CHILDREN (NI) ORDER 1995

Guidance and Regulations

Volume 5

Children with a Disability

The Children Order series of regulations and guidance consists of the following:

Volume 1: Court Orders and other Legal Issues
Volume 2: Family Support, Child Minding and Day Care
Volume 3: Family Placements and Private Fostering
Volume 4: Residential Care
Volume 5: Children with a Disability
Volume 6: Co-operating to Protect Children

PREFACE

This series of volumes of regulations and guidance builds upon "An Introduction to the Children (NI) Order 1995" published by the Department of Health and Social Services and the Office of Law Reform. The regulations and guidance in this series are primarily addressed to Health and Social Services Boards and Trusts. However, as they will have an impact upon the work of a wide range of agencies and individuals who work with children and young people in both the statutory and voluntary sector, they are of major importance to all involved with the welfare of children in any capacity including education and library boards, schools, those responsible for the management of children's homes, those providing child minding and day care services.

THE STATUS OF REGULATIONS AND GUIDANCE

The regulations and guidance in this services build upon the legislative framework of the Children (Northern Ireland) Order 1995. The Children Order is law and must be compiled with. The ***regulations*** *made under the Children Order include permissions and restrictions as to what may or may not be done and also requirements on what must be done. As with the Order itself the regulations carry the full weight of law. The* ***guidance*** *issued under the Children Order is not law in the way that regulations are. Where the guidance explains the requirements of the Children Order or regulations it is reaffirming the law. Where it goes beyond regulations it conveys the message that 'it is highly desirable to ' or 'Unless there is good reason not to, you should …' rather than 'You must'. This is intended to give some degree of flexibility in the application of what the Department considers to be good practice. However it should be noted that whilst they are not in themselves law in the way that regulations are law it is possible that guidance documents may be referred to in court proceedings and that courts may expect justification for not following guidance.*

NOTE ON TERMINOLOGY

Although nothing in the Children Order turns on the sex of the person referred to references in this volume to the child follow the legislative convention of the Children Order itself in referring to "he", "his" or "him".

The Children Order includes statements as to the powers and duties of Health and Social Services Boards and Trusts. The Order itself uses the term "authority" to refer to a Board or Trust. The powers and duties will be exercised by a Board, except where a function is exercisable by a Trust by virtue of an authorisation for the time being in operation under Article3(1) of the Health and Personal Social Services (Northern Ireland) Order 1994. in this series of guidance references are to a Trust except in the case of the registration and inspection functions in relation to children's homes described in Volume 4.

FURTHER READING

Whilst these volumes are designed to provide a comprehensive guide to the Children Order they do not purport to be a comprehensive survey of good practice.

It is suggested that reference might be made to:

The Social Services Librarian
Queens University Medical Library
Institute of Clinical Science
Grosvenor Road
Belfast
BT12 6BJ

GENERAL PRINCIPLES ON WHICH THE CHILDREN ORDER IS BASED

In considering the detailed provisions of the Children Order in this volume attention is drawn to the major principles on which the Order is based.

- *The welfare of the child is the paramount consideration.*
- *Wherever possible, children should be brought up and cared for within their own families.*
- *Children should be safe and be protected by effective intervention if they are in danger, but such intervention should be open to challenge.*

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- *When dealing with children, courts should ensure that delay is avoided, and may only make an order if to do so is better than making no order at all.*

- *Children should be kept informed about what happens to them, and should participate when decisions are made about their future.*

- *Parents continue to have parental responsibility even when their children are no longer living with them. They should be kept informed about their children and participate when decisions are made about their children's future.*

- *Parents with children in need should be helped to bring up their children themselves and such help should be provided in partnership with parents.*

- *Services provided to children and their families should draw on effective partnership between Health and Social Services Boards and Trusts and other agencies.*

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combine assessments with those made under other specified legislation.

Assessments process for children with a disability to take a longer perspective *than for other children in need.*

Trusts to have regard to the Departmental policy paper "People First" when assessing need. Specifies the process characterising care management viz ***Case Finding; Screening; Assessment; Care Planning; Monitoring and Review.***

Trusts required to work in partnership with parents and children provided child is of sufficient understanding). Trusts to draw up a plan for service provision once a need has been identified. Plan to take account of child's needs in relation to health, development, disability, education, religious persuasion etc. Listening to children and need to avoid assumption as to child's ability to share in decision making.

Trusts required to facilitate the provision of services for children in need by voluntary organisations and others. Need to develop effective co-ordination, communication and mutual respect between and with professionals and services in the community.

Provision and development of family support services to enable children with a disability to live at home. Role of education and library boards and health visitors. Range of services and activities provided by ***Family Centres Befriending Schemes and Day Care Centres.***

CHAPTER 1: INTRODUCTION

1.1 The Children Order brings together most public and private law relating to children and establishes a new approach to services provided by Trusts for children and their families. Apart from the Chronically Sick and Disabled Persons (Northern Ireland) Act 1989, Trusts' functions towards children with a disability are covered by the Order. This guidance considers the implications in respect of such children.

1.2 The Children Order provides a legal framework for the provision of services for a child with a disability and seeks to ensure the integration of these services. It requires Trusts to offer children with a disability the benefit of those powers and duties which they have in respect of all children. Hence the **provisions in relation to children with a disability must be considered within the context of the wider range of provisions for children.** This volume of guidance is intended to help Trusts to consider afresh their policies and strategies for the provision of services.

1.3 The specific provisions in the Children Order in respect of services to children with a disability are set out below.

- **Article 27(9)** requires that where a Trust provides accommodation for a child whom it is looking after and who is disabled, it shall, so far as is reasonably practicable, secure that the accommodation is not unsuitable to his particular needs (see Chapter 11);

- **Schedule 2, paragraph 3** places a requirement on Trusts to open and maintain a register of children with a disability in their area (see Chapter 3);

- **Schedule 2, paragraph 4** provides that a Trust may assess a child's needs for the purpose of the Children Order at the same time as any assessment under certain other legislation (see Chapter 4);

- **Schedule 2, paragraph 7** requires Trusts to provide services for children with a disability which are designed to minimise the effects of the disability and enable the children to have the opportunity to lead lives that are as normal as possible (see Chapter 6). Trusts should adopt a positive approach to paragraph 7 and plan services which are designed to give such children opportunities to lead their lives to their full potential.

1.4 Trusts have a clear, positive and separate duty to provide services to children with a disability in their area. Trusts developing policies for children with a disability should ensure that they have a specific policy on integration of their services which meets their general duties and powers towards children and families under the Children Order. Policies should take account of the wishes and views of the local community, including user groups. Every effort should be made to work collaboratively in team and multi-agency structures in order to avoid the creation of segregated services.

1.5 Trusts should ensure that work with children with a disability is carried out with particular regard to the following:

- The welfare of the child should be safeguarded and promoted by those providing services;
- A primary aim should be to promote access for all children to the same range of services;
- Children with a disability are children first;
- Recognition of the importance of parents and families in children's lives;
- Partnership between parents and Trusts and other agencies;

- The views of children and parents should be sought and taken into account;

Volume 1 in this series provides further information on the concept of parental responsibility as it applies to all children.

CHAPTER 2: CHILDREN IN NEED

Definitions

2.1 The Children Order defines those children for whom the Trust should provide services, if necessary, to safeguard and promote their welfare (Article 17). These are children in "need". A child is defined as being in need if:

(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a Trust;

(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or

(c) he is disabled.

"development" means physical, intellectual, emotional, social or behavioural development, and

"health" means physical or mental health.

2.2 The Children Order provides that a child is disabled if he is:

"blind, deaf or dumb suffering from mental disorder of any kind or substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed" (Article 2(2)).

This is the legal definition within which Trusts must work. However, Trusts should be alert to the fact that parents, children and others may find some of these words to be stigmatising. Wherever practicable Trusts should encourage the use of language which is sensitive to these feelings.

General duty to provide services

2.3 The Order's definitions of children in need and disability pave the way for a general duty on each Trust to provide an appropriate range and level of services to safeguard and promote the welfare of children in need and so far as is consistent with that duty to promote the upbringing of such children by their families. This general duty is supported by other specific duties and powers such as facilitation of the provision of services by others, and a duty to publicise services provided by others including in particular voluntary organisations (Article 18(5) and Schedule 2).

2.4 These provisions encourage Trusts to provide services such as guidance and counselling, respite care and a range of other services as a means of supporting children in need (including children with a disability) within their families. The Children Order recognises that sometimes a child can only be helped by providing services for other members of his family (Article 18(3)) if the service is provided with a view to safeguarding or promoting the child's welfare. Family, in relation to such a child, includes any person who has parental responsibility for the child and any person with whom he has been living. The Trust may make such arrangements as it sees fit for any person to provide services and support may include giving assistance in kind, or, in exceptional circumstances, in cash (Article 18(6)). However, where it is the Trust's view that a child's welfare is adequately provided for and no unmet need exists, it need not act.

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2.5 The Children Order imposes a general duty on Trusts to provide day care services and supervised activities for children in need aged five and under and not at school and for school age children outside school hours and in school holidays. Children have common needs in terms of care, affection and a stimulating environment in which to develop. The definition of children in need and the range of duties and powers provided in Part IV of the Order should be seen as an important opportunity to ensure that children with a disability are treated as children first and have access to the range of generic and specialist provision available to support children and families in their own homes and their local communities.

2.6 The Trust is not obliged to provide all the services which may be needed itself. Article 18(5)(a) states that every Trust shall facilitate the provision by others (including in particular voluntary organisations) of services which the Trust has power to provide by virtue of this Article or Articles 19, 21, 27, 35 or 36. Trusts may also arrange for others to provide services on their behalf (Article 18(5)(b)).

2.7 In deciding which services are needed by individual families, Trusts will need to give careful attention not only to families' stated preferences but to the contribution which other statutory and voluntary agencies might make. Co-ordinating packages of services from other service providers will require time and resources and the compatibility of services offered should be carefully assessed. Individual children and families will have very different levels of need which may fluctuate throughout the year according to other pressures of family life. The provision of education, respite care and day care will not be effective unless they are tailored to the needs of the child and family. Arrangements must be such that parents are reassured that the child will receive good quality care and that the child's interests are met. In some instances provision of a discrete service (eg aids and adaptations to a house or transport in order to use a local after school club) may assist the child and his family to lead fulfilling lives without other service provision.

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Identification of need and publicising services

2.8 Paragraph 1 of Schedule 2 to the Children Order requires Trusts to identify the extent to which there are children in need in their area. Paragraph 2 requires them to publicise services. Trusts should build on existing links with community groups, voluntary organisations and ethnic minority groups to involve them in planning services. The publicity required must include information about services provided both by the Trust and, to the extent it considers appropriate, about such provision by others (eg voluntary organisations). **Publicity should be clearly presented and accessible to all groups in the community, taking account of linguistic and cultural factors and the needs of people with communication difficulties.**

CHAPTER 3: CO-ORDINATING SERVICES

Collaborative working

3.1 New links between professional groups of staff in Trusts may need to be developed if they are to implement the Children Order and fulfil their duty to take reasonable steps to identify the extent to which there are children in need in their areas by identifying the numbers and needs of children in their areas who are disabled through physical, sensory, communication or learning disablement, mental disorders and chronic illness. Trusts will need to consider, in co-operation with other relevant agencies, the individual child's overall developmental needs – physical, social, intellectual, emotional and behavioural in assessing what sort of services are required. The Children Order requires any HSS Trust, Board or special agency, any education and library board, the NI Housing Executive, any district council or other such persons as the Department may direct to comply with a request from any Trust for assistance in providing services under Part IV of the Order. However, the organisation from which help is requested is only required to comply so long as this is compatible with its own legal duties or other obligations and does not unduly prejudice the discharge of any of its functions (Article 46).

Register of children with a disability

3.2 Paragraph 3 of Schedule 2 to the Children Order requires Trusts to keep a register of children with a disability. Trusts may wish to consider building upon an existing data base such as Module V or SOSCARE. The requirement to keep a register is designed to help service planning and monitoring. There is no corresponding duty on parents to agree to registration and services are **not** dependent on registration. Registration can contribute positively to coherent planning of service provision for children with a disability. However, registration will necessitate clear criteria for definitions of disability. This will be decided best in discussions between Trusts and education and library boards as will the fact that registers should be regularly updated.

3.3 Trusts, whilst acknowledging the legal definition of disability in the Children Order will need to liaise with their education and library board colleagues to achieve an understanding of disability which permits early identification and which facilitates joint working. The understanding of disability should be one which encourages parents to agree to registration and which is meaningful in terms of planning services for the child in question and children in general.

