

RIGHT FROM THE START GUIDANCE AND PROCEDURE

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Integrated Services Project (disabled children, young people and their families)

Right From The Start 
Promoting good practice in the communication of a child's additional needs

Right from the Start – Newham

- * Guidance and procedure for informing parents and carers that their child is or may be disabled. For Newham Primary Care NHS Trust, Newham Healthcare Trust, Child and Adolescent Mental Health Service, and integrated services with disabled children, young people and their families in Newham.
- * A checklist of good practice from SCOPE and the Royal College of Paediatrics and Child Health.
- * Leaflet for parents and professionals about local and national services and information for disabled children, young people and their families.

Right from the Start – Newham

Guidance and Procedure

Purpose and background:

This guidance and procedure includes suggestions about how parents and carers¹ can best be told their child has or is likely to have a disability². This may be either during pregnancy, following the birth of the child or during development and adolescence.

In 1994 SCOPE established a working group with other voluntary sector groups, and professionals from the Royal College of Nursing, Royal College of Midwives, British Paediatric Association, and others. The final report (1999) was called 'Right from the Start' (www.rightfromthestart.org.uk).

Good Practice is rooted in 2 primary values:

- the value of the child
- respect for both child and parents.

Good practice depends on good planning and procedure.

The Right from the Start procedure is recommended for use by senior health professionals and all staff across Newham Healthcare NHS Trust, Newham Primary Care NHS Trust, East London and the City Mental Health NHS Trust, and through integrated services with the Local Authority and other agencies.

¹ Carers, other than parents, may include other family members or friends, and may also be foster carers or residential carers employed or contracted through the Local Authority.

² Disability is a generic term to describe children or young people who are diagnosed or may be diagnosed with a condition which is or is likely to lead to a long term functional impairment. This impairment is likely to have an adverse effect on their day-to-day activities (Disability Discrimination Act, 1995; World Health Organisation definition).

Primary points for use of the procedure are:

- * Newham General Hospital maternity wards and Special Care Baby Unit (SCBU), and Rainbow ward.
- * Child Development Centre (Integrated Child Development Service).
- * Newham Child and Family Consultation Service (Child and Adolescent Mental Health Service).
- * Other community and locality children's services, including the epilepsy service, Community Children's Nursing Team, G.P. and health visitor services, schools health services.

This guidance is in addition to, and may be used alongside the 'Breaking Bad News' guidance required by the Royal College of Paediatrics and Child Health.

The procedure will be made accessible to all staff through policies and procedures, and through induction programme of new and locum staff. The procedure will be supported through training and support materials.

Practice Implications:

1. The need for continuity as to which professionals parents meet.
2. Observational and communicational skills and training.
3. Support and training of professionals.
4. Whole team (integrated) approach so that e.g. other professionals working with child and family are aware of diagnoses and treatment and when and how parents have been informed.

5. Recognition of cultural and language differences and appropriate response (e.g. language parents understand; use and training of health advocates).
6. Recognition of cultural, sensory or cognitive differences that may require a different approach (e.g. parents with learning disabilities or hearing impairment).

Right from the Start template

1. Valuing the child

The child is central to the situation. In the case of diagnosis during the early months it is valuable for the baby to be present when being discussed, and responded to in a way that reflects that the child is valued, for example by using the child's name.

In some circumstances either parents or professionals may not feel that it is appropriate, advisable or practicable for the baby or child to be present; it is then all the more important that language and the manner of communicating should reflect respect for the child.

Discussions about the child should have a positive focus.

Predictions about the child's future should be avoided – no one can claim to know what any child's capabilities would prove to be.

2. Respecting parents

Professionals should demonstrate respect, understanding and warmth in their manner towards parents.

Honesty on the part of professionals in sharing information with parents, and acknowledging the limitations of professional knowledge, is essential if respect for parents is to be conveyed effectively. Any uncertainty should be shared.

Plain and understandable language accessible to the parents should be used in giving explanations that will build up parents' confidence to handle the situation. They need ample opportunity to ask questions and explore the situation, a process that should also allow professionals to check whether parents have fully understood what they have been told.

3. Initial concerns

If it is the parents or carers who are concerned about their child; their concerns should be treated seriously and responded to quickly and honestly. Available information should be shared and its limitation acknowledged.

If it is thought that professionals are the first to suspect a disability, their suspicions should be thoroughly discussed with senior staff as a matter of urgency before being shared with parents or carers. Subsequently parents or carers should be included in discussions.

Staff should be made aware of the danger of giving unconscious messages through body language and behaviour before the concern has been shared with parents.

Details of how parents are told will depend on the stage at which diagnosis is made. This will be

reflected in the points that follow.

