



**Norfolk** County Council  
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**Enabling Parents with a Disability**

**or**

**Long Term Illness**

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**Joint Policy and Protocol for Practice**

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## Enabling Parents with a Disability or Long Term Illness

### Joint Policy and Protocol for Practice

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## 1. Introduction

This document describes the processes related to work with parents, prospective parents or people with parental responsibility who are disabled or have a long term illness. These are **based on the social model of disability** and aim to ensure that people in this situation and their child(ren) have:

- their health and social care needs properly considered (assessed)
- access to co-ordinated services which are focused on meeting these needs effectively

In reality, the rights of disabled/ill adults to found families and live as other families, and the rights of children to live in families that provide for their needs as children, are entirely compatible and are upheld in law (Human Rights Act 1998, Articles 8, 12 & 14). The needs of children are best met when disabled/ill parents' support needs are acknowledged, assessed, facilitated and regularly reviewed.

No single agency can meet all the needs arising in families where there are disabled/ill parents. This protocol aims to create collaboration between community care, learning disabilities, mental health, substance misuse, children's, sensory support, health,

education, and all other relevant statutory and voluntary services to provide effective and co-ordinated services to support disabled/ill parents and their child(ren).

The protocol covers parents who:

- have learning disabilities
- have physical, sensory or cognitive impairments
- have mental health problems
- are problematic drug and/or alcohol users
- are older and frail people
- have long term or terminal illnesses (including HIV)
- have autistic spectrum conditions (including Asperger's)

Children are those up to the age of 18.

The protocol aims to highlight the importance of the parenting role and acknowledges the need to provide additional support to families who may not previously have been seen to meet the threshold for services. The protocol provides the foundation for good practice across specialist areas of work. It is intended as an overarching document relating to all disabled/ill parents and their children.

However, if concerns for a child's welfare exist, then this protocol should, where appropriate, be read in conjunction with the four relevant Norfolk Safeguarding Children Board protocols:

- [Protocol 10 – The Principles of Working Together to Provide Services for Children, Young People and Parents where Substance Misuse is a Concern](#)
- [Protocol 19 – The Principles of Working Together to Provide Services for Children in Need Who Have Parents with Mental Health and/or Substance Misuse Problems](#)
- [Protocol 23 – Multi-Agency Pre-Birth Protocol](#)
- [Managing Cases of Neglect: Multi-Agency Practice Guidance](#)

The practice guidance should be read with an understanding of its ethical and legal context. [Appendix 1](#) provides a comprehensive summary.

The first version of this protocol was jointly produced with the assistance of representatives from the following agencies, to whom thanks are due:

- Disabled Parents Network
- Community Services (Adult Care)
- Health Service
- Young Carers – Crossroads
- Norfolk Coalition of Disabled People
- Children's Services

For the sake of brevity in this document, all services working with adults, whatever their impairment, will be referred to as 'adult services'. References to 'a child' or 'children' may be taken to cover one or more children or young people.

## **2. Principles Underpinning Good Practice**

2.1 The protocol should ensure that there is a shift in the balance of power in the relationship between professionals and parents. Disabled/ill adults are often fearful

and anxious about approaching Adult Care or Children's Services for support with their parenting role, thinking they will be viewed as inadequate parents and that their child(ren) may be taken away.