3.4 Where a Trust identifies a child with a disability it should initiate discussions with the parents about services or procedures which might be beneficial to both child and family. An explanation should be given of the register and of what other agencies can provide. **The registration of children with a disability will be effective and productive only if parents and children are regarded as partners in the assessment process** and as experts in their own right. They should be treated as people from whom professionals may have to learn. **Parents and children are likely to be less anxious about the registration process if they are given clear and comprehensive information in accessible formats about the purpose and use of the register and if they are encouraged to contribute directly to what is recorded about their child's special needs.**

3.5 It should be stressed that the register has no connection with child protection registers and that child protection registration is an entirely separate process. In making use of the register Trusts should ensure that confidentiality about individual children and families is maintained. If the register is computerised, the provisions of the Data Protection Act 1987 will apply.

3.6 Decisions about registration should not be made when a child or parents are still under considerable emotional stress at the identification of the child's potential disability or special need. Here the child's parents' need for support should be the first consideration and discussion of registration should be deferred to a later date. Counselling provided should be sensitive to individual racial, cultural, linguistic, religious needs or communication difficulties.

CHAPTER 4: ASSESSMENT AND PLANNING PROCESS

4.1 Trusts will need to develop clear assessment procedures for children in need within agreed criteria which take account of the child's and family's needs and preferences, racial and ethnic origins, their culture, religion and any special needs relating to the circumstances of individual families. Trusts should also have clear time limits as to assessments and reviews and should make this information available to parents and carers. The assessment procedures are laid down in primary legislation or regulations, but assessments under the Children Order should be undertaken in the context of Part IV of, and Schedule 2 to, the Order (as part of the process of recognition of need and the identification of appropriate services). The Children Order empowers Trusts to combine assessments under the Order with those under other legislation such as the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978, the Education and Libraries (Northern Ireland) Order 1986, the Disabled Persons (Northern Ireland) Act 1989 or any other statutory provision (paragraph 4 of Schedule 2 to the Children Order). Formal assessment under the Education and Libraries (Northern Ireland) Order 1986 already involves collaboration between Trusts and education and library boards and parents. The procedures under the Education and Libraries (Northern Ireland) Order 1986 are likely to contribute significantly to assessment by Trusts and can be used as a basis for further collaborative decision-making about the wider needs of children and families. The Disabled Persons (Northern Ireland) Act 1989 requires Trusts to assess young people with a disability at the time they leave school for a range of welfare services as outlined in the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978.

4.2 **In many cases children with a disability will need continuing services throughout their lives. It will therefore be particularly important that for these children, the assessment process takes a longer perspective than for other children in need.**

4.3 The requirements of children with a disability may need to be met from a number of sources. In conducting assessments and managing the care provided, Trusts will need to ensure that all necessary expertise is marshalled and that all those providing services are involved from both within and beyond the Trust. The outcome of assessment should be a holistic and realistic picture of the individual and family being assessed, which takes into account their strengths and capacities as well as any difficulties and which acknowledges the need to make provision appropriate to the family's cultural background and their expressed views and preferences.

4.4 The Trust's provision of services to children with a disability should involve an initial assessment of need, a continuing process of reassessment and review of the plan for the child. Continuity should not be broken for reasons which concern organisational or administrative convenience rather than the welfare of the child or young person. A smooth transition, when the young person reaches eighteen and comes within the scope of adult services should be the objective.

CHAPTER 5: ASSESSMENT AND PLANNING PROCESS
PEOPLE FIRST – CARE MANAGEMENT

5.1 In the Departmental policy paper "People First" and subsequent policy guidance care management and assessment are key processes in the provision of community care services. This has relevance for Trusts in planning services for children under the Children Order and may provide a useful model for consideration.

5.2 "People First" requires the Trust to assess the needs of persons who may require community care services. If, during the course of assessment, it appears that a person is disabled, the Trust is required to decide upon the need for services under the Disabled Persons (Northern Ireland) Act 1989 and to inform the person that it is doing so and of their rights under that Act. Over time, these assessments arrangements will be expected to form part of wider care management systems that cover all arrangements for the care of the service user from the beginning to the end of his contact with the Trust.

5.3 The People First policy guidance "Care Management: Guidance on Assessment and the Provision of Community Care" describes 6 distinct processes which characterise care management in its most comprehensive form:

- Case Findings: this includes publicising services in such a way as to assist both those who are likely to require them, and referring agencies (including general practitioners) in making appropriate referrals;

- Screening: this is the initial examination of all referrals in order to determine the appropriate response, ie the level of assessment likely to be required;

- Assessment: this is the systematic determination of need. It should take account of the perceptions and wishes of

potential clients and their carers and of relevant professional views. Assessment will continue to be performed by members of the appropriate professions. When a comprehensive assessment is being carried out, the contributions of all those involved will have to be coordinated by one professional officer to produce an overview of care needs and circumstances;

- Care Planning: this should emerge from the assessment of need and should aim at preserving or restoring as far as possible normal patterns of living;

- Monitoring: this should be designed to identify unmet needs; to measure the effectiveness of the care provided, and to identify gaps and inadequacies;

- Review: this involves the review of clients' needs and the needs of their carers for appropriate support and, where necessary, for services in their own right.

5.4 An important feature of the care management process is that it is based on a needs-led approach within resource availability. Responsibility for assessment and care planning has been separated from service provision in order to focus on needs, where possible having the tasks carried out by different staff. **The intention is to ensure that people are not fitted into existing services, but that services are adapted to individual needs.** This separation enables discrepancies between assessed needs and available service to be identified.

5.5 Care management arrangements also take account of the multiple service providers required to meet the majority of special needs. The approach aims to encourage the identification of the full range of services which may be needed. The Trust will have overall responsibility for the co-ordination of the services required. However, the day to day management and provision of these services may rest

elsewhere. Packages of support can be put together using the statutory and the voluntary and independent sectors thereby making use of whatever pattern of provision has been developed within the context of a particular Trust.

Child care practice

5.6 There is further similarity between child care practice and care management in that the aim is normally to provide one worker with continuing responsibility for providing and co-ordinating services. This is one means by which care management may be delivered, and may be the means best suited to meet the needs of children with a disability. It should be emphasised, however, that the appointment of a single care manager is but one way of delivering care management, the responsibility for different aspects of which may be shared by different workers. Moreover, it should be emphasised that where responsibility is given to a single care manager, that care manager should be from the agency most relevant to the current needs of the child with a disability, and that this agency may change over time.

5.7 The distinction between the terms “key worker” and “care manager” should also be noted. The range of responsibilities carried by care managers and the fact that they are not involved in direct service delivery distinguishes their role from that of key workers.

5.8 Standards of service are agreed between the Trust and service providers and the individual package of care may reflect a very wide diversity of service provision. The parents and children concerned are important contributors to the planning process. But the development of a flexible child care service for children with a disability will not be possible without the chosen liaison between the education and library board and the Trust and the use of whatever team approach to special needs is available in the locality, such as multi-disciplinary community teams.

The management process

5.9 Many children with a disability will require support from a very wide range of services. Their need for services will often be a continuing need. An ongoing process of assessment, monitoring and review will be essential in order to ensure appropriateness and effectiveness of service provision. Where a multi-disciplinary team already exists, the appointment of key workers or care manager may pose no problems. Since the development of individual packages of care will necessitate negotiations with service managers and budget holders across a range of agencies, a team base for such an arrangement may be the most effective. But care management will require skilled support, training and regular appraisal. In implementing the new arrangements for children with a disability under the Children Order, Trusts will need to look carefully at:

- the range of existing assessment arrangements within agencies providing services for children with a disability within the Trust in question;
- the recording and monitoring systems to be used by the Trust in assessing and planning to meet needs;
- the use of the register with regard to recording and reviewing provision;
- the extent to which existing multi-disciplinary teams can be utilised and developed in creating shared assessment systems;
- how best to involve consumers – parents and children – in the assessment process and to ensure that they have ownership of the outcomes of any assessment process; and
- procedures when the young person reaches the age of eighteen and the provisions of the Children Order overlap.

The aim must be to ensure by early planning that a seamless transition to adult services takes place.

5.10 Trusts will need to have available published information accessible to all potential service users and carers, including those with any communication difficulty or difference in language or culture. The information should set out the types of community care available, the criteria for provision of services, the assessment procedures to agree needs and ways of addressing them and the standards by which the care management system (including assessment) will be measured.

5.11 Trusts should include in this information care management and assessment arrangements for children with a disability. Such information could be linked to wider duties to provide information on the full range of local services and could be made available to children and families undergoing assessment through procedures relating to the Children Order and other relevant legislation.

CHAPTER 6: PLANNING OF SERVICES IN PARTNERSHIP WITH PARENTS AND CHILDREN

6.1 A key theme in the Children Order is that of partnership with parents and, where the child is of sufficient understanding, with the child. The concept of partnership is not new, but is based on well established beliefs that:

- the family home is the natural and most appropriate place for the majority of children;
- families are already caring for children, and supporting them to do so is, in most cases, in the best interests of the child and best allocation of resources in the Trust;
- children are individuals with their own needs, wishes and feelings;
- the family has a unique and special knowledge of a child and can therefore contribute significantly to that child's health and development – albeit often in partnership with a range of service providers; and
- families provide continuity for children throughout their childhood – and, in the context of the Children Order, families are recognised as being more widely defined than parents and brothers and sisters and other relatives, and often play an important part in the life of a child.

6.2 Parents and children from all backgrounds, ethnic origins and different lifestyles, will require clear information and sensitive responses when they seek support. The services needed may be day care; health services and educational provision which all parents and children will use sometimes or a targeted service to meet a particular need.

6.3 The Arrangements for Placement of Children (General) Regulations and the Review of Children Case's Regulations together with specific placement regulations are the framework for the provision of the service of accommodation to children looked after by Trusts or accommodated by voluntary organisations or in privately run children's homes (see Chapter 11). Good practice requires that the same approach is taken to the provision of services other than accommodation. This is implicit in the provision contained in paragraph 7 of schedule 2 to the Order which requires that:

every Trust shall provide services designed –

(a) to minimise the effect on disabled children within its area of their disability; and

(b) to give such children the opportunity to lead lives which are as normal as possible.

Attention should be had to the need to adopt the positive approach to paragraph 7(b) noted at paragraph 1.3 above.

Planning a service for the individual child

6.4 Once a need has been identified a plan for the best service provision will be required. This may amount to no more than matching the need with an existing service in the community. Where the Trust has to allocate resources to arrange a service – for example, a family aide for the family or day nursery place for the child – the plan should estimate how long the service may be required, what the objective of the service should be and what else others are expected to do. In order to be effective this plan should form the basis of an agreement with the child, parent or other carer and be reviewed at appropriate intervals. In planning for the individual child, the Trust should take account of the particular needs of the child – that is in relation to health, development, disability, education, religious persuasion, racial origin, gender, cultural and linguistic background, the degree (if any)

to which these needs are being met by existing services to the family or child and which agencies' services are best suited to the child's needs. The needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability. They may, however, be in need in their own right and require separate assessment. Trusts must be sensitive to the needs and requirements of ethnic minority families and in particular ensure assessments take into account individual circumstances and are not based on a stereotypical view of what may be required. Equally partnership and consultation with parents and children on the basis of careful joint planning and agreement is the guiding principle for the provision of services whether within the family home or where children are provided with accommodation under voluntary arrangements. Such arrangements are intended to assist the parent and enhance, not undermine, the parent's authority and control. This approach should also be developed when a child is in care, provided that it does not jeopardise his welfare.

6.5 Where a child is looked after by the Trust the Children Order requires that his views should be sought subject to his understanding (see Articles 26(2)(a) and (3), 76(2)(3) and 92(2)(3) of the Order). It is required that the child's views as expressed be discussed, recorded and given due consideration when plans for the welfare of the child are in hand, before a placement decision is made and at every review meeting and at case conferences.

