



**Right From The Start**   
**Template** good practice in  
sharing the news

Time to get equal

**scope**

About cerebral palsy.  
For disabled people achieving equality.

In partnership with the  
Right From The Start Working Group



Special thanks to all those who agreed to have their photos featured in the Template.

“I think that conveying difficult news to parents is just as much of an art form as doing an operation and it’s just as important to be self-critical.”

Professor Sir David Hall  
President of the Royal College of Paediatrics  
and Child Health 2000 – 2003  
Patron, Scope



## Foreword

*Roger Thompson, Education Adviser, Nursing & Midwifery Council  
and Chair of the Right From The Start Working Group*

The Right From The Start report examined parents' first experiences of hearing of their child's additional needs\*. Research and other evidence had highlighted very mixed professional practice in sharing such significant news. As a result Scope initiated a national working group of parents, professionals and disabled people committed to influencing policy and practice in this area.

A range of national and local initiatives including conferences, workshops, training events, audit programmes and good practice guidelines have subsequently been developed, disseminated and evaluated.

This template is a working document, founded on respect for parents and the value of their children as children first and foremost. It offers a framework for organisations to develop effective policies and procedures that ensure a quality service and to encourage individuals working in this area to continuously reflect on and enhance their practice. Effective communication at this sensitive time is central to establishing positive relationships between parents, professionals and the child.

The Right From The Start project continues to evolve, heightening awareness and creating and nurturing new networks. However, the issues are not yet fully resolved. The impact of the news of a child's additional needs is critical to the lives of parents, children and their families. Please use this document to make what improvements you can to enhance the lives of disabled children and their parents and the work of professionals supporting them, to ensure inclusive practice, right from the start.

**\*Additional needs** encompasses a wide range of conditions including physical impairments, sensory impairments, developmental delay, learning difficulties, behavioural difficulties and complex health needs. This phrase was adopted following consultation with parents and disabled people.



## Endorsement

*Professor Sir David Hall, President of the Royal College of Paediatrics and Child Health 2000 – 2003*

When I began my first training post in paediatrics there were many doctors who believed that parents should not be told when their child was thought to have a disabling condition or serious illness. They believed it would be kindest to keep the parents in ignorance for as long as possible. When eventually it became obvious to the parents that there really was a serious problem, the information given was often scanty, inadequate and incomprehensible.

Largely through the efforts of parents and voluntary organisations, we have come a long way since then. Listening to parents, talking to children and respecting the rights of individuals to accessible information are now part of mainstream health professional training but there is still some way to go before we can be confident that we have put our house in order across the whole spectrum of healthcare.

The principles set out in the template are based on what we have learned from parents and disabled people, both by listening to individuals and in formal research studies. They are underpinned by solid evidence. It is the duty of all of us to make sure that we and our colleagues and trainees try to live up to these standards. Everyone who works in this field should be monitoring their own performance and aiming constantly to improve it.

“Despite publication of research and recommendations on good practice, this remains a subject of dissatisfaction to a significant number of families.”

NHS Executive Guide to Good Practice: Child Health in the Community



## Sharing the news: key principles

### Valuing the child

- All children are unique – it is vital that professionals see the child first and their condition/disability second
- The child's name should be used at all times
- Keep discussions about the child positive and avoid making predictions
- Whenever possible keep the baby or child with the parents when sharing the findings and diagnosis
- If it is not appropriate for the baby or child to be present, remember to communicate in a way that shows respect for the child
- When sharing the news of additional needs identified in an older child, consideration should be given as to whether the child should be present

“I made a decision to portray my daughter in a positive light – if she's my daughter and I think it's awful news, how can I expect anyone else to be delighted with her?”

A parent





## Sharing the news: key principles



“They (parents) need to be treated with dignity as individuals who have the right to respect and not as stereotypes.”

A parent

### **Respect parents and families**

- Support and empower parents
- Treat all parents’ concerns seriously
- Listen to parents and share information sensitively and honestly
- Use plain and understandable language and give explanations to build parents’ confidence
- Acknowledge and respect cultural difference
- Give opportunities to ask questions and check parents’ understanding of their situation
- Avoid giving negative non-verbal messages before concerns have been shared with parents



## Good practice framework

“An enabling approach to working with families requires that professionals re-examine traditional roles and practices and develop new ones which promote mutual respect and partnership.”

