first baby conceived by *in vitro* fertilisation, our data draws attention to a number of challenges. Firstly, emphasis needs to shift, more than it has already, from achieving a successful pregnancy to achieving a successful outcome [for the child].’**

***(Helmerhorst et al., 2004)***



'There will be many more known genetic causes of disability, most of them rare.'

*(Bailey, 2002)*

**Parents and professionals will need access to comprehensible information about genetics in general and specific disorders in particular.**

*(Barr, 2004)*

# Prevalence of autism

60 per 10,000 (1 in 166) children under 8 years

***Medical Research Council,  
2001***

91 per 10,000 in the total population (1 in every 110 people)

***National Autistic Society,  
2002***

1 in 800 school children (previously 1 in 1,000)

***Department of Health,  
2002***

# The MMR controversy

Outcomes of an analysis of 2000 research studies:

‘We found that [this] study does not establish MMR as a cause of inflammatory bowel disease, autism or developmental regression, and that its hypothesis had been satisfactorily tested by scientifically reliable studies.’

*(Muthu et al., 2002)*

**‘Over recent years there has been a major rise in the rate of diagnosed autism. The main explanation for this is to be found in better ascertainment and a broadening of the diagnostic concept’**

(Rutter, 2005, p. 231)

Rutter, M. (2005) Invited Review: ‘Aetiology of autism: findings and questions’. *Journal of Intellectual Disability Research*, 49 (4), 231-238

**Anxiety is a common problem in people with Autism. Grandin (2000) writes that, at puberty, fear was her main emotion.**

**People with Autism are particularly vulnerable to mental health problems such as anxiety and depression, especially in later adolescence and early adult life.**

*(Tantum and Prestwood, 1999)*

# Attention Deficit Hyperactivity Disorder (ADHD) – recent findings

- ADHD affects 1 in 20 children in the UK (around 500,000 children) (National Institute for Clinical Evidence)
- Further twin studies have indicated the roots of the disorder are 80% genetic.
- Brain scans indicate that ADHD is a biological phenomenon.
- At its severest level, it is a hyperkinetic disorder, (about 100,000 children).
- Increasing prevalence of co-morbidity (e.g. learning difficulties, autism)
- Scans of the right frontal lobes, the basal ganglia and the vermis of the cerebellum are appreciably smaller in children with ADHD.
- These regions involve self-control and inhibit impulsive behaviour.

*Continued.../*

- **7 million school children in the USA – nearly one in five – are on Ritalin (Angold, 2005)**
- **In the UK prescriptions of Ritalin rose from 2,000 in 1991 to 259,000 in 2004**
- **ADHD is not linked to inadequate parenting.**
- **‘Chaotic environment’ may trigger the condition in genetically susceptible children.**
- **Children with ADHD are four times more likely to experience mental health problems in adulthood.**
- **‘[ADHD] should be seen as a long-term, subtle disability.’**

Sources:

***Professor Eric Taylor (2004),  
Institute of Psychiatry, University of London***

***Mark Henderson and Nigel Hawkes (2004),  
British Association of Science Conference***

***(Reported in ‘Scans show it’s not easy to be good’, The Times, 9<sup>th</sup> September 2004)***



**In a survey of 450 parents by the NAS (2001), 32% said their son/daughter had experienced mental ill health. Of the people affected by mental ill health, 56% had experienced depression, a further 11% a nervous breakdown, and 8% had felt suicidal or attempted suicide.**

# FAS and ADHD

- “We believe that a proportion of children who have ADHD may have developed it as a result of their mother’s drinking during pregnancy”
- “The startle movement (in the womb) is clearly not normal and would seem to indicate the child has the traits of fidgeting which we see in ADHD”

*Margaret Barrow (2005)*

*Clinical Geneticist, Leicester Royal Infirmary, UK*  
*quoted in*

*Carr-Brown, J. and Halle, M. (2005) 'Twitches that indicate alcohol may hurt babies', The Sunday Times, November 20*

*(<http://www.acbr.com/fas/AlcoholFetusUltrasound.htm>)*

*Also, Royal Society of Medicine Conference (2005)*

*“Alcohol in the Womb”: The link to FASD*

*<http://www.fasdconnections.ca/id108.htm>*

# The Mental Health of Children and Young People in Great Britain 2004

- About one in 10 children and young people aged five – 16 had a clinically recognisable mental disorder.
- 4 percent of children had an emotional disorder (anxiety or depression)
- 6 percent had a conduct disorder.
- 2 percent had a hyperkinetic disorder.
- 1 percent had a less common disorder such as autism, tics/Tourette's syndrome, eating disorders and elective mutism.