Listening to children

6.6 The Children Order places new duties with regard to involving children in planning their futures. These arrangements apply whether or not the child has a disability or special need. There is a fine balance between giving children a voice and encouraging them to make informed decisions – and over-burdening them with decision-making procedures where they have insufficient experience, knowledge and understanding to make an appropriate judgement without additional support. Learning to make well-informed choices

and making some mistakes should be part of every child's experience. Children and young people should be given the chance to exercise choice and their views should be taken seriously if they are unhappy about the arrangements for them. Plans should be explained, discussed and if necessary, reassessed in the light of the child's views. The social worker should be aware and acknowledge that there may be good reasons why the child's views are different from those of his parents or the Trust. The more mature the child, the more fully he will be able to enter into discussion about plans and proposals and participate in the decision-making process. When older children are involved, and particularly in a case of self-referral, there may well be a different perception of the child's needs and interests as seen by the child and his parents. With young children, the social worker should make efforts to communicate with the child and discover his real feelings. All children need to be given information and appropriate explanations so that they are in a position to develop views and make choices. They should also have access to the representations procedure (see Chapter 14).

Sufficient understanding

6.7 If the child has complex needs or communication difficulties arrangements must be made to establish his views. Decisions may be made incorrectly about children with a disability because of ignorance about the true implications of the disability and the child's potential for growth and development. Children with a disability have the same rights as other children and adults to have access to information held about them in official records. Their ability to give consent or refusal to any action including examination, assessment or treatment is only limited by the general conditions regarding sufficient understanding which apply to other children under the Children Order. However, sufficient understanding may be misunderstood. Even children with severe learning disabilities or very limited expressive language can communicate preferences if they are asked in the right way by people who understand their needs and have the relevant skills to listen to them. No assumptions

should be made about 'categories' of children with a disability who cannot share in decision-making or give consent to or refuse examination, assessment or treatment.

6.8 Consulting children with a disability requires expertise and staff may need special training. In the case of a child (or a parent) with communication difficulties provision of a sign language interpreter, large print, tape and Braille may need to be made if communication is to be effective. The need for an interpreter should be considered where the family's first language is not English. For children with no verbal communication, information technology aids should be used. Necessary experience and expertise should be provided for in staffing of services and through relationships with other professionals and services and with the community. Such training might usefully be linked to existing training on equal opportunities and anti-discrimination.

Participation

6.9 Participation will be a token exercise unless careful consideration is given to supporting and informing children and parents about the consequences of any decision being taken – and about the options which they need to consider in making a preference. Only a clear and consistent policy of involvement of children and parents during assessment, at decision-making meetings and in case reviews and conferences from this early stage will avoid conflicts and adversarial debates. Participation by parents and children will be limited if they do not have adequate information or if the professional agencies concerned are not aware of relevant sources of information. Parent-held health records presuppose eventual transfer from parents to their older children. Many schools operate records of achievement, which provide statements of positive achievements in social as well as educational areas. Children who are looked after may have lifestory books and other documentation about their lives and preferences.

CHAPTER 7: WORKING WITH THE COMMUNITY

7.1 The Children Order requires Trusts to provide services to support families in bringing up children in need. Trusts are also required to facilitate the provision of such services by others including in particular voluntary organisations. The Children Order requires Trusts to facilitate the provision of family support services, day care, accommodation and after care by others and to publicise such services provided by others (Article 18(5) and paragraph 2(1) of Schedule 2). Family support will require effective co-ordination, communication and mutual respect between and with professionals and services in the community. It will necessitate sensitive assessment of parents' and children's preferences in terms of family support. It will require the provision to parents and children of full information in order that they can make an informed choice. Some families caring for children with complex or multiple disabilities may have neither the time nor the energy to contribute to assessment and planning unless they are given personal counselling, support and representation. Working with the child and family in the family home may also contribute to realistic assessment of overall needs and preferences and contribute to a real partnership in assessment.

7.2 Trusts have a duty to inform parents of the local range of services which can support families with children in need at home. Voluntary organisations, as well as education and library boards may provide a range of services which is flexible and can be adapted to individual family needs. The voluntary sector has always been a rich and creative resource for consumer groups in Northern Ireland. There are many local and national voluntary organisations in Northern Ireland concerned with disability and most have local groups and increasingly collaborate with other organisations in the wider voluntary sector. Apart from providing personal support for parents, they offer a range of practical services ranging from loans of equipment and holiday play schemes to residential or education services. All provide information and most offer counselling and advice.

7.3 Voluntary organisations are not only concerned with the important area of consumer support. Many have pioneered new ways of working with children with complex needs and from minority groups, for example those with multiple disabilities or challenging behaviour. Voluntary organisations, like Trusts, cannot provide services in a vacuum. As they become part of the wider network of provision used by Trusts clear policies for their inclusion in planning local services – as well as arrangements for accountability and procedures such as complaints – will be essential. They need access to advice from a range of professionals, including psychologists, social workers, therapists, and the education and library boards. The use of voluntary agencies for direct service provision should, therefore, be accompanied by:

- early involvement in planning services within the Trust.

- explicit service agreements which involve children and families and ensure access to relevant professional advice.

- agreed assessment, recording and review procedures.

- shared training opportunities – both as trainers and for staff working in the voluntary sector to have training opportunities with their Trust counterparts.

7.4 In some instances, the role of the voluntary agency may not be to provide specific regular services such as day or residential care, but to offer representation and advocacy for the parents and child or to develop formal representation schemes on behalf of the Trust in question. Some Trusts are already utilising their local voluntary sector to provide representation schemes or to provide support for "hard to reach" groups of children such as those living in Travellers' families or in homeless family accommodation.

CHAPTER 8: SERVICES TO CHILDREN LIVING WITH THEIR FAMILIES

Domiciliary services

8.1 As noted in chapter 6, services for children with a disability may be appropriately provided in the home. Investing in a package of family support services to assist parents looking after a child with a disability will in most cases be a better alternative than residential care. A home care service can provide valuable day to day support to families. Health visitors, community nurses, home liaison teachers, psychologists, social workers and (in some instances) volunteers have learned how to work as a team, how to work directly with parents and share skills and expertise and, most importantly, how to be able to offer parents positive involvement with their child to help maximise the child's potential. Health visitors have an especially important role in providing support on a range of issues relating to the care of young children. They also have the advantage of providing a service for all young children and their families and are widely accepted as practical advisers.

8.2 Services in the home for young children with a disability may also be provided by education and library boards. Some provide peripatetic or home liaison teachers (particularly when a child has a specific disability such as hearing or visual impairment).

8.3 There are considerable advantages to caring for a child in his own home during the absence of his parents or other carer, rather than placing the child in residential care. This might be particularly important where the family home has been adapted to suit that child's particular needs. Equivalent provision may not necessarily be available in the respite care home, and there could be positive benefits in minimising disruption to the child's normal lifestyle.

Family centres

8.4 Every effort should be made to enable families with young children with a disability to use local services generally available to children and their families wherever possible. The family centres, which Trusts are now required to provide for children in their area as a community resource (paragraph 10 of Schedule 2 to the Children Order), may provide a range of activities ranging from counselling and general support with parenting to occupational, social, cultural and recreational activities. Family centres work with whole families and can provide a base for friendship, support and access to local services. A family centre may offer opportunities for collaborative work with the education and library boards and act as a referral point for families seeking other services such as day care. In addition to family centres, preschool playgroups, mother and toddler groups and local parent organisations may provide opportunities for families with a child with a disability to participate in the lives of their local community. Sometimes a family centre or playgroup may need some extra help or advice from the Trust in order to help a child with special needs. Specialist advice to such family support services should therefore be part of wider Trust planning for children with a disability and their families.

Befriending schemes

8.5 In addition to services provided through statutory agencies, some voluntary agencies run a range of early support and home visiting programmes. For example, volunteer befriending schemes will provide home visitors – usually a more experienced parent who has had some training – who help parents under stress cope with young children. Volunteers also help parents use or attend other community resources such as parents/toddler groups, toy libraries and playgroups. In the case of parents with a child with a disability a volunteer may ensure that they have opportunities to discuss the natural concerns common to all parents as well as the more specific ones relating to the child's particular disability. It is desirable to consider the need for training or information for the volunteers so that

they can help the family in the most effective way. Attention should be paid to providing support and back-up for such volunteers and the befriending scheme itself.

8.6 Many national voluntary organisations have local groups which can support parents or children with developmental delay, health problems or disabilities. Most areas also have informal self-help groups. Meeting other parents with a child with a disability may be a positive experience and can alleviate the isolation and depression which many parents acknowledge in the early years. In some instances parents may hesitate to join a special group, either because they are still coming terms with their child's disability or because they are anxious that they or their child may not be accepted. Visits to parents at home in advance of a first meeting (or support by a friendly professional such as a health visitor, social worker or another parent) should be considered. Parents additionally should be encouraged to use toy libraries, playgroups and opportunity groups and other local resources which will provide support and friendship in the family's own neighbourhood.

Day care

Guidance on standards, quality and regulation of day care services for young children is contained in **Volume 2: Family Support, Child Minding and Day Care** together with advice on the new duty to review such services every three years, consulting others as part of the process and publishing a report.

8.8 The development of young children with a disability or special educational needs is more likely to be enhanced through attending a day care service or other pre-school educational provision for all children of similar age. Staff with responsibility for registering child minders, providers and practitioners need to consider the means whereby this aim might be achieved, in discussion with experts in the field such as health professionals and people working for relevant voluntary organisations and parents and children.

In making arrangements for integrating children with a disability with other children in a day care or pre school setting, particular attention should be paid to the physical environment, staff/child ratios, and training (eg in sign language or alternative methods of communication for the profoundly deaf).

8.9 Trusts will wish to ensure that integration is properly addressed as part of the registration system under which they have to decide about the fitness of intending day care providers and child minders, and the suitability of the premises and equipment where the children will be cared for. This should involve finding out about intending providers' or child minders' views on caring for children with a disability and their understanding about what this involves. Depending on the particular circumstances of the applicant, the Trust may wish to impose specific requirements on a person's registration so that children with a disability receive an acceptable standard of care when they are placed in a group day care setting or with a child minder.

8.10 Some intending providers or child minders may be reluctant to take on the responsibility of caring for a child with a disability because they are concerned about their capacity to provide adequate care. This needs to be handled sensitively, but registration officers should seek to clarify the needs of individual children and the support that will be available in appropriate cases.

8.11 In the exercise of their day care review duty (Article 20), Trusts will wish to ensure that the process covers services for children with a disability, access to them, information about them and parental involvement. The arrangements for the review should enable all those concerned about services for children with a disability – parents, providers, health professionals and voluntary bodies – to play a full part so that their concerns are fully represented.

CHAPTER 9: WORKING WITH EDUCATION SERVICES

Education and library boards involvement with Trusts

9.1 Assessment cannot be seen as a single-agency approach, whatever the specific purpose or outcome of the particular assessment procedure. When it is thought that a child may need special educational provision, the positive and constructive approach is to focus on his needs rather than on disability. The feelings and perceptions of the child concerned should be taken into account and older children and young persons should be able to share in discussions on their needs and any proposed provision.

9.2 The extent to which a learning difficulty hinders a child's development does not depend solely on the nature and severity of that difficulty. Other significant factors include the personal resources and attributes of the child as well as the help and support provided at home and the provision made by the school and the relevant education and library board and other statutory and voluntary agencies. Hence a child's special educational needs are related both to abilities and disabilities and to the nature and extent of the interaction of those within his environment. Furthermore it is necessary to acknowledge the multifactorial nature of assessment and the extent to which a range of factors will encourage or impede a child in his development.

9.3 There will be a need for communication between Trusts and education and library boards at senior management level. Assistance before a situation becomes critical will be more effective than formal assessment procedures initiated too late and in isolation. The needs of some children will be first identified while they are living with their family. Statutory assessments under the Education (Northern Ireland) Order 1996 (when commenced) may sometimes be required for children who are living in accommodation arranged by a Trust and the Trust may wish to consult the appropriate education and library board of the child:

- has a medical condition likely to affect future learning ability;

- has been admitted as a result of a social condition likely to affect future learning ability (eg negligence, neglect or child abuse);

- is receiving treatment likely to affect his future learning ability;

- has been admitted to a children's or adolescent psychiatric ward.

9.4 When assessing a child's special educational needs, an education and library board will seek educational, medical, psychological and any other appropriate advice relating to the child. Advice is interpreted as written advice on any features of the case which are relevant to or which affect the child's educational needs and on the best way of meeting these needs. All education and library boards will have their own structured forms for the collection of information on particular children. Education and library boards must provide all professionals with copies of any representations or views submitted by or on behalf of a child's parents. Parents have the legal right to see all advice used in drawing up a statement. Having considered such advice, and any other evidence submitted by the parents, the education and library board is responsible for determining the appropriate special educational provision for the child.