- 2.2 Disabled/ill parents should be supported enabling their families to stay together and succeed in the interests of their child(ren). The needs of a child are best met when disabled/ill adults' support needs are acknowledged, assessed, facilitated and regularly reviewed.
- 2.3 The needs of a disabled/ill adult in their parenting role should be identified and assessed whenever a disabled/ill adult's needs are assessed.
- 2.4 Adult Care should lead the care management process unless complex child care issues dictate otherwise – whether the initial referral is via Adult Care or Children's Services.
- 2.5 Children always have the right to be protected from harm.
- 2.6 The assessment and support plan should reflect the needs of both parent(s) and child(ren). 'The Framework for the Assessment of Children in Need and Their Families ... has very little recognition of the needs and circumstances of disabled parents' (Jenny Morris, September 2003: 'The Right Support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role').
- 2.7 Services should be targeted at families who have additional needs, which means a different interpretation of the criteria relating to the threshold for service provision from that operated by specialist teams at March 2006.
- 2.8 Any disabled/ill adult who can manage life on their own without support, eligible or not, may immediately become eligible for support when they have a child.
- 2.9 It must be recognised that the combination of impairment and parenting responsibilities within the overall context of the individual family's circumstances may generate a higher degree of need for support than a personal assessment of the disabled/ill adult alone.
- 2.10 Disabled/ill parents or children of disabled/ill parents should automatically be entitled to an assessment.
- 2.11 Early identification of parents' needs is essential and multi-agency assessment in the antenatal stage is likely to achieve more positive results. It may be relevant to refer to [Protocol 23](#) from the Norfolk Safeguarding Children Board.
- 2.12 Agencies should strive to deliver early support in a non-judgemental and empowering way. The requirements of disabled/ill parents and family members for interpreters, facilitators, information in accessible formats and advocates should be established at an early stage.
- 2.13 Clear referral, assessment and service commissioning and review procedures should be in place.
- 2.14 A 'joined-up' approach to both assessment and service provision between community care, learning disabilities, mental health, substance misuse, children's, sensory support, health, education, and all other relevant statutory and voluntary services is in the best interests of parents and children.
- 2.15 Disabled/ill parents should be supported to fulfil day-to-day tasks concerned with maintenance of their child(ren)'s welfare, personal care, domestic routines, education, relationships, social and peer group support systems and community life. This may include assisting with dressing, feeding, travelling to school and age

appropriate activities. Disabled/ill parents should also be supported to access, participate in and benefit from their child(ren)'s education.

- 2.16 The needs of all carers, including young carers, should be recognised. Time consuming and/or inappropriate tasks and responsibilities which adversely impact on a young person's physical, emotional, educational or social development should be avoided by providing adequate and acceptable support services to the disabled/ill parent and their family. This may include services from Young Carers projects.
- 2.17 Assessment processes should not be unnecessarily intrusive. One jointly produced assessment report should identify the needs of the parent(s) and the needs of the child(ren) and a plan produced as to how these needs will be met with the available resources.
- 2.18 Assessments should be kept in proportion to individuals' needs and circumstances, and ensure that referral and assessment processes discriminate effectively between different types and levels of need, and produce timely service responses.
- 2.19 Budgets and services should be flexible to make sure that disabled/ill parents' needs are met. Where there are complex, interrelated child and adult care needs to be met, cost sharing arrangements between Adult Care and Children's Services should be in place to promote 'joined up' practice. It has been agreed in practice that funding will be **50% each**, to reflect that both the child(ren) and the parent(s) are being supported.
- 2.20 Support should be offered to any disabled/ill parent who is identified as needing it in an assessment and regardless of which parent is disabled/ill. The employment and training needs of the disabled/ill parent and their partner should be taken into account.
- 2.21 There should be information on the assessment process and services available for parents, children and professionals. This should be published and disseminated widely and in accessible format as necessary.
- 2.22 Where services are required, a key worker should be identified to co-ordinate them.
- 2.23 Specialist teams should provide a professional consultation service to other professionals or agencies.
- 2.24 This protocol must be used in full compliance with the County Council equality standards. No parent should be excluded on the grounds of age, sex, disability, gender, gender reassignment, pregnancy, maternity, race, religion and belief, or sexual orientation. Diversity must be taken into account and fully respected.

### **3. Practice Guidance**

#### **3.1 Eligibility for Assessment**

The County Council's eligibility for assessment criteria must be applied. These require that in the case of adults, an assessment under the NHS & Community Care Act 1990 will be carried out if:

- the individual appears to have a social problem causing significant disruption to the person's or carer's level of independence, or ability to lead an ordinary life

- the issue appears to be one for which the department has a statutory duty to provide, or arrange for the provision of, community care services or, in the case of a child, services for children in need (under the Children Act 1989)
- the person is disabled (under the Disabled Persons (Services, Consultation and Representation) Act 1986) or a person who provides care for a disabled person (under the Carers (Recognition and Services) Act 1995)
- the person is a young carer (under the Children Act 1989, the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000, and the Carers (Equal Opportunities) Act 2004)

These criteria determine which people have the right to an assessment. The next stage in the process is a decision about those who are entitled to a service, or services, as a result of the assessment.

