Better at home? Benefits of case management for children with complex needs

Abstract
Care at home for children with complex health needs is recommended in health policy and advocated by professionals and voluntary organisations. Measuring benefits for the child and family is difficult and burden is known to be high for the family, especially when support for home care is inadequate. Case examples are used in this article to demonstrate the clinical and cost effectiveness of home care for children following acquired brain injury in the context of case management of an intensive package of support for each child. A first step to more widespread adoption of case-managed home care packages is to share examples of best practice that can demonstrate good outcomes and cost effectiveness.

Accurate estimates of the number of children and young people living with complex health needs are difficult to obtain, partly because of the variation in definitions of disability and complex needs (Carnevale et al 2008). In a study reported in Paediatric Nursing (Kirk 2008), nearly 600 children who were dependent on some form of technology and being cared for at home were identified in one area of England. Managing care at home and reducing hospital admissions have been core aims of government reports and policies over many years (for example, Department of Health and Social Security 1976, Department of Health 1991, Department of Health and Department for Education and Skills 2004). Drivers for these policies have been the increasing demand on resources and a belief that home is better for the child and family – but is it?

This article describes the experiences of one child with acquired brain injury (ABI) and his family, providing evidence of how care at home is better for them; it is also clinically effective and cost effective. The approach described here could be applicable to all children with complex health needs; however it is perhaps easier to demonstrate benefits and cost savings for children requiring rehabilitation following ABI. Such evidence is essential in the early days of establishing the credibility of case management. All names in the following account have been changed to ensure anonymity.

Care options
Adam was three years old when he was knocked down by a car while on holiday. He suffered multiple internal organ injuries and severe brain injury. He was initially treated in the paediatric intensive care unit (PICU) before being transferred to his local hospital. The paediatric neurology team contacted the community matron for children for assistance in co-ordinating an appropriate rehabilitation package. Adam’s mother is a single mum with two other children and a supportive extended family.

During his treatment in PICU, Adam’s mother was able to stay with him, while his grandmother looked after the other two siblings at home. The family were anxious that Adam had the best chances possible but also wanted to minimise further disruption to the family. Three options were considered by the family and multidisciplinary team:

- Adam could stay in the acute hospital – this was inappropriate because it meant an acute bed was blocked to other admissions; resources for long-term rehabilitation were not available in the acute setting.
- A stay in a residential rehabilitation unit – Adam could be resident there for between two and six months; his mother would stay with him, while his grandmother looked after the other children. This would provide access to high-quality rehabilitation facilities.
- A bespoke rehabilitation package in the community that would enable Adam to go home, to access a specialist nursery and have intensive therapy input in all settings.

After much consideration and discussion the third option was chosen. This felt risky for the family as it was less proven than the residential option. However, they were reassured by the benefits of having Adam at home with his family around him, and with the backing of the multidisciplinary team. Such negotiation is essential but often missing when considering child and family needs (Kirk 2001).

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Key words
- Children
- Complex needs
- Community nursing
- Technology in health care

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Outcomes
The package of support included specified weekly hours of physiotherapy, occupational therapy and speech and language therapy, and sessions with a community play specialist. The family was also offered rapid access to specialised nursery provision in a choice of several local nursery settings which included access to therapy (Adam began attending within three weeks of discharge). There was follow-up and support from various hospital professionals as required, including additional support for Adam’s mum while recognising and supporting her role as the expert in Adam’s care (Kirk et al 2005).

Two years on Adam has made a good recovery: he is walking, talking, and achieving, albeit with some ongoing issues, which continue to be supported appropriately. The experience has been a positive one for the whole family (Box 1). This is one of several examples used locally to care for children at home.

Costs of rehabilitation
Between 2002 and 2004 there were four children in this primary care trust who sustained significant ABIs necessitating intensive rehabilitation. Although the children were treated in three different hospitals, they were all transferred to a residential rehabilitation centre because no other option was available. Units such as these cost more than £220,000 per annum per child plus equipment costs. The children required stays of between six months and two years. Transfer of the children’s care to the community was not begun until they were ready for discharge and there was no overall co-ordination; reintegration was complicated and prolonged because there were minimal links between the unit and community provision. The cost to the primary care trust for these four children was £570,000 plus equipment costs.

In July 2005 a community matron for children was appointed with a remit to case manage this group of children. Case management of the child with ABI requiring rehabilitation includes:

- Support and advice for the child and family.
- Early liaison with the acute services – weekly attendance at neurology team meetings when they have a child with a significant ABI.
- Communication across all agencies, providing early warning of child’s need.
- Co-ordination of multi-agency services.
- Facilitation of creative solutions.
- Design of bespoke packages, including identifying extra resources when needed.
- Ongoing oversight of child’s progress and care.
- Identification of lead professional once the children’s community matron is no longer providing this role.

Since 2005, there have been eight children with significant ABIs, one of whom died. ‘Significant’ in this context is defined as the consultant neurologists judging that the impact of injury requires therapeutic intervention and a package of support to enable optimum recovery that is beyond local services.