9.5 All relevant advice, evidence and information will form part of the statement, thus providing a comprehensive picture of the child's needs. Where a Trust has parental responsibility for a child, it will have a dual role. Firstly the Trust should play the part of a good parent. Secondly it should ensure that a social services contribution is made to the assessment. Although every child with a disability will have special educational needs which cannot be met without a statement, some will come within both groups and more effective participation in assessment should be a priority for Trusts.

Notification of Trusts by education and library boards

9.6 When an education and library board notifies the parent of its decision to assess formally a child's special educational needs, a copy of the notification must be sent to an officer nominated for this purpose by the Trust. This is intended to offer the Trust an opportunity to consider whether it knows of any problems affecting the child relevant to the education and library board and the range of services it might offer and to indicate to the education and library board whether the social services has information relevant to the assessment of a child's special educational needs. Any advice provided by the Trust will be attached as an appendix to the statement. Parents have a right to see such advice. The education and library board may also seek advice from the Trust of its own accord.

9.7 The notification of Trusts by education and library boards may be an important opportunity for a Trust to meet with and inform parents of children in need with a disability at a very early stage and to provide information about available services. This notification affords an opportunity to link educational assessment to the assessment of a wider range of personal, social and health needs.

Provision of information

9.8 Where a Trust, in exercising any of its functions, forms the view that a child under school age may have special educational needs it must notify the child's parents of its opinion and of any relevant voluntary organisation which would be likely to help them (Article 14 of the Education (Northern Ireland) Order 1996). Information provided by Trusts with regard to provision for children in need under the Children Order could usefully be made available to give to parents when making such a referral. In any event Trusts will be working in supporting particular children and families and a collaborative approach is likely to be the most helpful. To promote early co-operation between agencies Article 14 also places a duty on Trusts, after discussion with parents, to inform the appropriate education and library

board of any children under school age who might have special educational needs.

Parental involvement

9.9 Parents have a right to participate fully in the assessment process. They have rights of access to the advice submitted to the education and library board and may make representations and contribute written evidence and advice. They also have rights of appeal to an independent tribunal against certain decisions made by education and library boards. In some instances, particularly where the family has a range of needs unrelated to the educational assessment, Trusts or voluntary organisations could support parents in assessment.

9.10 An important outcome of such partnership could be a strengthened understanding of the needs of child and parents and an opportunity to learn from the wider advice on the child's medical and psychological as well as social and educational needs. When a child is subject to a care order, the Trust should ensure that it involves those with parental responsibility for the child in any assessment procedure (supporting them in travelling to an assessment if necessary). The Trust should also act as a good parent, contribute positively to assessment and encourage the child to do likewise.

Reviews of statements of special educational needs

9.11 Every statement of special educational needs must be annually reviewed. Although Trusts are not necessarily involved, every effort should be made to ensure that a member of staff from the Trust (normally the child's social worker) attends the review of a child looked after. This will ensure that the Trust is informed of the child's progress and of any special difficulties which the school may be encouraging. If there is anxiety about the arrangements made for the child, then reassessment may be considered.

9.12 The DENI code of practice on special educational needs provides

that the first annual review after the child's 14th birthday should include a Transition Plan. The Plan will draw together information from a range of individuals, within and beyond the school, in order to plan coherently for the child's transition to adult life. The code of practice specifically requires the education and library board to consult the relevant Trust in drawing up the Transition Plan. The education and library board is required to seek information from the Trust as to whether the child is disabled. It should inform the Trust of the date of the first annual review after the child's 14th birthday and inform the Trust if, at any time after this review, the child's circumstances change and as a result the child may be considered to be disabled. The DENI code of practice also requires the education and library board to advise the relevant Trust of the child's expected school leaving date between eight and twelve months in advance.

Children under school age

9.13 Articles 21 and 13 of the Education (Northern Ireland) Order 1996 place respective duties on education and library boards with respect to children under two and from that age until school leaving age. The early identification of special educational needs is crucial for the young child with disability and/or delayed development. Suitable provision right from the start can considerably enhance the child's future progress.

9.14 The Children Order contains important new provisions to help education and library boards, district councils and Trusts work in a co-ordinated way. The new review duty - Article 20 in Part IV – requires the three authorities to work together in looking at the pattern of day care services in their area, consulting others and finally publishing a report. The legislation requires the review to be undertaken every 3 years, and Volume 2 in this series makes it clear that the process should involve follow up so that it is not to be treated as a one off exercise.

9.15 The new legislation on the regulation of independent day care services and child minding – Part XI and Article 46(1) of the Children Order – gives Trusts power to ask the education and library boards for advice if it seems to them it would help them in the exercise of their functions. These provisions in the Order will make co-ordination and co-operation easier to achieve and thus help to ensure acceptable standards of services for all children.

Assessment of children in social services settings

9.16 A child placed in a specific setting with an existing statement of special educational needs will already have considerable information on record about his needs. The identification of an actual or potential learning difficulty when the child is already placed in a care setting requires staff training and should be covered by clear procedures with regard to notification of the appropriate people and agencies.

9.17 If a child's special needs are identified when already using a day care or residential service provided by a Trust, the education and library board may wish to carry out part of the assessment in the setting which is most familiar to the child. Parents may be very anxious and distressed at the potential identification of a disability or learning difficulty and may need counselling and support. Both care staff and parents should have accurate and clear information on the assessment process and should be aware of the possibility of a special need before any formal assessments are initiated. Parents and staff working with children can provide invaluable information for assessment if encouraged to do so. As noted elsewhere, change in the educational arrangements of a child may produce difficult behaviour and problems at school which may be short-term in the first instance, but predictive of longer-term difficulties and failures if not dealt with properly.

9.18 Schools provide social networks for children and may provide positive role models for very disadvantaged children. Every effort should be made to sustain a child's educational placement so that

there is familiarity with his needs. Such a course will also enable the Trust to work with the education and library board and share knowledge and expertise. Participation by Trust staff can extend to a range of activities which an ordinary parent might expect to share. It should include participation in home/school activities such as paired reading schemes or sharing in school-based social and other activities. Many schools now operate records of achievement for children and every effort should be made to ensure that children and young people with a disability are enabled to contribute positively to recording their own achievements and progress and planning for the future. When a child is being formally assessed for a possible statement of special education needs, staff working closely with a child should make their contribution to the assessment process and should have access to development checklists, Trust guidelines and any material developed locally to help parents carry out a similar exercise.

Co-ordination of services

9.19 Trusts and education and library boards have new opportunities to use the Children Order, the Educational and Libraries (Northern Ireland) Order 1986 and the Disabled Persons (Northern Ireland) Act 1989 in tandem to ensure well co-ordinated and cost effective services for children with a disability and special needs. An appropriate and early diagnosis of a child's difficulty in learning may be as important to that child's and family's future as a medical diagnosis or the provision of practical support to the family. Poor quality school work arising from family problems which are unknown to the teacher, difficulties in communication or unacceptable behaviour quickly isolate children and lead to a rapid erosion of self esteem and confidence. Equally, a child's capacity to develop educationally will be directly affected by adverse home circumstances or unmet health needs.

9.20 The full benefits of early identification and the register of children with a disability will only be achieved if there is a genuine partnership between Trusts and education and library boards.

Trusts have duties under Article 14 of the Education (Northern Ireland) Order 1996 to inform education and library boards of any child who has not attained the lower limit of compulsory school age who might have special educational needs. Anxieties expressed by many parents about the association between Trust intervention and the diagnosis of potential child abuse will necessitate open and honest discussion between parents, carers, Trusts and health service staff about the role of the individual agencies and their agreed procedures for transfer of information. Indeed transfer of information is unlikely to occur unless the Trust and parents have clear, intelligible and relevant information on the Children Order and unless parents are confident of the purpose and subsequent use of the register.

9.21 Under the Education and Libraries (Northern Ireland) Order 1986, Trusts are required to contribute medical and social services advice when an education and library board is carrying out an assessment of a child's special educational needs. Although the purpose of such an assessment is to identify the educational special needs of the child, the assessment process will be a useful additional source of information about the child who receives help from the Trust. In such cases, discussion should take place on the relevance of the information contained in the medical advice for the future planning of services.

Education supervision orders

9.22 Under Article 55 of the Children Order a court may make an education supervision order on the application of an education and library board if it is satisfied that the child concerned is of compulsory school age and is not being properly educated. Details about education supervision orders are provided in **Volume 1: Court Orders and Other Legal Issues** but in essence the order will be put into effect by an educational supervisor, whose duty it will be to advise, assist, befriend and give directions to the supervised child and parents in order to enable the child to be properly educated.

9.23 The wishes of parents and children must be sought before any directions are given. In the case of a child with a disability not attending school, the Trust should, in liaison with the relevant education and library board, discuss with parents why they are reluctant to use a particular school and what their wishes and concerns are. In some instances refusal may reflect concerns over assessment of special educational needs under the Education and Libraries (Northern Ireland) Order 1986 and anxieties about the use of a particular school, when another is preferred. Many parents have themselves had poor experiences at school and without support, will be unable to negotiate with a school about non-attendance, difficult behaviour or their own reluctance to agree to a particular provision.

9.24 Non-attendance may also be due to purely practical reasons, such as difficulties with transfer or when the parents feel that the school is unable to cope with their child's particular special needs. Whether these parental perceptions are well founded is less important than the fact that school non-attendance has serious long-term consequences for child and family. If the education supervisor is not able to achieve school attendance in partnership with child and parents, the Children Order gives the Trust further powers to intervene on behalf of the child. But the new process should provide a new opportunity for a more constructive relationship between families, schools and the Trust over school attendance – and a better understanding of the reasons why parents and children sometimes resist regular school attendance.

CHAPTER 10: THE ROLE OF CHILD HEALTH STAFF

10.1 The Trust's role with regard to children with a disability and their families under the Children Order cannot be effectively implemented unless there are shared arrangements for the transfer of information about children and joint planning for their futures. In addition to identification and assessment, children and young people with a disability will have a range of health care needs including health promotion advice which should be considered when planning for their futures. Trusts have to consider health and development as part of their assessment of children in need.

10.2 Children with a disability should be identified at an early stage through access to effective surveillance programmes. Trusts should ensure that children looked after by them – or children who receive services from the Trust – have access to good quality locally provided health care (**see Volume 3: Family Placements and Private Fostering** for guidance on health care arrangements for looked after children). Children with a disability are children first and should have access to the same services for health surveillance and promotion as are available to children generally.

10.3 Trusts should encourage parents to share in recording their child a development and health care needs and ensure that, where children in need are identified, parents and child can contribute to decisions on the type of care and support provided to the family. For example, parents of a child with multiple disabilities may find attendance at a local clinic impossible without day care arrangements for brothers and sisters. In order to inform themselves of local policy with regard to early identification and surveillance and protection, Trust staff could usefully create links with other services which work directly with a wide range of families. Prevention - and surveillance – are multi-factorial and social services staff (including those working in day care provision and as foster parents and child minders) should also understand local arrangements for early support from child health staff.

10.4 Child health staff have an important role to play in assessment of a child's needs in the context of a proposed day care, residential or foster placement. Disabilities which carry special health care needs should not be regarded as automatic barriers to integration and use of local children's services. In many instances advice from child health staff on, for example, the management of anti-convulsant medication can reassure a foster family, child minder or teacher so that a child need not be removed from local community provision, including schooling. Child health staff have an important role in providing relevant and helpful information which can facilitate the integration of children with a disability in the community. Steps should be taken to forge links between the general medical practitioner, the hospital paediatrician or other specialist medical service so that medical information is collated and interpreted for the benefit of the child and family. The child health service is also in a position to ensure that referral is made to therapy services, which in turn can support the child's integration into local services. **The role of GPs, health visitors and community nursing services and other paramedical services is crucial to the effective support of many vulnerable children at home.** They have an important and non-stigmatising role in dealing with a wide range of needs relating to general parenting problems as well as to needs specific to a child's disability or chronic health problem.

Children with life threatening conditions

10.5 Some children have major health care needs or life threatening conditions. In these cases staff may also provide advocacy and parental support for the children and their carers. The wishes and feelings of the child should be of paramount importance – with some children and carers wishing to talk to supportive and well informed medical advisers about the management of their condition and the prospects for the future. Sensitive support, including counselling, home nursing and the provision of appropriate respite care, may enable families who wish to contribute to care for their children at home through the duration of their illness

Including the terminal stage. The management of very sick children – or those with very complex disabilities – will require a holistic approach which involves the Trust, education and library boards and often the voluntary sector in planning with the child and family for the future. A real partnership between all involved agencies and the parents and child wherever possible should ensure that a range of services used by children generally is available to children with chronic and life threatening conditions. It should also ensure that children with a disability receive care and support in the home. Where it is not possible for a child to remain at home, they should be placed in residential settings where their specialist health care needs can be met (for example physiotherapy) and where access to specialist health care advice (for example a paediatric neurologist) is readily available. Staff in children's services (including residential staff and foster families) may need support in continuing to care for very vulnerable children.