### 3.2 Determining Eligibility for Accessing Adult Social Care

The County Council's Fair Access to Care Services (FACS) eligibility framework includes the following risk to independence, which is in the 'critical' band: **vital family and other social roles and responsibilities cannot or will not be undertaken**. The 'substantial' band includes the following risk: **the majority of family and other social roles and responsibilities cannot or will not be undertaken**. In many instances where disabled/ill parents request support with parenting roles, this level of risk to independence is likely to apply.

It is important that those responsible for determining eligibility are mindful about establishing whether a disabled/ill adult is a parent and if they have needs in this role. Where the request for assistance concerns a child, it is important to establish if the parent is disabled/ill, and the nature and effect of the disability/illness.

Where it is unclear whether the parent and/or child(ren) are likely to be eligible for services, staff are reminded that the combination of impairment and parenting responsibilities within the overall context of the individual family's circumstances may generate a higher degree of need for support than a personal assessment of the disabled/ill adult alone. In these instances an assessment visit should be arranged to determine service eligibility. The FACS framework can be found in [Appendix 2](#).

'Disabled/ill parent' includes parents who have learning disabilities, physical, sensory or cognitive impairments, mental health problems, long term or terminal illnesses (including HIV), or autistic spectrum conditions (including Asperger's), or are problematic drug and/or alcohol users, or older and frail people. It also includes prospective parents and any people with parental responsibility who are living with and caring for children, eg grandparents, step-parents, same sex couples, and adoptive or foster parents or guardians. The protocol may also be applied when a disabled/ill parent needs support for contact with their non-resident child(ren).

### 3.3 Consent

It shall be the normal working practice of all agencies to obtain the consent of the parent(s) and/or child(ren) prior to sharing information unless it is judged that to do so may place the child(ren) at risk of significant harm. Care should be taken that any request for consent is made in a way that is accessible to the parent(s) and/or child(ren). The potential need for **advocacy support** should be considered in order to facilitate informed consent and the process of assessment.

With regard to information sharing, it should be noted that the Data Protection Act 1998 may apply, and staff should refer to the appropriate instructions and information sharing protocols (Adult Care staff, see [Operational Instruction 853: Protection of Data](#)).

### 3.4 Professional Consultation

Each specialist team or agency needs to be able to discuss the issues related to referrals and/or joint work. Parental consent must be gained prior to such discussions, unless there is clear evidence that a child or vulnerable adult would be put at risk of significant harm. Each team should offer a facility enabling timely professional consultation to partner teams or agencies at whatever stage this is needed. In Children's Services, a professional consultation is provided by the Children's Services Team Manager or delegated person.

Within Adult Care and Children's Services teams:

- each specialist or assessment team will offer professional consultation and provide a designated contact number
- consultation will be provided by the team manager or a delegated person
- if the consultant is not available at the time of contact, advice may be sought from the team manager's line manager
- the outcome of consultations will be recorded on CareFirst and sent to the consultee within the agreed timescales (two days)

Professional consultation lines for both Adult Care and Children's Services are published in the [Disabled Parents section](#) of the Community Services intranet. All team managers are responsible for keeping these up to date. Those without intranet access can call Customer Services on 0344 800 8014 for an Adult Care contact number, or visit [Child Protection and Safeguarding Consultation Lines](#) or call Customer Services on 0344 800 8020 for a Children's Services contact number.

### 3.5 Referrals

- 3.5.1 Norfolk CareConnect will decide whether to 'signpost' the referrer or family to other services or to make a referral to the appropriate specialist team to undertake a fuller assessment.
- 3.5.2 Assessments in Adult Care under the protocol are all classed as 'complex cases'. As such, they must be passed to district or locality teams for assessment. It is not appropriate that telephone only assessments are done. Once a service is received, all future requests or calls should go straight to the locality.
- 3.5.3 All other referral routes will apply exactly the same principles when there is a request for an assessment involving a family which includes a disabled/ill parent. This may apply primarily in Mental Health, where **GPs may refer to the team directly**.

