ISWA Working in Partnership towards Solutions
MANCHESTER

1st December, 2006

ASSESSING PARENTS WITH LEARNING DISABILITIES

Sue McGaw

Special Parenting Service
Cornwall Partnership NHS Trust
www.cornwall.nhs.uk/specialparentingservices
Special Parenting Service
Truro, Cornwall

- Founded 1988
- Funded by NHS, UK
- Multi-disciplinary team
- 2,500 ID Population
- Parents ID unknown
- Over 1000 families with ID
Special Parenting Service
Cornwall

SPECIAL PARENTING SERVICE
100 Families a Year
50 Families any one time

Initial Assessment
Parent Assessment Manual
4 Visits: 8 hrs

Capacity Assessment
8 hrs

Home-Based Intervention

Post-intervention Assessment

Group Programme

Evaluation Feedback

Truro FE College
"Open Doors"

Home-based: Sure Start 0-16 yrs.

Research
DoH Steering Group - J.Rowntrees
Service Evaluations & Publications
Professional Training
Media storm puts pressure on Essex

Essex County Council's decision to take the children of a couple with learning difficulties and low IQ into care has provoked a furious reaction from the press, but what implications does the case have for the sector as a whole? Ruth Smith investigates

Hysterical press coverage of child protection cases is nothing new. But "Victims of the child snatchers," a typical headline from the Daily Mail's crusade against Essex County Council's decision to place two children for adoption, has provoked outrage across the sector. The Essex case came to the Mail's attention after a High Court judge agreed with Essex social services that a four-year-old girl and 14-month-old boy would be at risk of harm if they remained with their parents. The mother has learning difficulties and the father a low IQ.

BAAF Adoption & Fostering has described the coverage as "dangerous and wrong" and has written to MPs to highlight its concerns. "These accusations will fuel mistrust in the system and could lead to fewer parents in need of help coming forward," it warns.

Getting to the real issue
But correcting irresponsible articles has eclipsed debate on the wider issue that the Essex case raises: what is the role of local authorities and family courts when parents are not actively harming their children, but are failing to support them effectively? Essex's record track record on adoption and child protection is described as strong by the Commission for Social Care Inspection, which stressed the range of support it gives to families.

"In most cases our staff work to support families and ensure children stay with their parents," says councillor Eunice Chapman, the cabinet member for children's services at the Conservative-controlled council.

In this case, the judge agreed with Essex's stance, saying: "The tragedy is that the parents are unable, even when the most concentrated and intensive support is deployed, to assist them, to adequately manage the day-to-day care of their children."

But is it clear whether there is consistency in support services for parents with learning disabilities across the UK? "It varies," says Anthony Douglas, chief executive of CareLeaves, the Children and Family Court Advisory and Support Service, and chair of BAAF Adoption & Fostering. And it is not just learning disabilities. "The number of children subject to care proceedings doesn't vary, according to the obvious criteria, there are reasons why the levels vary, which are worth examining," he says.

"It would be good to have more research on whether those parts of the country with good support services are not just able to keep the children at home, but are also better at positive parenting programmes to parents with learning disabilities and secure better housing and support networks for them."

The Daily Mail has attacked the council's decision, saying: "Essex County Council cannot be good parents but they need support."

Volunteers provide general support to help parents with learning disabilities bring up their children. "They offer practical support, such as helping them attend parent and toddler groups," explains Newton.

Links between adult and children's services is another issue highlighted by the Essex case. "It isn't a concern," says Dougall. "Especially as adult and children's services split off from each other because the degree of joint working between community learning disability teams and family court or childcare teams is patchy."

But the relationship needs to be sold to parents so they can be given an integrated service," Ian Johnson, director of the British Association of Social Workers, agrees.

There should be good links between the two. "But the whole of social work is understaffed, with a high staff turnover so staff don't always have time to invest in these relationships," he says.

The legal viewpoint
Legally, following a European Court of Human Rights ruling in February 2002, the Government must make a greater effort to support parents with learning disabilities before taking a child away from them.

"As far as I know, it's the only case of parents with learning disabilities that has gone this far," says Liz Goldthorpe, the chair of the Association of Lawyers for Children. Although the European case must be read with care since it relates to a German family, under the Human Rights Act 1998 the ruling is applicable to UK cases. Despite support for the parents from an early stage, the European court said it was not enough had been done to help keep their children and ruled there had been a violation of Article 8 of the European Convention on Human Rights, the right to respect for private and family life.

But getting that balance right is difficult, says Goldthorpe. "How long do you give on testing the situation when you should be putting children first," she asks.

