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Leading Children's Services

SIGNPOSTS

***See me, hear me, talk to me
– talk to my family as well***

**Working together to improve outcomes for young
carers in families affected by enduring parental mental
illness or substance misuse**

13 October 2011

SIGNPOSTS

ABOUT THIS PAPER

Status

Professional practice, guidance, experience, skills and research are developing all the time. This short paper aims to share evidence based practice, promote local discussion and encourage improved outcomes. It does not seek to amend or replace existing statutory guidance that may be in place. Rather, it offers some signposts to effective practice, local conversations and partnership working with a focus on improved outcomes for young carers and their families. These can be shared and taken forward locally in line with local needs and circumstances. A list of resources that may be helpful appears is included.

Focus

The focus of this paper is on young carers who give care and support in families affected by enduring parental mental illness and/or substance misuse. The paper does not seek to cover the position of young carers within families where there are children with additional or other needs.

Its intended audiences are: Directors of Adult and Children's Services, Lead Members, Carers' Leads, Commissioners, Health and Well-Being Partnerships and Carers Organisations working with young carers and their families.

This paper has been developed and funded in relation to England. The content may also be relevant within devolved administrations.

Young Carers – a shared understanding

The central issues are those of recognition, adverse impact and support, including emotional support. This approach relies on the premise, within a *whole family* approach, that:

“a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well being or educational achievement and life chances”¹

Source: Working together to support young carers, ADASS/ADCS 2009²

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FOREWORD

Working Together to Support Young Carers noted that around a third of young carers³ supported a parent with enduring mental illness. Young carers, however, are children first. They become young carers when, for whatever reason, there are unmet care or support needs within their family. Young carers tell us that they value their caring roles and are often proud of what they do within their families. There is a risk, however, that filling gaps in care and support can, over time, impact adversely on their health and well being.

Young carers have also said consistently that they want agencies to work together to ensure more support for parents to be parents and for their family to be a family. The refreshed national strategy for carers: *Recognised Valued and Supported*⁴ recognised this. It reaffirmed the commitment to the 2008⁵ outcome relating to young carers:

“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....”

The vision in *Working Together to Support Young Carers*⁶ was one of prevention. It promoted the active protection of children from excessive or inappropriate caring. It highlighted the importance of parental roles being supported, risks managed and children being safe. This review points to a continuing need for:

- Leadership and ownership by Directors, senior managers linked to perseverance and commitment in sustaining partnership working.
- Improved information, earlier identification and a range of opportunities for engagement of children at risk of becoming young carers or who are already in this role as a result of supporting a parent with enduring mental illness or a parent affected by substance misuse
- Robust partnership working and effective first line response mechanisms across schools, council access/contact services, health, treatment services and local organisations with a no “wrong doors” approach for those seeking advice and support linked to safe environments in which to say something and to respond.
- Integrated assessment mechanisms and recording so that young carers and their families do not have to keep repeating their story to professionals they come into contact with.
- *Whole Family* working for enhanced outcomes and to promote resilience and parental responsibility whilst recognising and managing risks to safety and well being of young carers where needed.
- Greater understanding of local population needs, use of feedback on what works and including this within service commissioning arrangements across agencies that are then kept under review.

We trust this review will be seen as a timely and supportive. Translating the evidence base we have into local practice is a continuing challenge. We want this review to encourage greater information and knowledge exchange and help identify key areas of learning and for progress. Feedback from young carers outlined in a recent research report⁷ shows the real differences we can make by working better together with a shared focus on outcomes:

My mum's not drinking. It makes me happy. I used to take care of my mum but now she takes care of me.

I get out of the house with my mentor. Without [the mentor] I'd probably have stayed in the house like before

I'm happier at school. The project has helped me make friends with people of my own age

Whilst a small study, the same research report, from which these young carers are speaking, had four policy messages that should encourage us:

- young carers are being identified earlier
- the support for families is more personalised, integrated and holistic
- the support is tackling the underlying causes of inappropriate caring roles
- young carers are being lifted out of inappropriate caring roles

We recognise the challenges of the present resource climate and do not underestimate them. We believe, however, that this report can provide a basis for further local conversations involving Directors of Adults and Children's Services and their partners around local needs, what works well and what else needs to be done to drive value and secure improved outcomes.

It also requires leadership and commitment, however, to ensure that young carers and their families are recognised, listened to, supported and respected by confident, skilled and competent staff across social care, schools, health and treatment services.⁸ In this way we can make best use of resources and ensure we deliver on the statutory guidance⁹ on carers we are all working to and has been in place for some time.