*Continued...*


- **Some children (2 percent) had more than one type of disorder.**
- **Boys were more likely to have a mental disorder than girls. Among five to 19 year olds, 10 percent of boys and 5 percent of girls had a mental disorder. In the older age group of 11-16 year olds, the proportions were 13 percent for boys and 10 percent for girls.**
- **The prevalence of mental disorders was greater among children and young people living in low income high unemployment areas classed as 'hard pressed' (15 percent) compared with affluent areas classed as 'wealthy achievers' or 'urban prosperity' (6 percent and 7 percent)**

*Office of National Statistics (2005)*

[www.statistics.gov.uk/statbase/product.asp?vlnk=14116](http://www.statistics.gov.uk/statbase/product.asp?vlnk=14116)

'One in five children have SEN, but children with SEN are three times more likely to have mental problems.'

*(Office of National Statistics, 2000)*



'4 in 10 young people with learning disabilities [in the age range 13–25 years old] will develop a mental health problem.'

*From Count Us In: The National Inquiry into the Mental Health Needs of Young People with Learning Disabilities*

# Social competence and mental health

- 25–35% of young children with an intellectual delay exhibit behaviour problems.
- 60–65% exhibit peer interaction problems.
- Quality of life issues are a major consequence.
- There is limited research in this area, and priority is needed.

*Guralnick, M. (2004) 'Early Intervention for children with intellectual disabilities: current knowledge and future prospects.' Keynote address to the 12<sup>th</sup> IASSID World Congress, Montpellier, France (June)*

# The Mental Health Problems of Young Children (DfES, 2002)

- Emotional disorders, e.g. anxiety states, phobias and depression
- Conduct disorders, e.g. aggression, defiance, anti-social behaviour
- Hyperkinetic disorders, e.g. disturbance of activity and attention
- Developmental disorders, e.g. delay in acquiring certain skills such as speech, social ability or bladder control
- Attachment disorders, e.g. children who are markedly distressed or socially impaired as a result of extremely abnormal pattern of attachment to parents or major caregivers
- Eating disorders, e.g. pre-school eating problems
- Habit disorders, e.g. sleeping problems, soiling, spontaneous urination
- <http://www.dfes.gov.uk/publications/>



# Challenges Facing Early Intervention



# The Agenda for Development in Early Childhood Intervention

Principle 2: Integration and coordination at all levels of the Early Childhood Intervention system is essential

# Agenda:

- Training on team process
  - evolving transdisciplinary models based on respect for, and contributions of various disciplines.
- Develop new models for collaboration
  - collaborative consultation
  - Team-around-the-child (Limbrick, 2005)
  - Coaching (Espe-Schwindt, 2005)
- Establish leadership groups at every service level to promote co-ordination and integration

# Barriers:

- Professional identification and training
- Administrative challenges to involve new agencies and professions (e.g. Mental Health)

*Michael Guralnick (2005)*

*'An Agenda for Early Intervention: An International Perspective'*  
*Keynote address to the European Conference on Early Childhood Intervention, Birmingham, UK*

*28/29 November 2005*

<http://www.sunfield-school.org.uk/eci/conference.htm>

# Fathers.... of children with disabilities.....

- The secondary partner
- The peripheral parent
- The 'hard to reach' parent
- The invisible parent

# 'Recognising Fathers' Research project

A few early findings:

- Fathers are keen to talk about their experiences – little previous opportunity
- Services and organisations are wanting to involve fathers
- A number of fathers' groups exist around the country – run by men/fathers (e.g. SunDads)
- [www.learningdisabilities.co.uk](http://www.learningdisabilities.co.uk)
- A briefing sheet  
[www.scie.org.uk?publications/briefings](http://www.scie.org.uk?publications/briefings)

**We need to remember however that**

**‘EVERY CHILD MATTERS’**

[www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)

**We want them to...**

**be healthy,**

**stay safe,**

**enjoy and achieve,**

**make a positive contribution, and**

**achieve economic well-being.**

'High quality service delivery to our most vulnerable children and their families can only be achieved by a well-trained and highly skilled workforce in the context of society's response'

*Carpenter and Campbell (2006)  
'Infants and Young Children' (in press)*



# The key to successful Early Childhood Intervention is responsiveness

- to society
- to its families
- but most of all to its children

Carpenter, B. (2005)

*'Early Childhood Intervention: possibilities and prospects for professionals, families and children'*

in B. Carpenter and J. Egerton (Eds) *Early Childhood Intervention: International Perspectives, National Initiatives and Regional Practice*