

Making it Work

Good practice with young carers and their families

Joint publication between The Children's Society and The Princess Royal Trust for Carers

Supported by the Balcombe Trust

The Princess Royal Trust for Carers believes that all young carers have a right to be supported in order to cope with their situation, and to have choices in determining what constitutes appropriate support. The network of PRTC Carers' Centres supports young carers through both specialist projects and partnerships with other local service providers. They provide support services directly to young carers, and they also seek to raise awareness of the needs and contribution of young carers within health, social care, education and other appropriate agencies. They also work to secure better services for the whole family. For more information visit the PRTC website: www.carers.org



The Children's Society Young Carers Initiative is funded by the Department of Health to develop a coherent focus for young carers, their families and those who work to support them, to promote common standards and to work towards realisation of equitable services. Listening to children and enabling them to have a voice is integral to all the activities of The Children's Society. In its work with young carers, the Society has always advocated considering a whole-family approach to meet the needs of the child, whilst enabling the child to be informed, consulted and supported. For more information visit website: www.childrenssociety.org.uk/youngcarers



Making it Work

Good practice with young carers and their families

Executive Summary

The Office for National Statistics estimated that there are up to 51,000 young carers aged 8–17 in the UK, with an average age of just 12. A recent growth in awareness of their issues has led to encouraging increases in levels of support for many young carers and their families – but this is patchy at best, and a significant number of children and families still remain in need.

This practice guide is an invaluable tool for all agencies and practitioners intent on improving this situation for young carers and their families. It brings together much of the thinking and experience behind good practice developed up to now, setting new standards and embracing new perspectives on the subject. The work provides comprehensive guidance in the areas of assessment, the provision of effective services, support for young carers in school, and the role of young carers' projects.

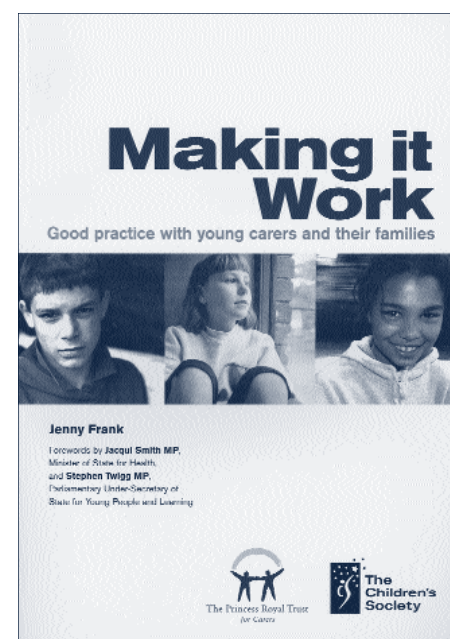
Much of the guide's content is shaped around the views of young carers and their families. In addition, the guide draws on findings from published research and a range of local practice materials, which include direct local consultation with children, young people and their families. The guide is informed by shared learning at Children's Society seminars for support professionals, and has benefited from case studies and project materials provided by the Princess Royal Trust for Carers. It offers realistic, practical and detailed methods for the development of support services; presents current legislation and policy guidelines clearly and relates them to recommendations for practical work; and promotes an inter-agency approach.

This guide will prove to be a useful starting point for good practice to evolve further across all agencies. Inter-agency and holistic approaches are vital to meet the needs of young carers and their families effectively and appropriately. The text of the guide draws directly on the views of young carers and their families. Listening to them needs to be the starting point.

“Recognise that our family is probably the ‘expert’ on the situation and work towards what our family wants.”

“This practice guidance is an important document. It has the potential to improve the lives of thousands of young carers and their families. There is an overriding need to listen to the children themselves, they have a right to be heard and are often best placed to know what is right for them and their families.”
Jacqui Smith
Minister of State for Health

“Chapter 5 of this guide contains powerful messages from young carers as well as practical advice for teachers and other professionals. This guide illustrates the value of a multi agency approach to working with young carers and schools and communities to ensure that they are provided with a suitable education in all circumstances.”
Stephen Twigg MP
Parliamentary Under Secretary of State for Young People and Learning.



Making it Work Good practice with young carers and their families

Jenny Frank

ISBN No: 1 899783 46 6
£14.95

Available from:
The Publication Department
The Children's Society
Edward Rudolph House
Margery Street
London
WC1X 0JL

Tel: 020 7841 4415
www.childrenssociety.org.uk



Setting the scene

The effects that inappropriate levels of caring can have on a child are well documented. Their physical and emotional well-being can be affected, as can personal, social and educational development. It is important to recognise that the reasons that children undertake inappropriate levels of care may be complex, including such issues as the nature of the family unit, the level of care needs and the level or lack of resources being provided by the statutory sector to the person who needs care. There is a need to differentiate between the needs of the child as a carer and the impact of the family member's illness/disability on the child.