Key statistics

- Parental illness or disability accounts for six per cent of looked-after children
- Abuse or neglect accounts for 20 per cent of looked-after children
- Source: Department for Education and Skills

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31 August-6 September 2005 | Children's News | 9
Can Parents with LD parent?

1. Purposeful abuse infrequent by parents (Booths, 2005; Whitman 1994)
2. Neglect - omission not commission (Booths, 2005; Tymchuk & Andron, 1990)
3. Parental Risk Factors:
   - Cognitive functioning & ability to learn (Tymchuk, 1992; Feldman, 1997)
   - Discrepancy between parent’s knowledge, skills, experiences & children’s needs (Bakken 1993; McGaw 1999)
   - Vulnerability to psychopathology (Tymchuk 1993; McGaw et al., 2005)
   - Poverty, stress, poor social supports (Feldman, 1997; Denny et al 2001)
   - Main predictor of abuse/neglect (Schilling1982; Lewellyn,1995; McGaw 2005)
Children Outcomes?

Developmental Delays
- Genetic vulnerability (Reed 1965; Scally, 1975, Garber & Heber, 1977)
- Developmental delays (Cleaver, 2005)
- Cognitive & Language skills (Feldman 1986)
- Boys more vulnerable than girls to behavioural problems (Feldman, 1997)
  - Low IQ mothers with children with higher IQs:
    - More involved/responsive; More restrictive/punitive
  - Low IQ mothers with children with low IQs:
    - Less concerned/interactive; Less restrictive/not punitive

Psychopathology & Mental Disorders
- CPR registration & mental disorders (McGaw, Shaw & Beckley, 2006)
  - 79% CPR emotional abuse (parents with childhood trauma)
  - 67% Attention deficits across children of parents (depression) vs. 32% (no depression)
  - 39% Conduct disorders children (parents OCD) vs. 6% (no OCD)
  - 64% Anxiety disorders children (parents anxiety disorder) vs. 56% (no anxiety)
  - 92% Autism children (parental depression vs. 33% (no depression

- “Huck Finn” Syndrome (O’Neil, 1985)

Long Term Outcomes (Booth & Booth 1997; Ray et al, 1994)
Court Issues

- Court systems disadvantage parents LD
  (Tartleton, Ward & Howarth, 2006)
- Discrimination in child protection proceedings
  (Booths et al. 2005; Taylor et al., 1991; McConnell & Llewellyn, 2000)
- Cases of substantiated abuse/neglect
  (Booth, et al. 2005; McConnell & Llewellyn, 2000)

“Decision-Making & Parents with Learning Disabilities”
Dr. Sue McGaw & Dr. Sue Candy
In: People with Learning Disabilities: Capacity to Make Decisions
Eds. Glynis Murphy & Isabel Clare, Wiley. 2006.
Service Issues

“Children Living with Learning Disabled Parents”
Cleaver & Nicholson, 2005, DFES

- Referral patterns
- Lack of specialist input & specialist tools
- Poor use specialist tools/methodologies-multi-agency assessments
- Poor collaboration between LD teams & Children/Family Teams
- Poor use of joint-commissioning & funding between child/adult services
- Need to improve resources, training programmes & understanding re co-morbidity
Study of families & factors:
High Risk vs. Low Risk Families

- Retrospective study (n = 101 parents IQ < 75)
- Comparison groups i) Parents, ii) Professionals, iii) Special Parenting Service
- Measures:
  a) Parent Assessment Manual – Perception of Family Need
     “I Need Help” & “Initial Screening Tool”
  b) Demographic Variables
     • Parent data: IQ, disabilities/mental health/childhood histories
     • Children data: special needs, no.in family/removed, child protection reg.
     • Socio-economic status, housing, state benefits, amenities, car owner
     • Partner relationships/support/resources
Parenting Assessments

- **Parenting assessments** - no one assessment covering multi-complex needs, subjective, ad hoc, poor predictors of capacity

- **Government assessments** - checklists/frameworks – general guidance

- **Standardised parenting assessments/related** - limited breadth
  (Parenting Stress Index/HOME Inventory/Webster-Carol Stratton)

- **Specialised parenting assessments** - non-standardised
  (Red Cross Programme/Esprit/Tymchuk/Feldman)

- **Functional/Diagnostic/Ecological models**
Knowledge/Skills/Practice Contingency

- **Knowledge**: Parents’ ability to acquire & retain knowledge
- **Skills**: Parents’ ability to transfer knowledge to skills
- **Practice**: Parent’s ability to maintain & generalise skills
PAM is a structured wide-ranging functional & multi-dimensional parenting assessment

PAM is aimed at vulnerable families: children (0-19 years) & their parents

PAM assesses 333 skills (364 incl. sub-skills) focusing on Parenting Knowledge-Skills-Practice for each parent/jointly couple