As a general rule, referrals for assessing the needs of disabled/ill parents should be directed to Adult Care teams, as the support is for the disabled/ill adult with parenting responsibility – unless specific Child Protection concerns dictate otherwise. If Child Protection concerns are apparent, Children's Services assessment procedures must be followed (Children's Services staff, see [Responding to Referrals and Initial Assessments](#)).

When referring to an Adult Care team, workers are advised that, since such referrals involve a child's well-being, they should be given a **high priority**.

The referral should indicate clearly that this is a referral for a **disabled/ill parent**.

Where Children's Services take the lead, they must involve the appropriate adult team in their assessments in situations where the parent or parents have a disability or long term illness.

- 3.5.4 The Common Assessment Framework (CAF) for children and young people was introduced in Norfolk in May 2005 and should be used, with consent from the young person, parent or carer, when a professional identifies that a child has additional needs which require a multi-agency response or where needs are unclear but do not meet the threshold for either Children in Need or Child Protection. Since its introduction, the CAF has been used in a number of cases where the difficulties experienced by children are, at least partly, due to the disability/illness of a parent and might be resolved if the disabled/ill parent had appropriate support. Invitations for attendance at a CAF meeting should be directed to the appropriate team in Adult Care.

### **3.6 Enquiries and Referrals between Agencies/Teams**

There should be criteria in place that indicate which contacts should be dealt with as an 'Enquiry' and which should be dealt with as a 'Referral'.

The following principles apply:

- Where families are self-referring, consent to share or gather information from other agencies should be gained where necessary to assist in deciding how best to help the family.
- Referrers should provide:
  - the name, address and date of birth of family members, including the child(ren)
  - details of any special needs, eg an impairment or a language problem requiring an interpreter
  - the reason for referral
  - the names of any other agencies known to be involved
  - information about any help already provided by the referrer

Information about the needs of the parent(s) and child(ren) should be recorded on an Observation of type 'Internal Referral' in CareFirst.

In situations involving Child Protection concerns, it should be noted that:

- all referrals, apart from those made by members of the public, recorded on the **LSCB1 Assessment/Referral Form** should be confirmed in writing within two working days
- if it is considered that the referral should not be discussed with the child(ren) or family because this is likely to increase any risk of significant harm, this should be recorded; in all other situations, the referral information will be discussed with the child(ren) or family and their agreement to the referral will be obtained
- if the family has been assessed using the Common Assessment Framework (CAF), it is helpful to receive a copy of this assessment, with the family's consent
- any concerns about a child suffering serious harm should be referred to Children's Services on the same working day and by telephone if necessary

Adult Care staff, see also [Operational Instruction 755: Inter-Team Transfers and Internal Referrals](#).

### 3.7 Assessment

Whichever specialist team leads the assessment:

- an **assessment co-ordinator** must be identified
- in each case, any eventual support plan will need to be jointly agreed between Adult Care and Children's Services together with the disabled/ill parent and their family (unless Child Protection issues dictate otherwise)

The role of the assessment co-ordinator is to:

- identify key contributors to the assessment
- record the assessment plan
- keep family and key agencies informed
- ensure analysis of the information is contained in the assessment
- collate recommendations for consideration when planning how to respond to any identified needs of the parent(s) or child(ren)

Whichever specialist team worker leads the assessment any other potentially 'stakeholding' specialist manager should be informed that an assessment is commencing which may have implications for their budget.

### 3.8 Assessment and Care Planning

#### 3.8.1 The Co-ordination of Assessments

- **Adult Care teams will co-ordinate assessments** when there is no indication of Child Protection issues and the disabled/ill parent needs support to carry out day-to-day practical tasks, including for the maintenance of, eg:
  - the child(ren)'s personal care
  - domestic routines
  - education
  - relationships
  - social support systems and community life

Relevant assessment and support plan forms must be completed. Where appropriate, financial assessment forms must be completed. Services to adults in the parenting role are free of charge. Financial assessments will only be required where the adult is to receive services in their own right.