Planning for the future

Children living in hospitals

10.6 For some children with substantial medical, therapy and nursing needs, hospitals will still have a continuing role in the provision of respite and longer term residential care. This is ultimately best decided through multi-disciplinary assessment properly involving parents and child. The use of health service provision should be part of a planned programme of support for the individual child. Every effort should be made to support placements near to the child's home. It is clear government policy that children with a learning disability should no longer live in long-stay mental handicap hospitals. Instead, where hospital provision is required, the aim should be to provide care in small, homely, locally-based units. The welfare of Children and Young People in Hospital Guide (HMSO 1991) should be made available to staff in social services, education and library boards and child health services to ensure that any care provided is appropriate to the needs of children and general provisions of the Children Order (see Chapter 13).

CHAPTER 11: ACCOMODATION AS A SERVICE

11.1 The Children Order intends accommodation to be provided as a service to children in need and their families and wherever possible under voluntary arrangements. The Order assumes a high degree of co-operation between parents and Trusts in negotiating and agreeing what form of accommodation can be offered and the use made of it. Where a child with a disability is provided with accommodation by a Trust the Order requires that, so far as is reasonably practicable, the accommodation should not be unsuitable to the needs of the child (Article 27(9)). For example, the Trust may wish to provide for suitable adaptations to a foster parents' home. By including children with a disability in the category of children in need, the Children Order requires Trusts looking after children in need to apply the same planning and review arrangements to them as are needed for other children in need.

11.2 **Volume 3: Family Placements and Private Fostering** contains regulations and guidance relating to the planning and review of placements of children looked after by a Trust or accommodated by a voluntary organisation or in a privately run children's home (all "responsible" authorities) and foster placements. The regulations and guidance provide a framework for the planning of arrangements for placement of a child and require pre-placement enquiries and preparation and subsequent supervision and monitoring of the placement. The regulations also define their application to short-term placements. Decisions made about placements must take account of the wishes and feelings of the child, the parents, any others with parental responsibility and any other relevant people. Such decisions must have regard to the child's religion, racial origin, culture and language. Responsible authorities should endeavour to place children with parents, relatives or friends, near their homes and with brothers and sisters.

11.3 Planning a placement for a child with a disability who will be living away from home should follow the same principles for placements which would apply to a child without a disability. All children need

arrangements which offer them a sense of permanence and security which, whenever possible, provide an experience of ordinary family life, ensure that appropriate education is available and encourage the child to develop a positive self-image and to enjoy the same opportunities for personal growth as would be available to other children without a disability. Trusts should not lose sight of the need to establish who exercises parental responsibility for the child on a day to day basis. Every effort should be made to ensure that children are not placed far from their family home and local community. If the use of accommodation away from home is necessary, family links should be maintained and encouraged. The child and his relatives should be enabled, through financial support if necessary,(see 11.5 below) to maintain a good relationship. Trusts should seek to involve parents where they have become peripheral to the child's life. Children with a disability may be among the most vulnerable children in terms of creating and maintaining family and community links. Their views may not be actively sought because of misconceptions about their level of ability to understand and communicate (see paragraph 6.6-6.8). As for all children, attention should be given to issues relating to racial origin, gender, cultural and linguistic background and religion – and to the child's preferences and personal aspirations and interests.

11.4 Misunderstandings about decisions are most likely to arise when children and young people have become isolated and little is known of their former life-style and family and social networks. Talking with children right from the start is an essential and integral part of any participation strategy and should be a key factor in planning services for particular children with a disability.

Promoting contact

11.5 When a child is being looked after by a Trust the latter must endeavour to promote contact between the child and parents, relatives and friends and anyone else connected with him (Article 29). The Trust also has a duty to promote contact between children

in need and their families where the children are not accommodated by the Trust but are living apart from their family, if it is necessary in the opinion of the Trust to safeguard or promote the child's welfare (paragraph 11 of Schedule 2 to the Children Order). If parents feel guilty or ambivalent about the residential placement – or if the cost of visiting is high – relationships may also suffer. One important consideration in any foster care or residential placement is reunification of child and family. This is more difficult to achieve if contact with parents and other significant figures in the child's life such as friends, brothers and sisters, relatives from the extended family or other people in the local community is lost.

11.6 Promoting contact should be seen as an integral part of a placement (except where this would not be in the best interests of the child). Trusts should assist the family, relatives and child with travelling expenses where they consider that there would be undue financial hardship if assistance was not given and the circumstances warrant it (Article 30). Families may feel inadequate and uncertain about maintaining links with a child in a residential setting. Encouragement and a positive welcome to visits on a regular basis are therefore extremely important. Similarly, residential care and foster family members should be reminded of the importance of their role in reunification by promoting the child's links with home through letters, phone calls, visits and open days. More detailed guidance on contact is contained in **Volume 3: Family Placements and Private Fostering.**

The independent visitor

11.7 Many children with a disability who need a residential service are placed at some distance from their family home, because of problems in finding acceptable accommodation with the necessary specialist facilities. Article 31(1) enables Trusts to appoint an independent visitor (see Chapter 9 of Volume 3 for further guidance). In general, such an appointment will not be made unless the child has not been visited by his parent or other people with parental responsibility for over a year.

The appointment of an independent visitor should only be considered when all possible means of promoting contact with the child's family or friends have been explored, and the assistance provided by the Trust has demonstrably failed to ensure regular and beneficial contact between child and family. If it is then judged to be in the child's best interests to have such a visitor, an appointment of a visitor may be made who will visit, advise and befriend the child. Expenses incurred during these visits may be recovered from the Trust.

11.8 Independent visitors offer an important opportunity to maintain contact between a child or young person with a disability and his local community. In a very limited number of cases there may be a relative who would be appropriate to fulfil the role of independent visitor and this arrangement might be the child's preferred option. Trusts will need to distinguish between the small minority of cases where the designation of a relative or friend as the child's visitor is appropriate and the more common situation where the child properly has ongoing contact with relatives and friends. In the latter situation the Trust should encourage such contacts and may pay expenses without the necessity of changing the status to that of independent visitor (Articles 29(1) and 30(2)). Children may object to a particular appointment or they may be able to suggest who might perform such a role.

11.9 Every effort should be made to ensure that the independent visitor is acceptable to the child and that he is familiar with the child's special needs and can communicate – if necessary through Makaton or in an appropriate sign language. A visitor may need guidance and support in identifying what key factors to consider in the child's environment and how to establish a relationship with a child with complex needs. Children should have opportunities to see their independent visitor in private if they so wish and the visitor's views on the current lifestyle and feelings of the child should be considered carefully by the appointing Trust. In appointing suitably experienced independent visitors, Trusts might choose to liaise with the voluntary sector to

ensure that visitors (if unknown to the child) do have a clear understanding of the child's disability and its likely impact on the child in question.

Planning

11.10 Under the Children Order regulations assessing and planning for a placement must be reinforced and updated by regular reviews which take account of the child or young person's views, with those of parents and others. Parents who retain parental responsibility for the child during a placement, should also be actively encouraged to plan for the child's future. Many families find relationships with carers very difficult to cope with and may, without help, perceive a residential or foster placement as family failure. Involvement of parents during the planning stage and subsequent placement is essential to the success of the placement and to any longer term plan for the child's return to his family.

Short-term or respite care

11.11 Respite care should be provided in the context of a package of care for families. Many children with a disability are cared for away from home or usual placement on a short-term basis as part of a planned programme or respite care. Respite or short-term care for families with a child with a disability has developed historically as an emergency service – frequently providing short-term care within a long-stay hospital or other institution in order to meet a family crisis. In the past decade there has been growing concern to provide more appropriate flexible short-terms care which offers:

- a local service, where the child can continue to attend school as if still living at home;

- good quality child care in which parents have confidence and which ensures that the child is treated first as a child and then for any disability which may require special provision;

- planned availability. Research into different models of respite care has clearly indicated the importance of parents (and older children) choosing patterns of use and being able to use a service flexibly;

- a service which meets the needs of all children. Concern has been expressed about the lack of respite care for children with complex needs. The service should be available to children living with long-term foster carers or adoptive parents;

- care which is compatible with the child's family background and culture, racial origin, religious persuasion and language;

- age-appropriate care – so that young children and adolescents are given relevant care and occupation; and

- an integrated programme of family support which sees planned respite care as part of a wider range of professional support services to meet family needs. Escalating use of respite care may indicate a need for other family support services.

11.12 Some children still receive such care in a hospital setting. This may be appropriate where the child has substantial medical, therapy and nursing needs. It is clear government policy that children with a learning disability should no longer live in long stay mental handicap hospitals. Instead, if a hospital setting is required, the aim should be to provide care in small homely, locally-based units. However for most children care provided by Trusts or voluntary organisations will be appropriate with an input from child care services if required. There are examples of community facilities run by Trusts and voluntary organisations, sometimes working in partnership, which achieve high standards of respite care.

11.13 A number of evaluations of respite care schemes have shown varied patterns of use by families, with some a few hours a week with occasional overnight stays while others opted for shared care arrangements in which the child spent regular periods away from home. It is important to acknowledge the stresses associated with the child using respite care for the first time and sensitive introductions are required.

Application of regulations

11.14 The Children Order regulations relating to placements make special provision for short-term placements within schemes which are variously known as respite care, phased care or family link schemes. Under such schemes, a Trust or voluntary agency makes arrangements for a child who normally lives with his family – and whose family continues to exercise full parental responsibility – to spend short or sometimes longer periods of time with an approved foster parent or in a residential home. These regulations apply to all placements for more than 24 hours. The arrangements for respite care vary greatly and many schemes only make provision for day-time or occasional over-night stay. In these cases, if the provision of services to the family does not include accommodating the child for a period of more than 24 hours, then the regulations relating to placements do not apply. However, good practice requires that all such provision is properly planned.

11.15 It is important to note that, in respect of arrangements which do not involve a Trust initially, that under the Children Order the private fostering provisions come into force after a child has been, or it is intended that he will be, living with a foster parent for more than 27 days. Up until then, the registration system regulating child minders applies. This requires the Trust to register a person who, for reward, cares for children aged under twelve on domestic premises, provided they are satisfied that the person is fit to care for such children. The Order requires Trusts to impose requirements on a registered person

about the number of children he may care for, safety of the premises and equipment, records to be kept and notification of changes. In cases where parents make their own arrangements for respite care for their child by contracting with a child minder, they are responsible for ensuring that these are satisfactory although the Trust's responsibilities in respect of child minding will apply. It is important that Trusts' registration officers find out about child minders who intend to offer a respite care service so that the appropriate requirements are imposed on the person's registration. In such cases attention needs to be paid to the sleeping arrangements, the type of equipment available, training needs and information about other resources in the community.

11.16 Some children may spend longer periods of time away from home and it is necessary from the start to clarify the purpose of the respite care, to plan for the child's use of a particular service and to acknowledge that respite care may or not meet all the needs of the child and family. Respite care may be only one component of a package of services.

11.17 Regulation 13 of the Arrangements for Placement of Children (General) Regulations allows for a pre-planned respite care arrangement involving a series of placements at the same place to be treated as a single placement. The length and timing of the individual placements within this arrangement need not be specified in advance, but all the placements should occur within a period which does not exceed one year, no single placement should exceed four weeks and the total time spent by a child in respite care should not exceed 90 days. The purpose of this provision is to allow the regulations to be applied once in relation to a series of placements if the conditions above are met.

11.18 Under the Arrangements for Placement of Children Regulations. Trusts or voluntary organisations are required to have a plan for each child setting out the proposed respite care arrangements as required under these regulations. The Foster Placement (Children)

Regulations apply in all other respects for family placements. Children may only be placed with an approved foster parent – but a foster parent may be approved if desired for a respite care scheme only and the chosen name of the scheme and the carers may be used within the agreement. Regulations require medical examination of the child at stated intervals, but do not set out the form the examination should take nor whether it should be a child's GP or a consultant who should carry it out. The matter should be discussed with the parents, the child, the carers, the consultant responsible for the child and the GP if doubt exists about the most appropriate person to carry out the medical examination. It is envisaged that these examinations will be part of the usual health care arrangements for the child.