We are grateful to all the people who gave so freely of their time and knowledge to make this paper possible.



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SIGNPOSTS

Introduction

This is a signposting paper. It aims to support Directors of Adult and Children's Services in stimulating local conversations and offer a basis for improving support for young carers and their families. It is not a prescription for specific actions. Rather, we have tried to bring together some resource materials for use at local level to help inform local practice, promote discussion and lead to improved outcomes for young carers and their families.

The focus of this paper is on two main groups of families where one or more parent has an enduring mental illness or is affected by substance misuse and a child is or is at risk of becoming a young carer. Most parents known to mental health or substance misuse services want what is best for their children. Being a parent in these circumstances, however, can be problematic. Many will have awareness of how their difficulties affect their children but may not fully understand the impacts of what can be an uncertain environment for them and the adverse physical and emotional impacts on children who assume heavy caring roles and responsibilities.

Children's safeguarding issues can and do arise. Timely and effective responses to such concerns by local agencies are essential. *Working Together to Support Young Carers*¹⁰ saw the central issues as being around recognition, adverse impact and support. This includes emotional support. It adopted the central premise from the "Key Principles of Practice"¹ that:

"...a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on her or her emotional or physical wellbeing or educational achievement and life chances."

The young carers involved in the **Whole Family Regional Conferences**¹¹ facilitated by The Children's Society provided powerful testimony about joint working and support services for young carers. [See also: **Appendix H**] The conferences showed how support can make a real difference by:

- reducing isolation and anxiety
- managing feelings of stigma or shame
- meeting additional needs
- keeping together as a family – being a family
- enabling young carers to keep up with school work; improve attendance and achieve at school
- enabling young carers to continue in education post 16 and gain employment
- recognition of what it means to be a young carer

¹ Jenny Frank and Julie McLarnon, *Key Principles of Practice: Supportive guidance for those who work directly with or commission services for young carers and their families*, Children's Society 2008. Note: the Key Principles are listed at Appendix F.

There are also other issues around problematic parental–school relationships. Here there is a need for availability to arrive at a shared understanding about what life is like and how to share and bridge school and parental concerns. Family engagement and involvement are integral to progress as shown below:

“Families want good quality, practical support in looking after their children and freedom from the fear of losing parental responsibility. Children and young people say they want relevant information about their parent’s illness, someone to talk to about their experiences and a chance to make and see friends.” [Source: SCIE, At A Glance 09 p 2]

The following pages summarise some of the main messages of this review around for themes:

- Challenges to self-identification by young carers
- Engaging young carers and meeting expectations
- Successful front line partnerships for whole family approaches
- Building strategic leadership and partnership for sustainable outcomes

The next part of the paper *Listening, Learning and Leading* summarises the workshop we organised. The paper concludes with *Growing Local Conversations*. This offers discussion points for further local exploration: building on what we know and how we can work together better with one another as professionals and with families and young carers.

These suggested local conversations need to embrace young carers and their families. This is essential if we are to understand what it is like for them, what would make a difference for them and build trust that outside help will be positive. *Working Together with Young Carers*, for example, encourages Statutory Directors to meet with young carers to find out “*what has gone well, what has not and what might make a difference in future*” [p.12].

A companion paper is also in preparation. This is called “*Young Carers: personalisation and whole family approaches*” and will be available shortly. It will be relevant to the development of local thinking around front line partnerships; the opportunities that personalisation brings to use resources more flexibly and *whole family* working. We also need to consider further how attuned first contact mechanisms in schools or council customer access centres are to the recognition of young carers and their families.

The changing resource parameters Councils and their partners have to work within need to be understood. We are not talking about more resources to do more. Rather, we are encouraging local conversations about how we can do things differently and how we can develop more effective support mechanisms that lead to better outcomes within what we have between us. It is about working together to achieve more with the same – or with less. It is about really using what we know works to secure the outcomes that we, young carers and their families are seeking. As a recent report states:

“It’s not that these conversations and plans weren’t happening before, it’s that these conversations weren’t happening together ... we’re [now] having these conversations together rather than in isolation”¹²

EXPLORING THE ISSUES

Identification

Particular concerns have emerged in relation to identification and support of young carers. Challenges to self-identification can and do arise [See: **Appendix A**]. Stigma from others is often an issue for young carers and families. *Juggling Harms*¹³ [**Appendix C**] noted this can lead to concealment or denial. It highlighted the need for greater co-operation between adult and children's social care. The key messages for professionals were:

- In the absence of early identification young people's disclosure tends to happen at crisis points.
- Professionals' awareness of parents' substance misuse does not necessarily, from a young person's perspective, translate into "knowing" what this involves or how it is experienced.
- Young people appreciate professionals who give them space to build trust as well as the choice to talk, what to tell and at what pace.
- Young people's repeated experiences of disrupted relationships with professionals may result in resignation and lack of engagement.