PAM provides Child/Parent Profiles & Teaching Programmes electronically

PAM is a quick accurate tool for measuring baselines & teaching evaluations
## GENERAL SAFETY

### PARENTS KNOWLEDGE

**Parent knows what to do in the event of:**

1. **A CLOTHES FIRE**
   - Good Knowledge (scores 4/3)
   - Adequate Knowledge (scores 2)
   - Poor Knowledge (scores 1/0)

### SKILLS

1. **Parent takes appropriate action when accidents/emergencies occur.**
   - Parent Booklet
   - Observation
   - Good Skill
   - Adequate Skill
   - Poor Skill
   - Child observed playing with lighter

2. **Matches/firelighters are kept out of child's reach.**
   - Observation
   - Good Skill
   - Adequate Skill
   - Poor Skill
   - Child observed playing with lighter

3. **Hot cups/ashtrays etc. are not left within reach.**
   - Observation
   - Good Skill
   - Adequate Skill
   - Poor Skill
   - Hot cups on the floor, knocked over near children

4. **Parent can turn off/reset mains supplies e.g. gas, electrics, water.**
   - Observation
   - Good Skill
   - Adequate Skill
   - Poor Skill

5. **Parent can change fuse.**
   - Observation
   - Good Skill
   - Adequate Skill
   - Poor Skill

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**PRACTICE**

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<th>Agreed Frequency</th>
<th>Actual Frequency</th>
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**Priority Rating**

- ☐ C
- ☑ 1
- ☑ 2
- ☑ 3

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**GENERAL SAFETY 23 (Skills 1-5)** 75
### Observation Form

**Quality & Frequency of Practice**

**Name of Parent:** Mary Smith  
**Completed by:** Chantal Bailie  
**Setting:** Home  
**Date:** 22.9.2003

**Instructions**
1. Insert 3 in Good/Adequate/Poor columns each time skill is observed (e.g. 333 = 4)
2. Use key to define quality of practice (Good/Adequate/Poor)
3. Total columns to show overall frequency

**Key:**
- **GOOD SKILL:** Skill demonstrated well without help
- **ADEQUATE SKILL:** Skill demonstrated but parent needed reminding
- **POOR SKILL:** Skill not attempted/attempted but unsuccessful

<table>
<thead>
<tr>
<th>PARENT/CHILD PROFILE</th>
<th>PRACTICE</th>
<th>COMMENTS</th>
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<tr>
<td><strong>SKILL</strong></td>
<td><strong>DATE</strong></td>
<td><strong>GOOD</strong></td>
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<td>Parent makes eye contact with baby for 5 minutes.</td>
<td>27.8.03</td>
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<td></td>
<td>1.9.03</td>
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<td>20.10/03</td>
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## Child Profile

**Parent:** Sam & Jon  
**Assessor:** Tamara  
**Date:** July 2003

### Physical Health & Development

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<tr>
<td>0-12 Months</td>
<td>19 skills</td>
<td>16 skills</td>
<td>17 skills</td>
<td>05 skills</td>
<td>15 skills</td>
<td>11 skills</td>
<td>23 skills</td>
<td>24 skills</td>
<td>07 skills</td>
<td>20 skills</td>
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<tr>
<td>1-5 Years</td>
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### Emotional Care & Development

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<tr>
<th>Stimulations</th>
<th>Guidance &amp; Control</th>
<th>Respons &amp; Indepen</th>
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<tbody>
<tr>
<td>01</td>
<td>02</td>
<td>03</td>
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</tbody>
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### Notes:
1. **Mother** (above diagonal line)  
2. **Father** (below diagonal line)

All skills scoring boxes are bisected by a diagonal line. Above the diagonal scores as **Mother**, below the diagonal scores as **Father**.

- **Core Skills**: Check if Core Skills from earlier age bands apply.

- **Priority Rating**
  - **1=High Priority**
  - **2=Medium Priority**
  - **3=Low Priority**
  - **C=Criterion Reached**
## Parent Profile

<table>
<thead>
<tr>
<th>Parent Support &amp; Resources</th>
<th>Knowledge</th>
<th>Skills</th>
<th>Practice</th>
<th>Priority Rating</th>
<th>(Mother/Father) X</th>
<th>Skill Not Assessed</th>
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<td>SUPPORT &amp; RESOURCES</td>
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<td>3</td>
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<td></td>
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<td>3</td>
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### TARGETED SKILLS

**in priority order**

- **2/2**. Parent can manage conflict with others.

