



## **YC-QST-20 (Mental Health) Guidance**

Notes for Researchers and Health, Social Care and Education Professionals

This questionnaire and screening tool is designed for use by researchers and health and social care professionals who wish to identify children who are providing informal care for a relative in the home who has a mental health problem (MHP). It is intended to be used as a screening tool among children who might be living with, and/or caring for, a relative in the home (such as a parent, grandparent or sibling) who might have mental health problems. The YC-QST-20 (Mental Health) is also intended to gauge children's level of understanding about their relative's MHP, the nature and extent of children's caring responsibilities and their needs as carers. Once young caring has been identified using YC-QST-20, other tools/measures are available to ascertain the extent and impact of caring on children's lives.

The YC-QST-20 can also be used in the following ways:

- As the basis for generating statistical data on the prevalence of young caring in a given location (local authority area, borough, county, state etc).
- Adapted and used by health, social care or education professionals to identify young carers and their support needs.
- Adapted by researchers and professionals to obtain data and information about children's understanding of mental health problems and illnesses and the role children play in helping to provide care for relatives who are affected by these problems/illnesses.
- As a self-administered questionnaire to be used in schools in order to identify and recognise children's roles and needs as carers and for appropriate referrals to be made to health and social care services where these are requested (that is, by children themselves).

Research has shown that living with a relative in the home (and particularly a parent in a lone parent household, for example) who has a MHP can mean children take on inappropriate caring responsibilities<sup>i</sup>. These can adversely affect children's lives (for example, their psychosocial development, education, physical health etc) and particularly if caring roles become long term and disproportionate to a child's age and level of maturity. The YC-QST-20 (Mental Health) has been designed as a questionnaire and screening tool for young caring based on tried and tested research methods used by the Young Carers Research Group (YCRG)<sup>ii</sup> in the UK over the past 20 years. YC-QST-20 should be used and understood with reference to the following explanatory model:

## YC-QST-20 (Mental Health): Explanatory Model for Professionals

Questions 1 -2: are intended to establish whether children are living with a relative who has a MHP and whether this is a parent, sibling, grandparent or other family member. Research suggests that children are more likely to care for parents who have MHPs and that they are also more likely to be providing higher levels of care in lone parent households when that parent experiences MHPs. When screening for young caring it should not be assumed that children who live with parents or other relatives in the home who experience MHPs are providing care. Parental MHPs should only be seen as a potential trigger for caring by children - young caring usually occurs when appropriate health and social care services are absent or are ineffective, particularly in supporting adults with MHPs in their parenting roles.

Question 3: is intended to establish the duration of family MHPs; research shows that parental MHPs can be a trigger for young caring and specifically when support services are lacking or are inadequate in terms of providing effective parenting support.

Questions 4, 4a, 5: are intended to establish children's understanding – from *their* perspective - about the nature of their relative's MHP as well as from a health or medical perspective (thus what they may understand by the medical diagnosis of the MHP, if there has been one – question 5). Research shows that children who live in families affected by parental MHPs may often have little understanding about the diagnosis and prognosis of the illness even when they are helping to provide care and support to their relative in managing this. A 'no' response to question 4 would indicate a need for the provision of age-appropriate information to children affected by family MHPs.

Questions 6-6a: are intended to establish the type of support services offered to the family member who has a MHP. Research tells us that without appropriate health and/or social care services for parents (or other relatives in the home) who experience MHPs, children are much more likely to take on inappropriate caring roles that can have adverse consequences for their own health and well-being. A 'no' response to question 6 would indicate a need for a holistic approach to understanding and assessing formally the needs of the whole family and not just the support needs of the parent/relative who is ill.

Questions 7-7b: are intended to establish if children have been involved in discussions with professionals from health and social care services about their relative's MHPs and their support needs. Research suggests that health and social care professionals often overlook the parenting needs of adult patients/service users and often do not include children in discussions about the support needs of their ill parents (or other relatives in the home). A 'no' or 'don't know' response to questions 7-7b would indicate a need for providing dedicated children's support and both a young carer's assessment and family needs assessment, underpinned by a children's rights approach (specifically, children's rights to participation and consultation in accordance with, for example, the UN Convention on the Rights of the Child, article 12). A 'yes' response to questions 7 and 7b would need further discussion with children about the types of support they have found helpful and the reasons why these have been helpful for children (and families).

Questions 8-8b: are intended to establish the level of communication between children and their ill parent/s (or other relative in the home) about the MHP. Evidence suggests that children cope much better with family MHPs when they are able and encouraged to talk openly and honestly with their parent/relative about this. A 'no' or 'don't know' response to these questions would indicate a need for interventions that would help facilitate and

encourage better communication in families about mental health issues that affect family life. A 'yes' response to questions 8-8b would require further discussion with children about how talking with their relative about MHPs has helped them.