The *My Care* report¹⁴ recognised the challenges around identification and the need to ensure better professional recognition that many adults with severe and enduring mental health problems may also be parents. The report highlighted a number of challenges for professionals working with young carers and their families. It encouraged them to:

*"... improve their recognition of and sensitivity to the needs of young carers whose parents have severe mental health needs, to co-ordinate their work more effectively and to work more creatively."*¹⁵

The report's recommendations included the need to explore:

- More age appropriate information about mental health and mental illness for young carers and those who work in young carers services.
- More effective co-ordination between professionals and the scope for lead professional roles in some circumstances.
- Improved links with black, Asian and minority ethnic communities to understand the specific needs of young carers and to find culturally sensitive ways of meeting them. [See also: **Appendix I**]
- Mental health services working in partnership with children's and other services to ensure that parents have adequate support in their parenting role and in recognising and responding to whole family needs.

Schools can and do play a major role in recognising and responding to the impacts on children and young people in these situations¹⁶. The Princess Royal Trust for Carers/Children's Society Resource Pack deals specifically with the identification of young carers. It includes potential indicators of the presence of a young carer and aims to:

- help identify young carers and their families before adverse impacts arise,
- assist young carers to feel it is safe to confide in school staff about their caring role, and
- provide appropriate opportunities for young carers to self identify.

Schools continue to be the setting most likely to be in a position to recognise the adverse impacts of inappropriate caring roles and the emotional impacts on young carers. Adult social care is also well placed to do so when responding to parental care and support needs. It may be helpful, therefore, to consider opportunities for “read across” on good practice for adult social care, mental health and adult treatment services on identification of young carers in other settings. The *Think Family* model is highly relevant in this context.

Engagement

Professional cultures and awareness of these issues can affect recognition and responses to them. Engaging with children and young people is not always easy. Conversation, communication and listening skills with children are not necessarily the same as those often needed with adults. The same is sometimes true for those professionals who work mainly with children but not with parents with mental health problems or involved in substance misuse. We need to foster professional skills and confidence to engage holistically.

The material we have seen suggests parents may be reluctant to share information on dependence with others. Sometimes this is because of concerns about negative actions and care outcomes. In the area of alcohol misuse some attitudinal and organisational barriers have been identified. See: **Appendix B** and the key themes from *Juggling Harms* in **Appendix C**. These materials may be relevant for young carers beyond parental alcohol misuse.

Consistency between professionals on engagement with young carers and consistent individual professional involvement are likely to be critical factors in generating an underlying sense of trust by young carers and their families. Having to re-tell the story, sometimes again and again, is often unhelpful. When adults don’t do what they said they would, or don’t say why they cannot do something, it can be seriously undermining of confidence and trust in them.

Appendix D sets out the ten key messages from children and young people for professionals engaging with parents with enduring mental health problems. Work by The Children’s Society¹⁷ emphasises that talking to families is integral to working with young carers about their situation. There is a need to:

- *“recognise that families may be fearful of acknowledging children’s caring roles*
- *be cautious about making assumptions*
- *equally, ensure parents do not feel judged when disclosing their child’s caring responsibilities*
- *acknowledge that families need to cope in different ways and that it is often lack of resources, services and sufficient income that result in children needing to provide inappropriate levels of care.”*

Successful Front Line Services

The Social Care Institute for Excellence [SCIE] report *“Think Child, think parent, think family”*¹⁸ of 2009 was an important step forward. It reviewed evidence and experience around what makes for successful services and encouraged services and support that:

- “offer an open door into a system of joined up support at every point of entry
- look at the whole family and co-ordinate care
- provide support that is tailored to need
- build on family strengths.”¹⁹

More recently an evaluation²⁰ of the *Islington Think Family Service*, a young carers extended pathfinder, reinforced these messages. It identified qualitative differences in the reasons for caring as between mental health, physical disability and substance misuse. The key messages from this piece of work are summarised in **Appendix E**. The evaluation and the workshop we held also identified challenges to successful working. These were around:

- different risk thresholds, service fragmentation, legislation and separate guidance on policy and practice
- anxieties around expertise, communication, professional trust and autonomy, and clarity about responsibilities for “who does what”
- resistance to change, shared organisational cultures and values
- levels of flexibility in support and understanding of needs
- having the right information and shared knowledge to inform practice