11.19 The formalisation of previously more informal arrangements is to safeguard the welfare of the child. Some parents perceive regulated foster care arrangements as relating to care proceedings and inadequate or uncaring parenting. Equally some of the families recruited for family-based respite care have never seen themselves as foster parents and may be alarmed at the prospect of a more regulated service. In practice all good family-based respite care schemes have always operated upon a firm principle of written agency and parent agreements and planning around the individual needs of children. The recruitment and training procedures for respite carers should now include opportunities to explain the new basis of regulating respite care and the mutual advantages to children, parents and respite carers of having greater accountability for the service provided. Positive publicity should emphasise the advantages of working within a planned framework which supports both parents and carers.

CHAPTER 12: FOSTER PLACEMENTS

12.1 It is generally agreed that all children benefit from the opportunity to grow up in a family setting. Although finding suitable placement for a child with a disability may create certain challenges, the past decade has seen a major growth in successful foster placements for children with a range of special needs. Trusts must take the lead but a number of national voluntary agencies also provide specialist fostering programmes for children with a disability.

12.2 Under the Children Order, there are three different types of fostering arrangements:

(a) placements by a Trust;

(b) foster parents with whom a child is placed by a voluntary agency; and

(c) private foster parents.

Foster placements under the Children Order are governed by the Foster Placement (Children) Regulations which apply to foster placements by Trusts and voluntary organisations (see **Volume 3: Family Placements and Private Fostering** for detailed guidance on foster placement). Without special exemption from the Trust no person may foster more than three children unless the children concerned are all siblings.

Recruitment of foster parents

12.3 Recruitment campaigns may need to be targeted at particular groups in the community, especially where the Trust has a need for foster families from particular racial, cultural or religious groups and with practical experience of disability. Many foster families for children with a disability may be identified among those who have had personal experience of disability through employment, local

community work or relatives and friends. In addition to positive policies on recruitment, training and support programmes for foster families should include opportunities to meet children with a disability and their parents, to visit local services (including schools) and to have practical information on particular disabilities and their management. Attitudes and expectations about the potential of children with a disability will be directly affected by the arrangements for recruitment and training. The possibility of involving people with a disability as foster parents or as contributors to training programmes should be actively considered. Many children with a disability lack positive adult role models and will gain greatly from contact with adults with a similar disability who are well integrated in their local communities and can give counselling and practical help.

12.4 Every effort should be made to avoid frequent changes of school and to ensure that children are not disadvantaged by the use of placements which involve major changes in their educational experiences. Continuation in education should be seen as a high priority in making a placement. Trusts should ensure that potential foster parents understand the central role of parents and be willing to participate with parents in the social, academic and community activities of the school in question. Such involvement might mean:

(a) sharing attendance at school activities such as open evenings; PTA meetings, assessment and reviews;

(b) taking an interest in sharing school-based learning programmes such as paired reading schemes, home/school diary, speech or physiotherapy and independence training exercise;

(c) taking up the facilities on offer for study – for example a 15 year old approaching GCSE will require space and opportunity for private study and access to libraries, books etc;

(c) a willingness to maintain friendship links and to encourage the child to bring friends home, or to attend leisure activities or play-schemes where such friendships may be nurtured and developed. Some children with a disability lead limited and often isolated social lives. Foster families should be asked if they are willing to help develop positive links with the local community and whether they have the time and commitment to support such networks.

Training and support for foster parents

12.5 In addition to initial training after recruitment, foster parents will need specific training around the particular needs of individual children. Successful placement of children with a disability will require understanding of the nature of the disability and its most effective management. For example, foster parents may need to know how to check and adjust hearing aids (or learn British Sign Language or use the Makaton Vocabulary or other communication systems where a child is deaf or has other communication problems). A chid with cystic fibrosis will need help with postural drainage and any carer will need to understand the most effective way of managing respiratory tract infections and diet. Children with a physical disability will not only need care but active encouragement to develop self-care and independence skills. Children with a learning disability similarly need support in acquiring new skills and in playing an active part in their local community.

12.6 Foster parents, like natural parents, will need supporting in acquiring the relevant skills. They should be encouraged to join local voluntary organisations for the relevant disability and to acquire any necessary skill through attending courses or using distance learning material such as those available through the Open University. Caring for a child with a significant disability can be tiring and foster families may feel isolated and concerned at how they balance other family commitments with a child's special needs. Many specialist foster schemes now offer respite care and access to day care and holiday play-schemes to foster families.

12.7 If a child has complex or multiple disabilities (and special health care problems), particular effort should be made to ensure that foster parents – like other parents – have information on the full range of services and are in contact with other parents and relevant professional and voluntary sources of help in the area. Many children with a disability will regularly attend paediatric or other child health service departments. Whenever possible, placements should ensure a child's continued use of such provision and foster parents should be encouraged to be active partners with parents if appropriate, in such visits and any treatment arrangement.

The foster home

12.8 Foster families provide children with a disability with an important opportunity to live in their local communities rather than be placed in more traditional forms of residential care. However, ordinary homes may be neither automatically accessible nor suitable for children with a disability.

12.9 The Trust shall make every effort to ensure that accommodation for a child with a disability is suitable for his needs. Article 27 (9) of the Children Order requires that the Trust "so far as is reasonably practicable, secure that the accommodation is not unsuitable to his particular needs". The provision of appropriate equipment or adaptations to bathrooms and bedrooms can make accommodation suitable and encourage independence. Where necessary, an occupational therapist can make an assessment of the child's future living environment and ensure that it is as barrier free as possible.

12.10 It is essential that children with a disability (who may have incontinence or special personal care needs) should have privacy in bathroom and bedroom and that they should not be excluded from the main areas of the home such as living rooms and kitchen (and the social activities which take place in these areas) because of access difficulties. In many instances access problems can be resolved through the use of relatively simple and cheap modifications such as the use of movable ramps and other aids. It is quite unacceptable for a child to be placed in

a setting where he is more restricted than would have been the case in the natural home or in a residential setting. Similarly, accommodation may be suitable in itself, but the child will be severely limited in his use of it if the carers lack confidence in the management of a child with, for example, a severe visual handicap or if the child concerned is hyperactive. The Trust should additionally ensure that the accommodation is safe for the child in question and that access (and egress) can be easily accomplished in the case of fire. If a child is hyperactive or for some other reason is liable to be at risk if playing outside the house, the safety of any garden gates and fences should also be assessed. It would be inappropriate for a child with a disability to have to be confined unnecessarily to particular rooms because of problems of safety relating to the physical environment of the placement.

Discipline and sanctions

12.11 Prospective foster families should be asked for their views about discipline and sanctions (including the arrangements which they use with their own families). The Foster Placement Regulations require that prospective foster parents agree not to use physical punishment on children placed with them as a condition of being approved as a foster parent. There should not be any restriction imposed on visits to or from parents or family members as a disciplinary measure. Foster parents may need advice and reassurance about how to manage difficult behaviour and what controls are acceptable in particular circumstances. Such advice and the opportunity to discuss different options in the management of difficult behaviour should be seen an important and integral part of the training and support programmes provided.

Private fostering

12.12 The provisions of Part X of the Children Order in respect of privately fostered children relate in the main to children under the age of 16. But in the case of a child who is disabled the age specified is under 18. The Trust must be notified of all private fostering within its area.

12.13 Trusts have a duty to satisfy themselves that the welfare of children who are privately fostered is being satisfactorily safeguarded and promoted. They are also required to give advice if it seems to be needed. Particular attention should be given to situations where a child with a disability is being cared for on a private basis and where the carer may have little knowledge of, or access to, support services in the locality. Although private fostering of children with a disability is probably relatively little used, the supervisory visits of all private fostering placements under the Children Order should ensure that such children have greater protection. The Children (Private Arrangements for Fostering) Regulations and associated guidance are contained in **Volume 3: Family Placements and Private Fostering.**

CHAPTER 13: RESIDENTIAL CARE FOR CHILDREN WITH A DISABILITY

Residential care

13.1 **Volume 4: Residential Care** provides guidance on children in residential homes and establishes important ground rules about the quality of the care and environment which should be provided. However, some children with a disability will have special needs over and above those of their non-disabled peers. The availability of privacy and domestic-style living arrangements for children with a disability may depend on access arrangements. Children with a disability should have access to all the accommodation and the same rights to privacy as their able-bodied counterparts. For example, the management of incontinence or other personal care needs in an integrated setting will necessitate suitable bathroom accommodation which offers space, privacy, sufficient hot water and convenient location to other living areas. No child with a disability should be placed where he cannot use the recreation, living or garden areas because he can literally not gain access to them. Homes which accommodate children with a disability are required to provide the necessary equipment, facilities and adaptations. The aim should be to integrate the child in every aspect of life in the home, not merely the physical aspects.

13.2 Safety is an issue, particularly in older or adapted buildings which have accommodated relatively few children with a disability. British Standards Institute publications (in particular BS 5588) give helpful guidance on access for disabled people. Careful attention should be given to the general fire precautions taken, including the nature of the furnishings and the arrangements made for fire drills and evacuations. For example, arrangements should enable children with physical or sensory impairments to be aware of and able to respond to fire alarms and evacuations of buildings. Trusts may find the **Child Accident Prevention Trust's Leaflet: Basic Principles of Child Accident Prevention – A Guide to Action, useful.**

Child accommodation in residential care home, nursing homes and private hospitals

13.3 Homes of this kind are registered and regulated under the Registered Homes (Northern Ireland) Order 1992. The person carrying on such a home must notify the Trust if a child is accommodated either for three months consecutively or the intention of the person who decides to accommodate him is that he should stay that long. The Trust must also be notified when the child ceases to be accommodated (Article 175(2)).

13.4 The Trust has the same functions towards the child as are described below in respect of a child accommodated by an education and library board. The Trust is empowered to enter a residential care home, a nursing home or a private hospital in order to ascertain whether the children's welfare is being satisfactorily safeguarded and promoted.

Secure accommodation

13.5 Under paragraph 8 of Schedule 2 to the Children Order every Trust must take reasonable steps to avoid the need for children to be placed within secure accommodation. However, in certain circumstances (Article 44(2)) children may, as a last resort, be placed in secure accommodation (ie in accommodation which imposes restriction of liberty). A child may only be placed in such accommodation if:

(a) he has a history of absconding, is likely to abscond from any other type of accommodation and if he absconds is likely to suffer significant harm; or

(b) he is likely, if kept in any other type of accommodation, to injure himself or other people.

13.6 The provision and use of secure accommodation is governed by Article 44 of the Children Order and by the Children (Secure Accommodation) Regulations. Article 44 and these regulations apply to children whose liberty is restricted in specified establishments. A child cannot be so accommodated for longer than an aggregated period of 72 hours without a court order. For detailed guidance on the Children (Secure Accommodation) Regulations and on the provision and use of secure accommodation generally, see **Volume 4: Residential Care.**

Children accommodated in hospitals administered by a Trust or accommodated by an education and library board

13.7 Although some children with a disability or with serious health problems may spend substantial periods of time receiving care or treatment in a hospital setting, it is against government policy that such children should be placed for long-term residential care in a hospital setting. The use of a hospital setting should reflect a child's need for assessment, treatment or other services which cannot be made in Trust provision or at home and should in no way constitute a permanent placement. Close working partnerships between different professional groups in Trusts should be an integral factor in local policies for implementation of the Children Order. Such partnerships will clearly identify the particular health care needs of individual children and the extent to which they should be met in a health setting. It should be emphasised that not all children with a disability have health care needs. In many instances advice from child health staff, with appropriate support, should enable children to continue to be cared for in Trust or voluntary provision.

Notification Duty

13.8 If a child is accommodated in a hospital administered by a Trust or is provided with accommodation by an education and library board for more than three months on a consecutive basis or the intention is that this will happen, the Trust or education and library board must notify the responsible authority. The responsible authority is

interpreted as being the Trust for the area in which the child lives or was ordinarily resident immediately before being accommodated or the Trust in whose area the accommodation for the child is being provided. The accommodating authority must also notify the responsible authority (Articles 174(3), 175(2) and 177(3) when it is proposed to end the child's placement. The responsible authority must take all reasonably practical steps to decide whether the child's welfare is adequately safeguarded and promoted in the accommodation and to decide whether it is necessary to exercise any of its functions under the Children Order.

