

New Writing: Guidelines on the discharge from hospital of children and young people with high support needs

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I am a qualified Social Worker and have worked freelance as a Disability Consultant since 2001 – doing training/teaching, research, writing and undertaking evaluations of services. I have a particular interest in the area of disability and complex health needs; firstly, on a personal level

I am the parent of a young woman who has multiple impairments and complex health needs. In 2007 I wrote the publication *Including Me*, a practical guide on the inclusion of children with complex health needs in schools and early years settings. In the process of writing this publication I met with many people who were developing services which were creative and flexible and ensured that this group of children could be included in an 'ordinary' life. The development of these *Guidelines* was an opportunity to work with staff across a range of health settings to produce a leaflet which promotes the principle that, despite the complexity of health needs, this group of children should be supported to 'be children' like all other children in their local communities.

Summary

These *Guidelines* are offered to inform the discharge process for children leaving hospital who will require an extensive package of support (day and night) in order to maintain their optimal health. An example of such children is that group who require long-term ventilation. The *Guidelines* offer six principles and a clearly defined process to ensure appropriate assessment of child and family, planning the support package, delivery of relevant and timely support, and regular review.

Introduction

The *Guidelines* provide a framework to help staff in hospitals as well as the commissioners and providers in Primary Care Trusts when negotiating and planning the discharge of children and young people with high support needs. It covers children who will require an extensive package of support during both the day and night in order to maintain their optimal health, for example, children who require long-term ventilation. The *Guidelines* set out six basic principles which ensure that children will be supported to 'be children', parents will retain their role in parenting and the home does not become a 'mini hospital'. The discharge process lays out the steps that hospitals and Primary Care Trusts should work through in order to ensure the child and family is appropriately assessed, and the support package is planned and delivered in a timely way and is regularly reviewed.

Why were the *Guidelines* written?

Staff from a number of Primary Care Trusts (PCTs) had expressed their concern about the difficult relationship which often develops during the discharge process between the PCT and the hospital with the parents caught in the middle. From the perspective of the PCT, staff felt that the tertiary hospitals were putting pressure on local services to provide very high levels of support – often, they felt, inappropriate in terms of supporting a child or young person to live in their local community. This meant that parents' expectations had been raised by the tertiary centre to demand and expect levels of service that are unrealistic.

How did we move the issue forward?

The issue was discussed with both the Department of Health and the Council for Disabled Children and it was agreed to bring together a range of staff from hospitals, PCTs and various national organisations working with children who have palliative care needs – to develop a balanced and rounded view of the issue. I was employed as a 'consultant' to facilitate the

meeting and then write the *Guidelines* which could be used by both staff working in PCTs and hospitals when negotiating the discharge of children with high support needs.

Initially, the focus was on children being discharged from the tertiary or specialist children's hospitals, however, the guidelines can apply to children being discharged from local district hospitals. The *Guidelines* cover those children and young people with the highest support needs requiring an extensive care package during both the day and night in order to maintain their optimal health. It will probably include children with the following conditions:

1. Children on long-term ventilation (LTV) or requiring long-term respiratory support.
2. Children with acquired brain injury.
3. Children with neurological degenerative conditions.
4. Children with Epidermolysis Bullosa.
5. Children with unstable respiratory conditions.
6. Children with tracheostomies or who need nasopharyngeal suction as they cannot independently manage their secretions.

What are the basic principles which should underpin the care package?

When the various stakeholders met, there was considerable agreement relating to the basic principles on which a care package should be based. Six principles were developed:

1. Different environments. In planning a care package all stakeholders need to bear in mind that the child or young person is moving from an environment where he/ she is cared for by health staff, namely the hospital to an environment – the child's own home, where health services will provide support to a family to enable them to care for their child.

2. Family life. The support provided should enable the family to lead as 'normal' a life as possible and should support the child to do the things that other children do, such as go to school or early years services, enjoy leisure and other activities and access their local community facilities.

3. Supporting parents to be parents. Support should be offered in a way and at a level which ensures that parents are supported to be parents and take responsibility for their child in the same way as other parents do. This role should not be undermined or usurped by care staff.

4. Recognising the parent's needs. Parents have a right to an 'adult' life, and where this involves going to work, other avenues used by all parents, such as working tax credits, paid child care, etc should be

explored and used. It is the additional costs, due to the child's condition, which may form part of the support package.

5. A safe environment. Support should be offered in a way which makes parents feel that it is 'safe' to have their child at home. Parents will need a 24-hour contact link and care pathway for times when they have concerns about their child.