Adult Care and Children's Services must jointly agree a support plan but Children's Services are unlikely to need to undertake a separate assessment of the child(ren)'s needs.

- **Adult Care teams will co-ordinate a joint assessment with Children's Services** (and other agencies as necessary) in these cases:
  - The worker from Adult Care identifies complex needs within the family situation affecting a child's development.
  - The worker from Adult Care identifies a role for the involvement of Children's Services.

Consultation between services will begin and a lead professional must be identified. A decision will be made about the appropriate recording of the assessment, with plans and financial assessments, as required.

- **Children's Services will co-ordinate the assessment** in these cases:
  - The disabled/ill parent needs support to prevent the child(ren) suffering significant harm or to facilitate a resumption of parental responsibility following Child Protection proceedings.
  - There is a risk of significant harm to a child in the family.
  - The child(ren)'s needs are complex and/or there is a child with disabilities in the family.

### **3.8.2 Disabled/Ill Parents Who Have a Child Known to the Children with Disabilities Team (CWD)**

Where there is a disabled/ill parent who has a child known to the Children with Disabilities Team (CWD), the Adult Care and CWD teams should work together with the family to agree care or support plans from both teams, as appropriate.

### **3.8.3 Personal Budgets (Self-Directed Support)**

The way in which all adults across all social care services receive support from the local authority has changed significantly and is now through a Personal Budget (Self-Directed Support). In brief summary, the disabled person completes a questionnaire relating to several aspects of support needs. This asks whether or not the person has a need and how frequently it needs to be met. In the latest version of the Personal Budget Questionnaire (issued on 17th May 2011), there is a separate section for disabled/ill parents to complete to indicate any support needed in their parenting role. Each level of need equates to a sum of money, according to a formula put together by the finance team, giving the person an 'indicative budget'. The disabled/ill parent together with the care assessor or independent supporter then decides what to spend the money on in order to meet the specific need and desired outcome. This is detailed in the person's support plan.

All sections of the questionnaire ask about any support already provided, or to be provided, by an unpaid person (friend, relative or partner). Care provided by a child or young person under the age of 18 must be identified, so that the parent is enabled to obtain that support from elsewhere, as appropriate. The parenting section was put together with the assistance of the Norfolk Disabled Parents Alliance, and the young carers references with assistance from the Norfolk Young Carers Project Advisory Group.

The process under the protocol is that Adult Care will contact the relevant Children's Services team after the support plan has been completed. This is to discuss the plan and determine the agreement to the plan and to joint fund. The protocol process remains the same. However, there is a possibility of parents choosing something that Children's Services cannot agree to joint fund. Family holidays are an example. Support such as personal care for the child, help getting to school, meeting the need for food, clean clothes or a nursery, or other resources to give a parent a break where fatigue is part of the parent's condition will usually not be problematic. It is impossible to provide a definitive list. The advice is that the way forward is discussion between teams. The care assessor should advise the disabled/ill parent at the first discussion of the support plan if this is likely to be the case.

**All services must work closely together where there is a disabled/ill parent in the family.**

**The resolution of disputes will be achieved through the relevant senior manager.**

## **Appendix 1: Ethical and Legal Context**

### **1. Commissioning the Protocol**

In 2001, the Social Services Directorate commissioned the development of a joint protocol between Children's Services and Adult Social Services to ensure that overall the needs of children and their parents or carers were assessed and support services provided in line with the requirements of the guidance from the government.

### **2. A Jigsaw of Services (2000)**

The Social Services Inspectorate and the Department of Health carried out an inspection of services supporting disabled/ill parents in their parenting role and published the report in 2000. As one parent said, 'trying to adapt services ... to support me as a parent is like doing a jigsaw where you can almost see the picture, but where the pieces just don't seem to fit together'. The report concluded that '[a]ll council directorates, together with other agencies, need to adopt and promote a policy statement that confirms ... the right of disabled or ill people, within the bounds of current legislation, to be supported in fulfilling their roles and responsibilities as parents'.