Young carers exist in a social, economic and political context in which there are a number of tensions and contradictions. For example, is the primary focus the child's or the parents' needs? The voice of the child is important and must be heard, but there should be a balance – the needs of **all** family members should be taken into account.

It would, of course, be ideal not to have children who are caring for family members to such a level that their emotional and physical responsibilities are impacting on their own development. However, the reality is that it is going to take considerable time and resources to meet effectively and consistently the care needs of all parents who are ill or disabled while many parents with substance misuse or mental health problems will continue to be hidden from services. And in the meantime, children **do** find themselves in inappropriate caring roles. Many find their own development affected and will benefit from various degrees of support.

There has recently been some debate about whether young carers' projects are the best way to support families experiencing disability, illness or substance misuse. The good practice guide demonstrates just how far support for young carers and their families has gone towards addressing those concerns. It is clear that levels of understanding, together with direct practice experience, will continue to evolve and develop in the future. This guide represents what is understood about best practice at this point in time. It owes its existence to the contributions made by young carers, their families and the professionals involved in working with them.

There is a need to move both debate and practice forwards and address how a major shift in attitudes and increased effective service provision for families can be developed. Legislation, guidance and good practice all require practitioners to consider the needs of the child within the context of the family. A holistic approach is always advocated: meeting the needs of the person who is ill or disabled; recognising family strengths as well as the difficulties and problems; and being careful not to undermine parenting skills. Work with young carers and their families should follow such guidelines.

It is also equally important to ensure that children's voices and feelings are heard and taken into account. Society has a duty to consult, inform, support and protect children who find themselves in a caring role which impacts upon their own development and aspirations. Children should be supported to make an informed choice about whether or not to take on a caring role.

Legislation and guidance offer frameworks which provide for interagency collaboration and a holistic approach to meet the needs of young carers and their families.

Key principles of practice

Supporting young carers

- Even when all the practical and physical care needs of the person who is unwell or disabled are being met, children still say that they care emotionally and worry about the person. Loss, anger and panic are common feelings experienced by children who live with or help care for a close family member who is ill. Young carers say that access to emotional support is one of their key needs, and it is important to ensure that this is available.
- Appropriate information should be accessible to children and young people.
- Recognise that children and young people may need help before the parent is ready to accept their level of care needs and the consequent impact on their children. There must be an accessible gateway to advice and services for such children.
- Recognise that some children give significant levels of care to a disabled sibling.

- Recognise the skill base that has developed in young carers' projects and build on it to develop further support to meet the needs of children and families.

Communication and consultation

- Open communication is crucial to providing appropriate support to young carers and their families. Service providers need to consider how they will consult effectively with users – both the person cared for and the children and young people – in order to inform development of services.
- Children and young people should be consulted and offered real opportunities to participate in shaping practice to meet their identified needs.

For the person who needs care

- Promote positive images of people living with illness and disability and provide environments which encourage families to seek help for any care needs at an early stage.
- Offer good, accessible information to families about services for people with an illness or disability.
- Offer timely, comprehensive and holistic assessments to families in order to avoid children undertaking inappropriate levels of care and to meet any identified needs that they and their family may have. Ensure assessments consider any needs for crisis provision.
- Provide support to meet any identified parenting needs.
- Consider how to meet the demands of episodic illness and the needs of those who do not meet eligibility criteria.

For policy makers and practitioners

A range of legislation and guidance is in place to inform statutory agencies of their duties and responsibilities. There is an emphasis on interagency collaboration and interdepartmental responsibility, including education, at both strategic and practitioner levels, to ensure effective provision for young carers and their families. Training and information should be available to all relevant practitioners, including

teachers, so that young carers can be identified and support offered to them and their families.

Recognise that children may be undertaking inappropriate care in a range of family situations and support needs may be complex.

Agencies need to be proactive and consider how best:

- (a) to identify and reach out to families in order to offer support to prevent inappropriate care being undertaken by children; and
- (b) to intervene if it is evident that this is already happening.

Although social services departments have a key role to play in supporting young carers and their families other agencies have key roles to play in the early identification of young carers. The National Strategy for Carers (Department of Health, 1999) states that GPs and other primary care staff, in particular, can provide valuable, sensitive support to young carers and their families. Health is likely to be the first agency that a family turns to for help with an illness or disability. Therefore it is important that questions are asked by health professionals about who is providing support and meeting care needs in the home and, if needed, that the family is directed to sources of help or referred for an assessment of need. Such timely intervention could help prevent children undertaking inappropriate levels of care.

Schools should identify young carers at an early stage and ensure that they have the same access to a full education and career choices as their peers.

Services need to be sensitive to any cultural needs and agencies should work in partnership with organisations that have specific links and responsibilities for Black communities and other cultures.

Services should consider the needs of refugee families who have a family member who is disabled or has mental health needs on arrival, and in subsequent provision of housing and services.

Extra resources may be required for those living in rural areas to enable services to be accessed and reduce social exclusion.

All services need to be monitored, reviewed and regularly evaluated.