13.9 The new notification duties are to ensure that children are not "forgotten" and that Trusts assess the quality of child care offered. Children with a disability are more likely than other children to be placed in establishments which are in remote and rural areas away from their home base. The new arrangements should ensure more coherent planning for children and will necessitate close collaboration with child health staff (including the specialist advice available through child development centres and multi disciplinary community teams).

13.10 Where a child's stay in hospital is prolonged, the hospital social worker may have an important role to play. Chronic illness places enormous strain on a family's emotional and financial reserves. Counselling, practical and financial support (for example for hospital visits, baby-sitting etc) during and immediately after hospitalisation will do much to avoid longer-term problems. Trusts' social services staff will need to work closely with GPs and health visitors to support families when the child returns home.

13.11 Some children with a disability and special needs attend independent or non-maintained residential special schools – some on a 52 weeks a year basis. The use of a residential school, after careful joint assessment by the Trust and the relevant education and library board may represent an important resource for the development of a particular child. Residential school placements should be made with

a clear understanding of the nature and objective of the placement. Close links with the Trust in question will ensure that there is clear and coherent planning for the school holidays, the maintenance of family and community links and future arrangements for the child when leaving school. Placements in a residential school should never be made by a Trust without consultation with the relevant education and library board.

CHAPTER 14: REPRESENTATIONS PROCEDURES

14.1 The Children Order requires Trusts, voluntary organisations and privately run children's homes to establish procedures for considering representations and complaints about children's services. The procedure should cover all representations or complaints about a Trust's actions in exercising its functions under Part IV of the Order (Support for Children and their Families). Voluntary organisations and privately run children's homes will also be required to set up representation procedures to consider representations or complaints made by or on behalf of children accommodated by them but not looked after by a Trust. The arrangements for such procedures are covered by the Representation Procedure (Children) Regulations (see **Volume 3: Family Placements and Private Fostering** for detailed guidance). Representations and complaints which do not come under the Children Order procedure may be considered under the procedure (see Departmental policy paper "People First") or may be more appropriately considered under another agency's procedure.

14.2 Children and other complainants should have access to a procedure which offers an opportunity to make statements about, and to challenge decisions made by, service providers. All those required to have representations and complaints procedures under the Children Order must ensure that the procedure in question is fully understood and accepted by service users and their representatives but also by the Trusts or service providing agency's staff. Local consumer groups and service users should be involved wherever possible in setting up the procedures so that the system arrived at is fair, equitable and usable in the context of local needs.

14.3 Complaints and representations may be made about the way in which the Trust is acting in relation to a child in need, by the child, the child's parents or any one having parental responsibility for him, any Trust foster parent or any other person who could be regarded as having sufficient interest in the child's welfare to warrant representations being considered by the Trust, voluntary organisation or privately run home.

14.4 The procedure developed by the Trust must have an independent element, which means that at the first stage of the procedure a person who is not a member or an officer of the Trust must take part in the discussion and consideration of such representations or complaints and in determining what action should be taken (Article 45(4)). If the complainant is dissatisfied with the action the Trust proposes to take the first stage, the complaint may be referred to a panel with an independent element for further consideration. Local voluntary organisations and consumer groups may be able to provide nominations for panel members and can be a source of independent advice and advocacy for the child or family concerned. Every effort should be made to work with local disability groups to ensure that the procedures are accessible, usable and effective when dealing with issues relating to disability.

14.5 Trusts will be expected to give due consideration to the findings of those who carry out the complaints and representation procedure. They are not, however bound to implement the findings. They will be required to notify in writing the person who made the complaint or representation, the child (if he has sufficient understanding) and anyone else likely to be affected by the Trust's decision, the reason for it and what action (if any) it proposes to take.

14.6 In the case of children with a disability, complaints and representations are likely to focus around assessment and the delivery of (or failure to deliver) certain services. Because of the multiprofessional support needed by the majority of children with a disability, the consideration of a complaint made by or on behalf of a child with a disability should:

- consider whether there is a need to consult a range of relevant expert opinion, for example from the relevant education and library board;

- ensure that children with a disability are given appropriate support in making complaints or representations and in participating in decision-making about their own futures; and

- consider whether the complaint is really about another agency's services and should be directed to a different procedure.

14.7 There will be occasions when children or young people (and indeed many parents) will need help, advice or support from another individual or from an outside agency in framing or pursuing a complaint. Support should be offered or advice given on where support may be obtained, where a complainant is vulnerable or unsupported or where language, cultural diversity or a complex communication disorder or disability may impede communication. Many children and young people with a sensory or learning disability will have more complex communication needs than can be met by the provision of an interpreter. If a written complaint is made or a verbal complaint recorded, they may not be easily able to verify the nature of the recording. Equally they are most unlikely to have easy access to information on complaints procedures which will be readily available to other potential users in the community. Trusts are required to give information on complaints procedures to children and young people with a disability, with relevant and useable information about how a complaint may be initiated (particularly in a residential setting where access to a private telephone may be problematic). Schools may be a useful source of information for both children and parents. As noted above, complaints procedures should not be seen as the only way of resolving differences of opinion about services and management. Every effort should be made to use assessment and review in a positive and constructive way in order to negotiate a clearly understood package of services, with accurate information for all concerned about what is being provided.

14.8 In some instances complaints may relate to inappropriate services for children with a disability, for example where there are poor access facilities, unsuitable furnishings or equipment or where children are unnecessarily excluded from the full range of activities appropriate to their ages, interests and general ability. In these instances expert advice on the particular disability should be identified eg from within the Trust or from a voluntary organisation and the Trust's existing

arrangements for placement reassessed to avoid similar difficulties in the future.

14.9 It is essential that complaints procedures are explicit about how such vulnerable people may learn about complaint procedures and how they may use them, particularly if they are receiving services within their own homes. Article 45(8) of the Children Order requires Trusts to publicise their complaints procedures. This might be done in a variety of ways, ensuring that information is available in any relevant minority language and that the local disability and user groups are part of the publicity process. Trusts might consider holding special meetings for their local voluntary sector to publicise the groups work in tandem in making the procedures work. **Written information should also be freely available in Trusts, GP surgeries, hospital out-patients departments, health clinics, schools, libraries, nurseries, citizen advice bureaux and any other appropriate local setting used by the public.** Because many people with a disability have limited access to public buildings where such information is most likely to be prominently displayed, consideration should be given as to how information on complaints procedures may be made widely available to children with a disability and their parents.

CHAPTER 15: CHILD PROTECTION AND COURT ORDERS

15.1 The Children Order's emphasis on partnership and prevention is designed to enable families resources to be strengthened and for children to be brought up and protected within their own home if at all possible. The Order also provides for situations where parental care may have broken down and where the child is seen as suffering or likely to suffer from serious risk of ill-treatment (including both physical or sexual abuse). The essential element in the Trust's decision to apply to the court for an order will be lack of co-operation by parents in safeguarding and promoting the child's welfare. The balance between the rights of the child and the role of parents is at its most delicate in the field of child protection. Child protection is always complex and potentially contentious. In the case of children with a disability who may have communication or behaviour disorders, assessment of degrees of risk will be even more complex. But the Children Order offers new procedures which attempt to strike a reasonable balance between the need to protect children and the rights and responsibilities of any others involved. The legal effect of the new orders is clear and before making any order, including an emergency protection order or child assessment order, the courts must be satisfied that doing so would be better for the child than making no order at all.

15.2 The Children Order places a major emphasis on social work practitioners collaborating closely with other statutory and voluntary agencies which may have relevant knowledge of a child and family. Detailed guidance on child protection and court orders is in **Volume 1: Court Orders and other Legal Issues.** Guidance on inter-agency working is contained in **Volume 6: Co-operating to Protect Children**. The management, supervision, training and support of staff in education and health settings with children with a disability will be critical for effective implementation of child protection policies and the early identification of children who may be at risk. Awareness of potential abuse in the disability field is comparatively recent, with a number of agencies developing new material and policies in this area.

15.3 The Children Order spells out the duties of Trusts to make investigations in a range of circumstances (Article 66) to enable them to determine whether any action should be taken to safeguard a particular child. The options open to a Trust will vary according to the degrees of risk to the child and the assessment of the extent to which those with parental responsibility are able and willing to co-operate in any plans for ongoing assessment and support. Relevant information must be provided by housing, education and health services unless regarded as unreasonable in the circumstances (Article 66 (10)). The Children Order states clearly that representatives of the Trust should try to see the child in the investigative process, unless they are satisfied that they have sufficient recent information (Article 66 (4)).

15.4 In considering the need to request a court order for a child with a disability, all agencies (whether within the Trust or not) must have clear views on what would be appropriate standards of health and development for the child in question. The use of court orders in place of earlier support and guidance for families would be against the principles of the Children Order. Careful baseline documentation will be essential and will require expertise and the involvement of appropriate professionals. Children who require considerable amounts of personal care, who have few communication skills or have a severe learning disability will require very careful assessment. Such children are particularly vulnerable to abuse and are the least likely to be able to articulate their fears or anxieties about inappropriate treatment. All statutory and voluntary agencies should ensure that their staff are aware of the inter-agency child protection procedure agreed by the Area Child Protection Committee (ACPC) in their area. Agencies should ensure also that their staff have information and training which will enable them to work responsibly if there is suspicion of a child being at risk.

Child assessment order

15.5 The child assessment order (Article 62) is not an emergency order

and notice is given between parties. It can be made on the application of a Trust or by an authorised person (for example the NSPCC), when the court is satisfied that:

- the applicant has sufficient cause to suspect the child is suffering, or is likely to suffer, significant harm.

- an assessment of the child's health, development or of the way in which he has been treated is required to determine whether he is or is likely to suffer such harm.

- it is unlikely that an assessment will be made or be satisfactory in the absence of an order.

15.6 The court can allow up to seven days for the assessment. The Order may specify the date by which the assessment is to begin. The applicant should make the necessary arrangements in advance of the application, so that it would usually be possible to complete within such a period the medical or psychiatric examination or other assessment directed by the court. This should be sufficient to establish whether the child is suffering, or likely to suffer, significant harm and, if so, what further action is required. Because of the limited timescale for the duration of the order, the assessment arrangements must be well co-ordinated and the Trust should give careful advance consideration to the expert witnesses which it may want to call upon. In the case of a child with a disability, these may come from a very wide range of professionals; an educational psychologist or child psychiatrist may need to be involved. Parents may wish to bring their own expert witnesses but the court may rule on this. However, even at the late stage of going to court for an order, the Trust should seek the parents' co-operation and agree on an expert to carry out the assessment and so avoid additional stress for the child. This needs to be considered in the context of:

(a) any rule of court which requires any party to obtain the leave of the court before adducing evidence based on expert assessments.

(b) the duty of the Trust to ensure that the assessment is adequate for the purpose so as to fulfil its child protection responsibilities.

The court can direct the nature and type of assessment to be carried out and, in exceptional circumstances, may require that the child stay away overnight. This should, however, only happen very rarely.

15.7 Child assessment orders will, therefore, require the obtaining of information from a variety of sources about a particular child. Definitions of "health" and "development" may be particularly difficult in some children with multiple disabilities and complex behaviour patterns.

Emergency protection order

15.8 The emergency protection order (Article 63) is an emergency measure to provide immediate short-term protection. An emergency protection order gives powers to the applicant to remove a child to accommodation and to keep him there or to prevent his removal from the existing accommodation (for example a hospital ward). The order provides the applicant with parental responsibility for the child, but only in so far as the applicant needs it to safeguard or promote the child's welfare. Although the legislation provides for anyone to apply for such an order, the applicant will normally be the Trust or the NSPCC and in most cases the order will be transferred to the Trust after it has been made. The order may only last for up to 8 days unless extended for up to seven days by application to the court. The order may be extended once. The original order can be made without notice and although there is no immediate opportunity to challenge it, there is right to challenge the making of the order after 72 hours. This only applies if relevant parties were not given notice of the hearing and were not present.

15.9 Under Article 65 of the Children Order, the police are given new powers to take a child into protection for up to 72 hours if the constable in question believes that a child might otherwise suffer significant harm. During this time the case must be investigated

by a designated police officer (the designated officer). The constable in question must inform both the Trust and the child of what is happening and take reasonable steps to discover the wishes and feelings of the child. Trusts and the relevant police station must have clear arrangements for dealing with any emergency protection order which concerns a child with a disability. Such arrangements should provide for expert advice to be available.