4. How to tell

Family circumstances vary enormously. Decisions as to how parents are told about a child's disability are best made on the basis of the team's knowledge of each individual family.

The varying cultural needs of families with different ethnic backgrounds need to be carefully and sensitively taken into account and accommodated.

a. Who should be there

Parents report that they would prefer not to be alone when told.

They generally say they would prefer to be told together.

However, this cannot be taken for granted. For example, a child may live with only one parent. For this or many other reasons the parent being told may need the support of a friend or relative, rather than the other parent. Arrangements should take these possibilities into account.

There will be occasions when sharing the concern with only one unaccompanied parent cannot be avoided. In these circumstances it is particularly important that professional support should include ensuring that arrangements are made that take into account the parent's needs for support and practical help immediately following the discussion (e.g. how will the parent get home?).

When only one parent has been told separately, arrangements need to be made for one of the professional team to tell the other parent as quickly as possible, with the agreement of the parent who already knows.

b. Which staff should be involved

Parents' vulnerability and right to privacy should be respected by keeping the number of people involved at the time of being told to a minimum.

Preferably, the senior health professional giving the news (usually but not always the consultant), should be known to the parents. One other member of staff should also be present – once again someone already known to the parents – who would also be available to talk to parents more fully at a later stage. Parents should be given the opportunity to consult expert opinion, as they feel necessary.

The family's general practitioner should be informed of the situation immediately, and provided with the notes of the disclosure meeting and whatever other information is necessary.

c. Tuning in to the parents

Respecting parents' reactions to the news. Once again, parents' reactions vary enormously and cannot be predicted.

Professionals should respect parents' individual reactions and attempt to be aware of them and respond to them appropriately and supportively.

Some parents will need immediate support from a

team member as they may be in a state of shock and do not want to be left alone.

Others may want to be left alone for a while, and will need to be given space. The opportunity to meet one of the professional team again before going home is known to be valuable in these circumstances.

Follow-up (preferably with the same team member) should always be made immediately on the parents' return home with early contact with community teams planned and guaranteed.

d. The need for privacy

Most parents say that privacy is important to them at the time of learning about their child's disability.

It is advisable to find ways and means of giving the news in private. However a mother and baby should not be segregated while in the maternity unit without discussion with the mother in each case. Her wishes should be respected.

e. Written information

Parents should be given notes immediately after the meeting to clarify what was said for future reference. These should be available in the language appropriate to the parents. Either the consultant or the second person should take accurate notes i.e. made by one of the professionals already there – not some one extra. Parents should be told in advance that this will be done.

A telephone number should be given so those parents can ask further questions as necessary.

5. Practical help and information

Parents' information needs will vary. They should be made aware that they may be eligible for various benefits and services, and where they can find out more about these. They should also be told of the support available from social services and education authorities.

Pamphlets should be made available, both about the child's condition and about practical help.

Several longer-term support arrangements should be made e.g. for telling the rest of the family (especially the disabled child's brothers and sisters) and friends.

Contact with another parent (or parents' group) should be offered and made available when the parents indicate they would like such contact.

The needs of parents whose first language is not English must be taken into account throughout all these processes.

Legislation states that parents should be put in touch with relevant voluntary organisations. Parents value the help they have received in this way, but many report that this information was not given to them or only found by chance. Collaboration between professionals and voluntary organisations should ensure that parents benefit fully from the help available through the voluntary sector.

6. Support for professionals

Launch of Newham's Right from the Start procedure.

Copies of Right from the Start procedure/ checklist/ information and contacts leaflet available through procedures manual and for new staff/locum induction.

Copies of Sharing Concerns 2002 - video and training pack, available at specific locations (Maternity Unit/SCBU; Rainbow Ward; CDC resources room; CFCS).

Copies of Right from the Start posters and postcards in staff and public areas.

Multi-disciplinary and agency training programme (available through SCOPE).

Right from the Start/ Integrated Service Project to audit and review.

7. Checklist of standards to be met:

For managers and staff supervisors

1. All families receiving news of their child's disability receive that information from staff working to Right from the Start procedure.
2. All staff, including locum staff, who have contact with children and families and are involved in sharing the news of disability with families are aware and have access to Right from the Start procedure.