### **3. The Social Model of Disability**

Disabled/ill people are clear that social care services should be delivered in accordance with the social model of disability. This is echoed in general in Department of Health guidance. The social model views disability as arising from social and environmental barriers restricting life choices for people with impairments. This leads to a loss or limitation of opportunities for people to take part in society on an equal basis. This protocol focuses on civil and human rights promoting non-discrimination, independence and equality.

### **4. Framework for the Assessment of Children in Need and Their Families (2000)**

A key component of the government's objectives for children's social services has been the development of a framework for assessing children in need and their families, to ensure a timely response and effective provision of services. It is acknowledged that delivering services to children in need is a corporate responsibility that falls on all local authority departments, health authorities and community services. The guidance was issued jointly by the Department of Health, the Department of Education and Employment, and the Home Office, under Section 7 of the Local Authority Social Services Act 1970, which means that it must be followed unless there is a compelling reason not to do so.

The guidance provides a systematic way of analysing, understanding and recording what is happening to children and young people within their families and the wider context of the communities in which they live. Effective collaborative work between staff of different disciplines and agencies assessing the needs of children and their families requires a common language to understand the needs of children, shared values about what is in the children's best interests, and a joint commitment to improving the outcomes for children. The framework provides that common language based on explicit values about children, knowledge about what children need to ensure their successful development, and the factors in their lives that may positively or negatively influence their upbringing. This increases the likelihood of parents and children experiencing consistency between professionals and themselves about what will be important for children's well-being and healthy development. This protocol emphasises the need for services for children and

those for disabled/ill adults to work together to improve outcomes for families with disabled/ill parents.

The framework guidance establishes a clear link with adult social services and Fair Access to Care Services (FACS) requirements.

## **5. Fair Access to Care Services (2002)**

Councils are required to apply a national eligibility framework to determine which adults are eligible for help. Councils should use this framework to specify their 'eligibility criteria', which describe the range of needs that will be met, and four grades, or bands, of seriousness of the risk to independence if those needs are not met. This eligibility framework and the criteria are applied to all adults seeking social care support, to decide whether or not they should be helped. The eligibility framework includes needs arising from all disabilities and long term illnesses and is based on the impact of needs on factors that are key to maintaining an individual's independence over time.

Implementation of the guidance promotes access to care services that is based on evaluations of individuals' assessed needs and likely risks to their independence. This includes both immediate needs and risks, and also needs and risks which are likely to worsen for the lack of timely help.

The guidance states that councils should recognise that disabled/ill parents may require support because of their parenting responsibilities: '[I]n addition to the provision of adult care assessment and support, councils should be prepared to address their duty under the Children Act 1989 to safeguard and promote the welfare of children in their area'. Where appropriate, councils should consider the use of the 'Framework for the Assessment of Children in Need and Their Families' to explore whether there are any issues relating to children in need and their parenting. The assessment framework should be used if it appears that there are children in need. 'On occasions, within one family, it may be necessary to concurrently assess the needs of an adult parent using the appropriate format for adult assessment, and the needs of the children and related parenting issues using the assessment framework.'

## **6. Every Child Matters and the Children Act 2004**

The Every Child Matters initiative, launched in 2003, and the Children Act 2004 have brought the need to safeguard and promote the welfare of all children to the fore. Within these initiatives it is clearly recognised that children normally exist within the wider context of their families and their communities and that therefore all professional agencies working with families, in whatever context, must consider the needs of the child.

Section 11 of the Children Act 2004 lays out specific duties on a wide range of statutory agencies (including adult services and health) to consider the safeguarding needs of all children they may become involved with.

It is clear from the tenor of the Children Act 1989 that wherever possible all efforts must be made to support children within their own families.

The government's aim is for every child, whatever their background or circumstances, to have the support they need to:

- be healthy

- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being

These form the Framework for National Outcomes contained within 'Every Child Matters' and The Children Act 2004.

## **7. Independence Matters (2003)**

This report, published by the Department of Health in December 2003, provides an overview of the performance of social care services for physically and sensorily disabled people. It identifies strengths and good practice and highlights measures that are needed to improve outcomes for disabled/ill people. A key finding is that 'apart from some good initiatives for sensorily disabled parents, few services support disabled parents effectively'. The action point is to 'support disabled parents in their parenting role through a range of flexible services, including Direct Payments'.