15.10 It is acknowledged that it is possible that misunderstandings about the most effective management of some children with a disability (in particular those with challenging behaviour) may occur without clear understanding of the nature of the child's needs. However, children with a disability are particularly vulnerable. They have the same rights as other children to be protected. At all stages it should be recognised that child protection procedures, however well they are managed, are traumatic for the child, his family and others caring for the child. Children with a disability should have clear explanations of what is happening and their views should be actively sought. Assumptions should not be made about the inability of children with, for example, a severe learning disability or communication disorders to understand the procedures. With support and the advice of a known and trusted individual, the majority of children with a disability can communicate their feelings and perceptions and articulate their needs. Children with a disability, like other children, also have legal rights with regard to consent to treatment and the withholding of consent to medical examinations if they are judged to be of sufficient understanding to do so.

Consent to medical examination or treatment

15.11 Under Article 62(8) of the Children Order, a child has the right to refuse to submit to a medical or psychiatric examination or other assessment if he is regarded as having sufficient understanding to make an informed decision. Such consent is not limited by a particular chronological age nor is it affected by disability or any other special needs. Where a child has a disability, however, special efforts should be made to explain the purpose and likely outcomes

of any examination or assessment. Children may be particularly reluctant to agree to an examination if it involves unknown people in a strange place, or if they are frightened of the procedures involved. They should have the opportunity to discuss the proposed arrangements with and trusted person, if at all possible, who can reassure them and emphasise the need for an examination or treatment. If the child already has a Guardian *ad Litem* or a social worker, he will be involved in the discussion. Where children have communications difficulties these must be addressed. A child's refusal to consent to examination or treatment may be due to an earlier absence of real discussion with the child concerned about his feelings and anxieties about what has happened.

CHAPTER 16: TRANSITION TO ADULTHOOD

16.1 Article 35(1) of the Children Order gives Trusts new duties to advise, assist, and befriend each child whom they or certain other agencies look after with a view to promoting his welfare when he ceases to be looked after by them. Trusts are also reminded that they should take steps to prepare a child for the time when he is no longer looked after by them (see **Volume 3: Family Placements and Private Fostering**).

16.2 General improvements in services for young children with a disability have led to increasing optimism about the feasibility of ordinary adult life experiences and independent living and employment. However, as the Warnock Report noted in 1978: "We are aware that greater independence particularly for those with a severe disability will not be achieved simply by administrative measures or the injection of more resources. In the end changes in the nature of education, training and supporting services will depend upon changes in attitude".

The need for ongoing support

16.3 All parents face problems in supporting and preparing their children for an independent adult life. Few young people (with or without special needs) are expected to become fully independent on their eighteenth birthday. The transition to financial independence and independent living is not usually a single event, nor does it happen quickly. The majority of young people achieve such independence in stages and many remain both economically and emotionally dependent upon their families in a variety of ways. Young people with a disability are particularly vulnerable at the transition to adult life. If they have left Trust accommodation, they may all be the more vulnerable if there has been family breakdown or unhappy early life experiences. Some young people with a disability may be vulnerable and ill equipped to cope with independence without ongoing support because their development may have been delayed in a variety of ways and they are less likely to have had access to the wide range of social experiences enjoyed by their non-disabled peers.

They may have been over-protected and not provided with the same opportunities to develop independence as non-disabled young people have at a comparable age. In many instances they will need some degree of ongoing care and may be more dependent on other family members than they may choose. Additionally and importantly adolescence may bring full realisation of the longer-term impact of disability on future job options and personal autonomy. In some instances disability may actually produce physical deterioration at this time. In other cases young people may become disabled through trauma or other injury and have to face adult life with the consequences of such injury.

16.4 Families also change at the time of transition. Parents themselves may be less physically able to cope or may have multiple family responsibilities with the additional care of elderly relatives. Brothers and sisters may leave home and families' capacity to care may be reduced. Importantly, the young people themselves may wish to leave home. Similarly it should be acknowledged that planning for adult life should take account of the real possibilities of assisted independence for many young people with a disability and the importance of planning services which develop life skills and create real options for families. There are encouraging developments in independent living schemes, vocational training programmes and in community support for even severely disabled young people. Although investment in transition may appear expensive, the longer term benefits of greater competence and independence will be positive for everyone concerned.

16.5 Assisting a young person with a disability to make a successful transition from childhood to adulthood requires that Trusts work closely with the youth service, schools and colleges to make certain that the arrangements are understood and also to identify any new needs. The local careers service should be involved in publicising information and also in identifying the full range of local services to which might require access. It should also be stressed that in some instances the young people and their parents will need independent advice, counselling and advocacy in the effective way of meeting them. For example, where a young person has been in a

residential school the holiday periods should be used to prepare the family for an eventual return home at the end of full-time education, or to test out alternatives explored as part of the review and planning process. Sometimes parents' and children's needs may appear to diverge when the young person grows older. Issues like the possibility of a move away from the family home, home adaptations or respite care should be explored in the light of the wishes and feelings of the young person and the family and should be given sensitive consideration. Where the young person comes from a minority ethnic group, efforts should be made to use every opportunity to identify the young person's and family's personal and cultural preferences. No assumptions should be made about what the parents or the young person want.

The Disabled Persons (Northern Ireland) Act 1989 – Working with the education and library boards

16.6 Section 5 of the Disabled Persons (Northern Ireland) Act 1989 requires education and library boards to notify the relevant Trust at the time of the first annual review of a statement following the child's 14th birthday, or at the time of a reassessment after that birthday, whichever is earlier. This notification is required so that the Trust may consider whether the child will require any future services from the Trust after they have left school. Education and library boards have a further duty to notify the Trust between twelve and eight months before the actual date of ceasing full-time education. Section 5 then requires the Trust to carry out an assessment of the young person's needs, normally three months before he leaves school. This assessment should cover the whole range of need for social and welfare services, and the Trust is also expected, as far as possible, to give appropriate advice about matters such as employment and further education, and other services which may be available. This assessment and the consequent provision of services is of crucial importance in setting the scene for the young person's transition to adult life.

16.7 Trusts should work constructively with education and library boards

in considering what further opportunities for education and vocational training might be offered. If mobility or access difficulties are going to be the real barrier to educational or employment opportunities, every effort should be made to involve the physiotherapy, occupational therapy and rehabilitation service at an early stage and to consider a range of options for encouraging access or personal mobility. In some instances a student may be able to attend an integrated course in further or higher education if he has some additional personal help. Although education and library boards do fund ancillary and support workers in schools, this arrangement does not apply in further and higher education institutions. An appropriate use of monies made available through after-care might be to buy personal support to enable an individual student to attend the course most suited to his needs. Awards officers in education and library boards can provide full information about any other awards which may be available to students with a disability.

Collaborative working

16.8 Planning for post-school provision will require careful assessment and ongoing planning. Parents and young people may have different preferences and views about where and when services should be provided. Realistic assessment should take account of the needs of both and should ensure that assessment takes account of the wider personal and social, health, occupational and vocational and educational abilities and needs of the young person in question. Education providers and their Trust counterparts will need to consider carefully how best to work together and with the young person and parents in planning for young people with a disability. Patters of collaborative working will vary, but existing collaborative mechanisms in multi-disciplinary community teams may need reviewing or strengthening in order to ensure that young people have access to inter-agency expertise and provision.

16.9 Although different agencies' statutory responsibilities for children vary by age, Trusts may wish to plan around existing team structures to provide support to young people beyond the statutory age of

responsibility and to provide support during the transitional period during adulthood. Unless the resources and experience of children's services can be used during the transition to adult life, it is unlikely that young people's special needs will be met. Additionally existing resources and professional expertise will not be used in the most consumer-sensitive and cost-effective way and the skills developed during the school years may be lost in adult life.

16.10 The support of the primary health care team is of crucial importance to successful community care. Trusts should therefore ensure that they have precise arrangements for working with the relevant agencies in order to ensure that joint planning is followed by joint service arrangements for young people with a disability. Joint assessment and review cannot underpin more effective planning and care management if they do not involve all relevant agencies and professionals. GPs are crucial contributors to the assessment process. Their contribution to community care through knowledge of the whole family and the local community and their ability to monitor the individual young person's health and well being – as well as the delivery of general medical services – are essential in terms of support to young people living in their local community. For all young people the maintenance of good health is important. For children with a disability the prevention of secondary handicaps or deterioration of an existing disability will require regular review.

16.11 The Children Order (Article 46) provides for co-operation between Trusts, education and library boards, and the Northern Ireland Housing Executive. Trusts will need to liaise with the Housing Executive over the housing needs of young people with a disability.

16.12 With regard to young people with a disability, Trusts should consider their existing duties under the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 and the Disabled Persons (Northern Ireland) Act 1989. In some instances the ability of a young person with a disability to return home from a residential school or home – or to move into more independent living on his own – will depend not so much on the availability of accommodation but on the aids and

adaptations that are provided to make existing accommodation suitable. Many young people with a disability are severely limited by access problems in their own homes as they get larger and heavier. If the disability is degenerative or is acquired in the adolescent years, there may be major difficulties for all family members for example, because of use of living areas limited by access and a consequent reduction in quality of life for the whole family. When the child has lived away from home for some years, reunification will be particularly difficult to achieve if the home is unsuitable and heavy burdens of care are suddenly imposed on the family.

16.13 The past decade has seen very encouraging development in independent living by a wide range of young people with special needs and disabilities. Many young people with a learning disability, for example, are able to live together in supported independence in an ordinary house in their local community providing that they receive sufficient support. The support may be from an accessible and supportive adult, who can provide continuity and regularity of advice and guidance and ensure that the young people receive the financial support that they need, that they acquire housekeeping and independent living skills and that they are encouraged to make the best use of the full range of neighbourhood facilities. Integration in the community depends on factors other than location and will require careful assessment, care management and regular review to be successful. Parents may feel very anxious about the ability of their son or daughter to live independently and they also will need support and guidance. Every effort should be made to ensure that parents and professional carers can work in partnership in supporting young people in becoming more independent.

16.14 Where a young person has very complex disabilities or where the family feel that they are unable to offer continued care, every effort should be made to find an acceptable local alternative. Residential care should not be regarded as a failure but as a positive option where parents, family and friends have a continuing role. With the cessation of admissions to long-stay hospitals for residential care,

Trusts should consider as a matter of urgency how they can work in partnership with their education counterparts to develop new patterns of residential services which provide good quality care in the local community. Such care may be provided through Trusts, voluntary or independent agencies or by combinations and consortia according to local provision. Wherever the young person is placed, Trusts and education and library boards will have a continuing role and every effort should be made to ensure that any placement encourages development and offers opportunities for continuing education.

16.15 Some young people will need additional educational opportunities, sometimes at residential colleges or schools outside the areas of their own Trust. The new arrangements for aftercare should enable education and library boards and Trusts to plan together to arrange and to provide funding for such arrangements. Specialist educational and vocational training will require clear planning agreements between the education and library board and the Trust.

The wishes and feelings of young people

16.16 Young people with a disability and their families will need clear information on the full range of services in an easy to read guide in order to begin to negotiate the most effective package of care. Access to local support groups and voluntary organisations will be particularly important. Some national voluntary organisations can put individuals in touch with local self-help or self-advocacy groups for personal support and guidance. Self-advocacy and counselling should not, however, be regarded only as external services. A growing number of further education colleges, day centres and other provision for young people now have students' committees or associations. Many schools are moving towards student or pupil councils and the encouragement of informed decision-making and peer support from an early age. Every effort should be made not only to refer individuals to appropriate sources of help (whether within the voluntary or the statutory sector) but to ensure that there are opportunities for working together within the Trust's own services.

16.17 Where a young person with a disability has been placed out of his local community, appropriate community support will be required. In some instances young people may not have any ongoing family relationships, and may, on leaving school find themselves living in localities where they have few personal contacts. Trusts should recognise the importance of relationship building and the need to assist such young people to develop friends and contacts in local communities. Every effort therefore, should be made to begin planning at an early stage to maintain family and community links. Social work support and counselling may be able to recreate lost family and friendship networks provided that such support is sensitive to changed life-styles and to real anxieties in some instances about the consequences of any re-involvement.

16.18 In some instances, the young person's difficulties may result from diminished opportunities to discuss his disability and the various life options which might be available. Some young people express anxieties about their personal and sexual development and say they feel lonely and isolated. Realistic and sensitive counselling about future relationships and parenthood, possible implications of a particular disability and the help which may be available should all be addressed when appropriate. The support of a key worker who can provide continuity during the time of transition will be important. Trusts may wish to liaise with their local voluntary organisations in developing support networks and ensuring that parents and young people are aware of any local sources of independent advice or support in their area.