Questions 9-12b: are intended to establish whether children are providing care for their parent/relative who has a MHP, the nature of children's caring responsibilities and whether they are solely responsible for care provision. Children may not necessarily identify themselves as carers or recognise the extent of their caring responsibilities as often these are either undertaken gradually or are assimilated into their everyday activities as part of regular family life. Some children may also recognise the practical tasks they undertake as caring but not necessarily consider the emotional support they provide to their relative in the same way. It is also much more likely that children will provide higher levels of emotional support to parents/relatives who have MHPs. A 'yes' response to questions 9, 10 and 11 (or a combination of 'yes' and 'no' responses) and a 'no' response to question 12 (and particularly when considered in conjunction with responses to questions 3 and 13 that would indicate parental/relative MHPs and caring activity are enduring/protracted) would indicate a need for a full young carer's assessment as well as a whole family needs assessment. It is also important to establish the type of caring activity children undertake as this could have a significant impact on their ability (and the time available to them) to focus on other aspects of their lives as children (social activity, hobbies, school work etc). A 'don't know' response to questions 9, 10 and 11 would also indicate a need to probe further into the nature and extent of children's domestic roles and activities in families affected by MHPs. Other people may also be involved in providing informal care in families affected by MHPs.

Questions 13 -14: are intended to establish the duration of care provision by children. Research shows that the early onset of caring in children's lives and/or when caring becomes long term and disproportionate to their age and level of maturity (the latter can also be ascertained from responses to questions 9a, 10a and 11a and a 'no' response to question 12), children often experience adverse consequences in respect of their health, well-being and self-esteem. Specifically, research tells us that such impacts can be more serious when children care unsupported for more than two years. Where responses to the questionnaire indicate that children have been living with and caring for a parent or other relative with an MHP unsupported and long term this should trigger a young carer's needs assessment as well as a whole family assessment.

Question 15: is intended to establish the impact of caring on children. Research has shown that caring can have a number of adverse consequences for children in terms of their psychosocial development, educational experiences, physical and emotional health and their transitions into adulthood. This is especially the case when caring has an early onset and becomes long term (question 13) and is disproportionate to children's age and level of maturity (see above). A 'yes' response to question 15 would indicate a need for a young carer's assessment and the provision of support services to ensure that children do not take on inappropriate caring roles long term. Caring can also have a positive impact on children and their family relationships and further assessments need to be made in order to establish in more detail the precise nature of the impacts of caring on children who answer 'yes' (or 'don't know') to question 15.

Questions 16-18: are intended to establish the type of support children may need both as children (who live with relatives who have MHPs) and as carers. It is important to understand children's needs from their perspective based on what they say they want in terms of their relative's MHPs and children's own broader support needs.



Question 19: gender is an important factor in respect of whether or how children are drawn into caring roles in the family. Research tells us that caring can be a highly gendered activity. Girls are more likely to be elected or socialised by other family members into caring roles for their parents or siblings who have MHPs, for example, even when older brothers are available to care. When girls provide care, and particularly when this is long term (that is, has continued for more than two years) and disproportionate to their age and level of maturity, they are more likely to experience low self-esteem and decreased energy levels. However, young caring also depends on the 'availability' of potential carers. Boys are therefore as likely as girls to be drawn into caring roles when no one else is able or willing to provide informal caring support.

Question 20: research tells us that the average age of children who provide informal care is 12. It is also recognised that the early onset of caring and/or long-term caring (more than two years), can result in children experiencing serious adverse consequences in terms of their psychosocial development, their educational achievements and their transitions into adulthood etc.

Note: The research evidence described and referred to in this document is available from the YCRG website (see: <http://www.ycrg.org.uk/publications.html> and: [http://www.ycrg.org.uk/downloadable\\_publications.html](http://www.ycrg.org.uk/downloadable_publications.html))

For further information about this document and for copyright information regarding the use of the YC-QST-20 Questionnaire and Screening tool please contact:

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<sup>i</sup> Research on young caring began in the UK in the early 1990s and evidence from numerous qualitative and quantitative investigations since that time has been used to inform and shape health, social care and education policy and practice in the UK. As a result, young carers have a right to a needs assessment and can access a range of services, including dedicated services offered by numerous young carers' projects operating across the UK.

<sup>ii</sup> See: [www.ycrg.org.uk](http://www.ycrg.org.uk)