For senior health professionals and accompanying staff

3. Checklist and information for all families receiving news of their child's disability:

(The following pages may be copied for child's records and information sheet given to parents)



CHECKLIST for (Child's name and date of birth):

		By:
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a)	Receive the information from a senior health professional (usually child health doctor or consultant)	
b)	Have a second staff member present with whom they are familiar	
c)	Receive information in a language they understand	
d)	Receive information in a quiet and comfortable place.	
e)	Have no interruptions	
f)	Be accompanied by other parent, a relative or friend	
g)	Receive written information	
h)	Receive detailed information within 24 hours of requesting it	
i)	Be put in contact with the Primary Health Care Team (General Practitioner, Health Visitor or School Nurse) who have received a written report of the information shared	
j)	Be offered a second interview with the initial professional team within 48 hours	
k)	Receive a contact phone number for further help if required	
l)	Be put in contact with voluntary organisations who may be able to assist them	
m)	Be aware of home, school and benefits support available through integrated services	
n)	Be asked if they are satisfied with the approach of the professionals	

Any additional points:



Right from the Start - Newham

Local and national organisations that can provide further advice, information and services for disabled children, young people and their families:

Child Development Centre (Integrated Child Development Service) can provide advice, information leaflets and resources. A referral may be made for assessments for integrated (health, education and social) services. Contact:

Integrated Child Development Service,
Child Development Centre,
West Ham Lane clinic,
84 West Ham Lane,
Stratford E.15. 4PT
Tel: 020 8250 7314
Fax: 020 8250 7357
E-mail: pat.clarke@newhampct.nhs.uk

Pre-school Home Visiting Service provide playgroups and support to families in the home, support to nursery placements for children with complex and profound learning difficulties, communication disorders and disabilities. Contact:

Toni Russell,
Tunmarsh Centre,
Tunmarsh Lane,
Plaistow, E13 9NB

Tel:020 8430 4801

Service for Deaf and Partially Hearing Children provides playgroups and support to families in the home, support to children in nursery and school placements for children who or Deaf or partially hearing. Contact:

Mary Clarke,
Tunmarsh Centre,
Tunmarsh Lane,
Plaistow, E13 9NB

Tel: 020 840 4819
Minicom: 020 8430 3830

Newham Service for the Visually Impaired provides support for families in the home, support to children in nursery and school placements for children who are blind or have visual impairment. Contact:

Michael Mednick
Tunmarsh Centre
Tunmarsh Lane
Plaistow, E13 9NB

Tel: 020 8430 4816

Kids Choice provides support, information and leisure opportunities to disabled children 5+ years and families, run by Mencap, Barnardos and Newham Primary Care Trust. Contact:

Tel: 020 8503 4277
Freephone: 0800 152 443
fax: 020 8475 0471
Kidschoice_newham@hotmail.com

Newham Children's Information Service is part of Newham Early Years and Childcare Service and provides information about childcare and early years facilities in Newham for 0-16 year olds, information on

choosing the right childcare, where to get help with paying for childcare and information for those who want work in childcare. Contact:

Newham Children's Information Service
Tel (freephone): 0800 074 101 7
Fax: 020 8430 6812
E-mail: cis@newham.gov.uk
Website (national): www.childcarelink.gov.uk

Disabled Children and Young Peoples Service (Newham Children and Families Social Services) can provide information, needs assessment for family and community support, child protection and care services to 18 years, where eligibility criteria are met. Contact:

Tel: 020 8430 5614 (duty desk)

SPINN can provide advice, information and support around education issues, e.g. admission into school, support in school for parents whose children experience barriers to learning.

Contact: -

SPINN (Supporting Parents Inclusion Network Newham)
743-745 Barking Road
Plaistow
London E13 9ER
TEL: 020 8470 9703
E-mail: suesmith@spinn.fsbusiness.co.uk

Newham Carers Network can provide information services and give advice on various local and national carers groups where parents and families will be able to meet others. These groups include Newham Autism Groups, SCOPE (cerebral palsy and related

conditions), Downs Syndrome Association. The Carers Network provides casework and advocacy services for all carers in Newham. Contact:

Newham Carers Network
Stratford Advice Arcade
107-109 The Grove
Stratford
London E15 1HP
Tel 0208 519 0800
Fax 0208 522 0477
E-mail: info@newhamcarers.org.uk

The Family Fund is an independent organisation providing grants and information to help families caring at home for a severely disabled or seriously ill child under the age of 16years. Contact:

Tel: 0845 130 45 42 (interpreting service available)
Minicom: 01904 658085
[Www.familyfund.org.uk](http://www.familyfund.org.uk)

Contact a Family provides information and support services for families with disabled children and children with rare conditions:

Contact a Family, 209-211 City Road, London EC1V 1JN
Tel 020 7608 8700 Fax 020 7608 8701
Helpline 0808 808 3555 or Textphone 0808 808 3556
Freephone for parents and families (10am-4pm, Mon-Fri)
e-mail: info@cafamily.org.uk
www.cafamily.org.uk