Box 1
Grandmother’s experience of a rehabilitation home care package following Adam’s head injury

My grandson, Adam, aged three years and two months was knocked down by a car, while away from home, and suffered multiple internal organ injuries and severe brain injury. The driver of the car did not stop and has not been found.

Admitting hospital neurologist evaluation: ‘In my experience, local facilities cannot provide as extensive a package of rehabilitation for children with this severity of brain injury as a specialised residential setting’.

Local hospital neurologist recommendation: ‘We believe it could be in his best interests to be supported by a comprehensive rehabilitation package at home and support in the community’.

Questions and dilemmas for the family: How can his recovery be maximised? What will it cost emotionally and physically to us as a family. We asked his brother and sister, ‘What do you think?’ They replied: ‘We think he should be at home with us.’ Thoughts of myself and my daughter: ‘How will I learn the skills; my stamina is already low; will they really do what they say; will the therapists have specialist knowledge of acquired brain injury as is offered in the residential setting?’

Were promises kept and has he fared well (six months since leaving hospital)? The provisions started immediately but some were phased to accommodate the adjustments that were needed by the family, especially by my daughter. We have appreciated the knowledge and warmth of everyone involved in my grandson’s support. Our experience of this provision has been one of amazement and gratitude. My grandson continues to progress well but with problems of concentration now emerging. The work of skill recovery and adaptation are being made in the context of ‘ordinary’ family life. This includes frustration and joy. The demands on my daughter have been great and continue to be so. A family needs to be realistic about their emotional and physical resources.

This rapid access to everyone added to my certainty that my daughter had made the right choice for her son.

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Assessment, case management and package of support for children with ABI

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Service provision

Table 1

Assessment, case management and package of support for children with ABI

<table>
<thead>
<tr>
<th>Child 1</th>
<th>Assessed locally, referral to rehab unit suggested by consultant</th>
<th>Local provision co-ordinated and deemed able to meet needs</th>
<th>Discharged home</th>
<th>Optimum recovery achieved</th>
<th>No additional cost</th>
<th>Saved 6/12 placement @ £110,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 2</td>
<td>Assessed locally, referral to rehab unit suggested by consultant</td>
<td>Local provision co-ordinated and deemed able to meet needs</td>
<td>Discharged home</td>
<td>Optimum recovery achieved</td>
<td>No additional cost</td>
<td>Saved 6/12 placement @ £110,000</td>
</tr>
<tr>
<td>Child 3</td>
<td>Assessed locally, referred to rehab unit, place offered</td>
<td>Local provision not adequate to meet needs</td>
<td>Discharged home</td>
<td>Optimum recovery achieved</td>
<td>Four month therapy package £20,000</td>
<td>Saved 6/12 placement @ £110,000</td>
</tr>
<tr>
<td>Child 4</td>
<td>Assessed locally referred to rehab unit, place offered</td>
<td>Home needs extensive adaptations, parents high expectation of rehab, 6/12 residential rehab agreed</td>
<td>Residential rehab</td>
<td>Cost £110,000 for six months</td>
<td>High level of co-ordination, managed return home, ongoing package of support</td>
<td></td>
</tr>
<tr>
<td>Child 5</td>
<td>Assessed locally, referred to rehab unit, place offered</td>
<td>Local provision not adequate to meet needs</td>
<td>Discharged home</td>
<td>Optimum recovery achieved</td>
<td>One year of local therapy package at cost of £25,000</td>
<td>Saved minimum 8/52 placement @ £38,000</td>
</tr>
<tr>
<td>Child 6</td>
<td>Assessed locally, referral to rehab unit considered</td>
<td>Local provision co-ordinated and deemed able to meet needs</td>
<td>Discharged to foster care</td>
<td>Currently making good progress</td>
<td>No extra cost</td>
<td>Saved 6/12 placement @ £110,000</td>
</tr>
<tr>
<td>Child 7</td>
<td>Assessed locally, referral to rehab unit considered but not done as consultant now confident in local ability to meet extra need</td>
<td>Local provision not adequate to meet needs</td>
<td>Awaiting discharge home</td>
<td>Optimum recovery achieved</td>
<td>No additional cost</td>
<td>Estimated cost of package (£20,000)</td>
</tr>
</tbody>
</table>

Extra spend = £65,000
Total savings = £490,000

Optimum recovery is defined as achieving as full a recovery of function as can be hoped for, monitored by the paediatric neurology consultant. Table 1 summarises the outcomes and cost savings made to date through case management of an intensive package of support for care at home for these seven children.

Conclusions

The service that we now provide is not unique but it is rare (Kirk and Glendinning 2004, Carnevale et al 2008). Such an approach requires dedicated time for complex, cross agency co-ordination, negotiation with the family and time to walk alongside them on this difficult path. It also requires authority to invest resources in bespoke packages along with clinical credibility to enable change. The enormity of caring for a child with complex health needs at home cannot be underestimated but neither can the benefits. A first step to more widespread adoption of home care packages is to share examples of best practice that can demonstrate good outcomes that are also cost effective. For all concerned care that is co-ordinated, negotiated, and properly resourced will ensure that it can be ‘better at home’ PN

References