## **8. Improving the Life Chances of Disabled People (2005)**

This guidance, published by the Prime Minister's Strategy Unit in January 2005, emphasises that 'by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society'.

## **9. The Disability Discrimination Act 2005 and the Equality Act 2010**

These acts emphasise the right to equality of opportunity between disabled/ill and other people. They also place a duty on public authorities to promote equality in the designing, setting up and provision of services. The acts emphasise the use of positive attitudes and a move away from stereotyping people.

## **10. Independence, Well-being and Choice (2005)**

This government green paper, published by the Department of Health in 2005, sets out the proposed future direction for adult social care services. Key proposals include 'greater focus on preventative services to ensure greater social inclusion and improved quality of life'. Outcomes include:

- improved health
- improved quality of life
- making a positive contribution
- exercise of choice and control
- freedom from discrimination or harassment
- economic well-being
- personal dignity

Since 2006, there has been an increasing interest and development in this area of social care provision, including the need for involvement of partner agencies, such as health and education agencies. A number of documents, including government legislation and guidance, and good practice guidance from voluntary and independent organisations, such as the Disabled Parents Network, the Princess Royal Trust for Carers and the Children's Society have been published. The Social Care Institute for Excellence (SCIE) has

produced a number of reports on the subject. A common theme has been to address the needs of the whole family rather than its members in isolation. The rights of disabled/ill parents to support and equality, and the support needs of children who are young carers, or potential young carers, and their families have also been recurring major themes. Included in these numerous documents are the following.

### **11. Reaching Out: Think Family (2007), and Think Family: Improving the Life Chances of Families at Risk (2008)**

Both of these came from the Cabinet Office Social Exclusion Task Force and identified the need to focus intensive support on families with multiple and complex issues. Many of the families requiring this support included those with disabled/ill parents (in particular those with substance misuse problems, or mental health disorders or impairments) and with problems that are often linked such as poverty, worklessness, or poor or inappropriate housing. The aim of the policy was to improve the life chances of the families, to improve well-being, and to break the cycle of disadvantage.

### **12. Putting People First (2008)**

This 'shared vision and commitment to the transformation of adult social care', published by the government, introduces a radically new way of working across all adult social care services. It introduces Personal Budgets (also called 'Self-Directed Support') as the new route by which all disabled/ill adults who are eligible for support receive that support. Decisions about what support is received shift from the local authority making the decision to the person deciding themselves. Agreement between both parties is then reached so that agreed outcomes are worked towards and, where possible, achieved.

Putting People First sets out a number of shared outcomes. It states that '[a]ll people, irrespective of illness or disability, should be supported to:

- live independently
- stay healthy and recover quickly from illness
- exercise maximum control over their own life and where appropriate the lives of their family members
- sustain a family unit, which avoids children being required to take on inappropriate caring roles
- participate as active and equal citizens, both economically and socially
- have the best possible quality of life, irrespective of illness or disability
- retain maximum dignity and respect'

This vision and commitment is shared by the current coalition government.

### **13. Carers at the Heart of 21st Century Families and Communities (2008)**

This strategy was produced by the government following consultation with carers themselves. It covers all carers and includes a section on young carers. The vision relating specifically to young carers is that '[b]y 2018, children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against the Every Child Matters outcomes'.

Young carers said:

- There is not always enough help for the person who needs care.

- Help is often needed for the whole family.
- Young carers do not have enough time to get on with their school work or to have fun.
- Local doctors, hospital doctors and nurses and teachers do not know about young carers or the issues they face.
- Young carers' services are really useful for young carers.
- There is a need for equipment and emergency cover in particular.

New funding was given to provide more services and training in identifying and supporting carers. This included a wide range of service providers such as those of healthcare (in particular GPs) and schools, and voluntary organisations.