6. Partnership and trust. Planning discharge should be done in partnership with the family so that they develop a trust in the ability of the PCT to meet their needs and be flexible to arranging care that may vary over time.

How should the discharge be planned?

In discussing the discharge process it was evident that each hospital and each PCT had their own processes, paperwork, assessments and ways of working. The guidelines aim to bring these together in a way which establishes a general process but allows the flexibility for each hospital or PCT to use their own local agreements and procedures. The process is summarised in a checklist which is part of the *Guidelines*.

The process should start as early as possible, as soon as it is agreed that the child will need a home care package – it is not necessary to wait until the child is medically stable – as this often unnecessarily delays the planning. It was agreed that parents and other family members should be offered support to come to terms with the child's condition and prognosis as early as possible and that this type of support should be on-going.

All the contributors to the guidelines felt there were a number of factors which could lead to the development of a relationship dominated by conflict between the parents and the PCT. It was therefore agreed that hospital staff should be discouraged from discussing the level of support, e.g. the number of hours, a family should expect as this sets unrealistic expectations. It is important that support is not referred to in terms of 'nursing care' as parents will expect carers to be registered nurses. Blanket rules about particular conditions requiring set levels of support are also considered unhelpful.

It was evident from the discussion at the meeting that the PCTs work differently and that this creates problems in terms of the hospitals knowing who to contact in order to start the process. PCTs can assist by clarifying who the lead person is in terms of commissioning support packages. PCTs should have a clear process outlining who is responsible for negotiating discharge, who should be involved in the assessments and attend meetings, and who should put together the package of support.

Some children will move from a tertiary hospital straight home whilst others will move first to the local district general hospital or to the children's hospice service before going home. If the child is moving to either a local hospital or hospice service then they need to be involved in the planning from an early stage. Whichever route the child takes, the support package should be based on an individual assessment of need – looking at both the child and the family.

Appropriate staff from both the hospital and the PCT should be involved in carrying out this assessment. This may involve other agencies, for example, housing or social services. The National Framework of Children and Young People's Continuing Care* sets out a useful process and assessment tool, with a nominated health assessor to take the lead and co-ordinate the assessment information – this framework should be used. The assessment should recognise that the child's needs are likely to change and that the child may make progress between the time of the first meeting and the time they are discharged.

One of the main factors which often delays discharge is the practical arrangements – such as house adaptations, equipment and training of staff. Therefore house adaptations and the provision of equipment should run alongside the other aspects of putting together the care package. There should be local arrangements outlining a clear process for reaching agreement regarding funding.

The PCT needs to set realistic timeframes in order to recruit, check and train staff to support the child. The arrangements to offer support vary considerably across the country and the support may be offered through the PCT's in-house provider; through a team from the local hospital or through an external private provider. In future this support may be offered through an individual health budget, controlled by the family. Whatever the arrangements, the PCT has a responsibility to ensure that the provider has appropriate skills, competencies and governance structures to support safe and effective care. The discharging hospital should support the PCT in meeting this responsibility.

Sustainability of the support package is as important as speed of discharge. There needs to be clarity as to who has the ultimate responsibility when the child is at home. In some areas an agreement or contract is drawn up between the family, PCT and discharging hospital. The support package should be reviewed on an agreed regular and on-going basis (at least once a year). Parents should be made aware that packages of support are likely to increase and decrease as needs change.

During the time that the child spends in hospital links to the child's school and peers is important to create a

sense of 'normality'. For pre-school children involving local Portage or pre-school services should be considered.

The process of applying for and agreeing the funding of the support package should be clear and transparent. The Children's Continuing Care guidance sets out a clear decision-making phase with time scales, which follows the assessment phase. This guidance states that disputes between agencies should not delay the provision of the care package and a protocol should make clear how funding will be provided pending the resolution of any dispute. Where there are disagreements between the family and the PCT over the support package, resolution at a local level should be attempted as early as possible. Families should be offered support through advocacy services. The Children's Continuing Care guidance recommends that disputes between the family and an organisation should be dealt with promptly through a local complaints procedure.

Where to next?

At present the Council for Disabled Children (CDC) together with a number of organisations are striving to ensure that the *Guidelines* are disseminated and distributed as widely as possible.

* Department of Health, 2010. National Framework of Children and Young People's Continuing Care

A copy of the *Guidelines* can be downloaded from the CDC website.
<http://www.ncb.org.uk/cdc/TertiaryCareFINALmk3.pdf>

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