Parent's best priority ratings from a total of 224 joint skills assessed

0% 5% 8% 39%
### Targeted Skills

**FEEDING - (Mother/Father) X - Skill Not Assessed**

- Parent feeds baby appropriately
- Parent provides three nutritious meals a day (CS)
- Parent provides nutritious snacks for child (CS)
- Parent can prepare a bottle for feeding
- Parent made sufficient bottle-feeds to feed baby throughout day
- Parent encourages child to eat with a knife, fork and spoon (CS)
- Parent ensures that child eats a balanced diet (CS)

**HEALTHCARE GENERAL - (Mother/Father) X - Skill Not Assessed**

- Parent is able to use medicines appropriately (CS)
- Parent recognises and deals with nappy rash
- Parent recognises and deals with cradle cap
- Parent recognises and deals with teething problems
- Parent keeps appointments for developmental checks (CS), e.g. dentist, optician health visitor
- Parent takes appropriate action to reduce temperature (CS)

**HEALTHCARE HYGIENE - (Mother/Father) X - Skill Not Assessed**

- Parent sterilizes feeding equipment
- Parent changes nappies appropriately
- Parent disposes of dirty nappies
- Parent ensures that child's nails are cut (CS)
- Parent ensures that child's teeth are brushed (CS)
- Parent encourages child to sit on potty for a few minutes
- Parent encourages child to wash and wipe hands after using the toilet/potty
- Parent encourages child to sort own clothes for washing
- Parent encourages child to put away clean clothes
- Parent ensures child is bathed/washed appropriately (CS)

**HEALTHCARE WARMTH - (Mother/Father) X - Skill Not Assessed**

- Parent dresses child appropriately for cold/warm weather (CS)
- Parent ensures the temperature of the child's bedroom is suitable (CS)
- Parent encourages child to wear appropriate clothing to school
Assessment & Capacity Teaching Programme
- Quality of Engagement & Perception of Need
- Parents/Child’s Intellectual/Physical/Emotional functioning
- Identify Parents’ Learning Style
- Target 3/4 Skills
- Skills Baseline
- Teach & Record Skills over 8 weeks
- Summarise Findings

Long-Term Family Support Programme
- Home-Based Programme + Group + POD
- Refer On
- Ongoing PAM Evaluation & Assessment
FAMILY CASE STUDY
PARENT ASSESSMENT MANUAL

MEASURES PARENTING
- Shorter & precise
- Evidence-based
- Defendable

CURRENT PRACTICE

DIAGNOSTIC
- Functioning

Measurable Teaching Programme
DISABLED PARENTS NETWORK
WWW.DisabledParentsNetwork.org.uk

• Newsletters
• Publications
• Lobby Group

The right support
Report of the Task Force on Supporting Disabled Adults in their Parenting Role
Jenny Morris
KEY FINDINGS

1. Wide variety of agencies & professionals involved parents LD
2. Professionals facing barriers to provision of appropriate support to parents
3. Holistic & wide ranging support
4. Court processes too complicated
5. Professionals training
6. Eligibility criteria “too low”
7. Need to “spread” good practice
• What’s the Problem
• What helps people with LD to be good parents
• What should the government be doing
• Policies & Services which help parents with LD
Teaching Parenting

I Want to be a Good Parent

Sue McGaw

Five illustrated booklets, giving practical and easy to follow advice for parents with learning disabilities.

Book 1  What’s it like to be a parent?
Book 2  Children need healthy food
Book 3  Children need to be clean, healthy and warm
Book 4  Children need to be safe
Book 5  Children need love

1995  See order form for ISBN numbers
BILD members £9.00 each or £40.50 the set
Full price £10.00 each or £45.00 the set
People with Learning Disabilities:
Capacity to Make Decisions:
Eds. Prof. Glynis Murphy & Isobel Clare.
Publishers: Wiley

1. Right to Private & Family Life
2. Professional systems confusing
3. Choosing a solicitor
4. Twin-tracking
5. Co-operation
6. Contesting applications for adoption

Decision-making & Parents with Learning Disabilities
Dr. Sue McGaw & Dr. Sue Candy
The Court and your child:
when social workers get involved
easy words and pictures
Summary

- **Flexibility & imagination:** *1989 Children Act, Assessment Framework; 1990 NHS & Community Care Act; Fair Access to Care Services*
- **Allocation of assessments:** *identify skills & experiences; knowledge gaps*
- **Quality of assessments:** *models/tools, needs/parent led & family centred*
- **Risk & discrimination in assessments:** *competence; risk outcomes; standards*
- **Child protection systems & court arena:** *facilitate & enable parents*

"Think Parent: Supporting Disabled Adults as Parents"

"What Works for Parents with Learning Disabilities"

"Support Services for Parents with Learning Difficulties"
2006. Tarleton, Ward & Howarth, Norah Fry