#### **14. Supporting Disabled Parents: a Family or a Fragmented Approach? (2009)**

As a follow up to 'A Jigsaw of Services', the Commission for Social Care Inspection conducted a national survey of local authorities to find out what progress had been made in policies, services and practice to provide appropriate support to disabled/ill parents and their families. The results were not encouraging as only 30% of the councils who responded had any kind of joint protocol, and services for children and those for adults by and large continued to work in isolation from each other. Norfolk County Council is amongst a small minority with a working protocol. Norfolk's protocol has gained national acclaim and has featured in a number of documents and articles.

#### **15. Working Together to Support Young Carers (2009)**

This describes itself as 'a model local memorandum of understanding between statutory directors for children's services and adult social services'. This sets out a model text for how services can work together. It asks local authorities to set out their own agreements suited to local circumstances. It includes all partner agencies and is based on a whole family approach. In many ways this protocol lays a firm foundation for this enterprise.

#### **16. The Autism Act 2009, and Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England (2010)**

The strategy set out by the Department of Health sets out a long-term vision to improve the lives of adults with autism, such that '[a]ll adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.' Parents with autism spectrum conditions and Asperger's have the same right to support as all other disabled/ill parents and FACS eligibility criteria apply in the same way.

#### **17. Prioritising Need in the Context of Putting People First: a Whole System Approach to Eligibility for Social Care (2010)**

This guidance from the Department of Health was issued to address concerns that Fair Access to Care Services (FACS) eligibility criteria, for access to adult social care services, were not always being applied as intended. The guidance sets out to clarify the requirements. The relevance for disabled/ill parents is that this document confirms that there is no hierarchy of need (support in the parenting role alone can be as critical as any other need) and that the impact on any carer, in particular a young carer or potential young carer, must be considered.

## Appendix 2: Eligibility Framework & Criteria for Accessing Adult Social Care<sup>1</sup>

<p><b>Critical – when</b></p> <ul style="list-style-type: none"> <li>• life is, or will be, threatened; and/or</li> <li>• significant health problems have developed or will develop; and/or</li> <li>• there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or</li> <li>• serious abuse or neglect has occurred or will occur; and/or</li> <li>• there is, or will be, an inability to carry out vital personal care or domestic routines; and/or</li> <li>• vital involvement in work, education or learning cannot or will not be sustained; and/or</li> <li>• vital social support systems and relationships cannot or will not be sustained; and/or</li> <li>• vital family and other social roles and responsibilities cannot or will not be undertaken.</li> </ul>	<p><b>Eligible for specialist social care</b></p>
<p><b>Substantial – when</b></p> <ul style="list-style-type: none"> <li>• there is, or will be, only partial choice and control over the immediate environment; and/or</li> <li>• abuse or neglect has occurred or will occur; and/or</li> <li>• there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or</li> <li>• involvement in many aspects of work, education or learning cannot or will not be sustained; and/or</li> <li>• the majority of social support systems and relationships cannot or will not be sustained; and/or</li> <li>• the majority of family and other social roles and responsibilities cannot or will not be undertaken.</li> </ul>	
<p><b>Threshold</b></p>	
<p><b>Moderate – when</b></p> <ul style="list-style-type: none"> <li>• there is, or will be, an inability to carry out several personal care or domestic routines; and/or</li> <li>• involvement in several aspects of work, education or learning cannot or will not be sustained; and/or</li> <li>• several social support systems and relationships cannot or will not be sustained; and/or</li> <li>• several family and other social roles and responsibilities cannot or will not be undertaken.</li> </ul>	<p><b>Eligible for preventive services – advice, information and signposting</b></p>
<p><b>Low – when</b></p> <ul style="list-style-type: none"> <li>• there is, or will be, an inability to carry out one or two personal care or domestic routines; and/or</li> <li>• involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or</li> <li>• one or two social support systems and relationships cannot or will not be sustained; and/or</li> <li>• one or two family and other social roles and responsibilities cannot or will not be undertaken.</li> </ul>	

<sup>1</sup> The headings and bullet points are quoted from the Department of Health document [Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care – guidance on Eligibility Criteria for Adult Social Care, England 2010](#). The threshold is Norfolk County Council's.

### Appendix 3: Support for Disabled/III Parents (Process Diagram)