McGonigel

### **Preparation**

- Allocate time for individual and team preparation prior to specific interviews/consultations
- Families and their circumstances vary enormously so professional teams need to share their knowledge of the family in order that the news is shared sensitively and effectively

### **Who should be present?**

- Evidence shows that parents, wherever possible, prefer to hear the news together and always in private
- It may be appropriate for another family member or friend to be there in support of one or both parents
- If it is unavoidable that a parent is alone, a member of the team should be present to support the parent during and after sharing the news
- When an unaccompanied parent has heard the news alone, arrangements should be made to inform the other parent and close family members as soon as possible
- The number of staff involved should be kept to a minimum, ideally the person responsible for sharing the news and one additional team member known to family
- If an interpreter is required care should be taken in their selection and on no account should a family member be expected to undertake this role

### **Tuning in to the parents: effective communication**

- Parents' reactions vary enormously and cannot be predicted
- Professionals need to be well prepared and confident to share the news, whilst flexible enough to respond to parents' needs
- Time and space should be available for parents to reflect on the news and meet again with a member of the team if they wish



## Good practice framework

### **Next steps: practical help and information**

- A record of the initial discussion should be made available to parents and their general practitioner. This could be in written or audio formats, but always in the parents' first language
- Contact details should be provided at the initial meeting and parents should be encouraged to ask further questions as they arise
- An early follow-up appointment should be arranged at the end of the initial meeting
- Written information should be provided at an early stage about:
  - the child's condition
  - statutory and voluntary services
  - practical and emotional support
- Support should be offered to parents to enable them to share the news with other family members and friends
- Parents should be made aware of their right to seek other professional opinions
- Early contact should be established between hospital-based and community services

“They (parents) want, and have a right to, full information about the services and benefits available... conveyed in a manner which recognises their lack of familiarity with systems and procedures that are complex and potentially daunting.”

Anne Leonard



## Good practice framework

### Support for professionals

- Acknowledge and address personal and professional development needs
- Ensure staff participate in training, clinical supervision and continuous professional development
- Promote inter-professional practice, mutual support and sharing good practice
- Give opportunities for de-briefing for all team members following meetings with parents
- Identify, acknowledge and seek to address inequalities between professionals and parents
- Promote an ethos of continuous quality improvement and auditing of practice

“It’s my preferred practice to always do the difficult job of sharing the news with at least one professional colleague... it means that we can do a good debrief afterwards and both go on learning and improving, by reflecting together after the event.”

Professor Sir David Hall





## Right From The Start resources

Information and support are available to assist the development of your practice, through audit or training for your service/team in the communication of a child's additional needs.

### **The following resources are available:**

- Right From The Start report (1994)
- Right From The Start Template (2006 edition)
- Audit Programme
- Further reading
- 'Sharing Concerns' video (West Birmingham Portage Service Parents Group and the University of Central England)
- Promotional material – Parents Charter
- Website: [www.scope.org.uk/earlyyears](http://www.scope.org.uk/earlyyears)

### **The following support can be provided by negotiation:**

- Conferences/workshops/meetings
- Development of policies/protocols/guidelines/procedures
- Audit of current service
- Training

### **Working group membership includes:**

Parents and disabled people and representatives from the following:

#### **Voluntary organisations**

Scope  
Mencap  
RNIB  
RNID  
National Autistic Society  
Contact a Family  
Down's Syndrome Association  
HemiHelp  
Barnardo's  
ASBAH  
Association of Disabled Professionals

#### **Professional bodies**

Royal College of Paediatrics and Child Health (RCPCH)  
Royal College of Nursing (RCN)  
Royal College of General Practitioners (RCGP)  
Royal College of Midwives (RCM)  
Nursing & Midwifery Council (NMC)  
Community Practitioners' and Health Visitors' Association (CPHVA)



“Parents are people who have children; parents of children with special needs are no different from other parents. They come in all shapes and sizes, ages, walks of life, backgrounds and cultures... they are simply parents.”

A parent



“I think we should be teaching that every child is an individual... a baby is a baby... I think we ought to develop a common attitude: that is my baby and I’m proud of him, no matter what.”

Alan Counsell

Teacher, advisor, counsellor and a disabled person

### Contact:

Early Years  
Scope  
6 Market Road  
London N7 9PW

Tel: 020 7619 7100  
Email: [earlyyears@scope.org.uk](mailto:earlyyears@scope.org.uk)  
Website: [www.scope.org.uk/earlyyears](http://www.scope.org.uk/earlyyears)

### Scope Response

For information and advice on cerebral palsy, disability issues and Scope’s services, please contact **Scope Response** on **0808 800 3333** or email: [response@scope.org.uk](mailto:response@scope.org.uk)

See the **Scope website** at: [www.scope.org.uk](http://www.scope.org.uk)

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