Building Strategic Leadership and Partnership

Young carers and their families are clear that they want agencies to work together better. Parents want good quality practical support to look after their children that is seamless, accessible, available, and not crisis driven. Successful front line and joint working also requires leadership in the context of partnership. Inclusion within local needs assessments for commissioning for best practice is essential. Understanding what helps or hinders successful partnership working at the individual, operational and structural level is also vital. **Appendix G** outlines some of the key aspects around partnership working. This includes summary information from SCIE *At a Glance 32*²¹, *Think Child, think parent, think family: a briefing for senior managers*. This review encouraged senior managers to:

- take a strategic approach
- clarify joint working arrangements
- demonstrate commitment and lead cultural change
- involve people who use services
- embed into local performance and quality systems
- improve staff skills and knowledge
- improve access to services
- collect the right information
- ensure commissioning supports families.

LISTENING, LEARNING AND LEADING

The workshop arranged by the ADASS Carers Policy Network in May 2011 considered the evidence outlined in this paper. It drew heavily on the experience of participants involved in working with young carers and families affected by enduring parental mental illness and/or parental substance misuse. We explored a range of issues and tried to identify those that might benefit from further local discussion designed to improve outcomes.

It was clear that a lot of innovative things were happening locally that we can all draw upon. There were also challenges and concerns. There were undoubtedly some common strands suggested for us all to think about when pursuing better outcomes for young carers and their families. We did not see progress as a “one size fits all” approach. Rather, the key was to reflect and focus upon local needs, practice and feedback and to pace and prioritise progress consistent with local priorities and resources of partners.

The key themes arising from the workshop discussions were:

- Some excellent work is taking place around the country. We need to know more about this and to improve information and knowledge dissemination about what really works.
- Many of the themes that emerged were not new. We need to use the knowledge and evidence we have and for everyone to “know what we know” and to draw on this experience in practice.
- Local commissioners and providers need to evidence how interventions have made lives better/made a difference. We need to focus consistently and sharply on the outcomes we are working towards for young carers and their families.
- Keep in mind and ask as necessary, what makes the most difference for young carers and their families. What is the feedback telling us?
- Health and social care professionals work in a complex world. Many of the issues are about the way we work and the way in which practice occurs within established policies and procedures.
- We need to get the basics consistently right. The more complex we make matters the more difficult it can be for professionals in the field.
- Aim to see families as a whole: understand strengths, resilience, and risks to be faced but without stigmatising or labelling people.
- Understand resources, the need to do more with less, finding what makes the most difference or offers the best return for the spend.
- It’s about what and how we do things locally and local fit. Time spent exploring these things as part of ongoing local conversations will help.
- In many ways we have enough to guide us toward these things now. It’s about “Go away and do”.

GROWING LOCAL CONVERSATIONS

This section offers some conversation points Directors may wish to pursue locally. There may be others that are more relevant to local needs and circumstances. The aim has been to offer a range of potential discussion points building on the material from this review that people can select from: you do not have to cover them all. Those questions we hope most colleagues may wish to follow through on are highlighted in *italic script*. The Appendices also offer information on some further resources to inform local practice and to support local conversations about the things that matter locally.

A recently published interim evaluation report by SCIE²² contains a number of important messages around emerging learning from *Think Family* implementation sites. It confirms that lots of small changes can have a far reaching impact. Responsiveness to opportunities and changes in practice, policy and priorities has been needed to help embed “*Think Family*” working.

If local conversations are to be fruitful, however, this approach needs to be owned by Statutory Directors and Lead Members and be consistent with the underpinning principles in *Working Together to Support Young Carers*. Strategic Leadership and ownership of the process remain vital components to achieving change that makes a difference and is sustainable. Overview and Scrutiny processes may offer just such an opportunity for engagement and discussion of the issues covered in this review.

As always, local examples of policy and practice in action would be welcome. Please send them to adasscarers@warwickshire.gov.uk

Tackling challenges to self identification by young carers

Do children see themselves as young carers?

Do young carers know a trusted adult to talk to? Is it OK to talk?

Do we create safe environments for children and parents to speak up and take forward what they say?

Is our messaging to young carers consistent, concerned, and communicated in ways that are age appropriate?

Are front-line staff in different settings aware of the potential barriers to self-identification?

Is disclosure only happening at crisis points?

How confident are we about local “first response” arrangements in this area?

Engaging young carers and meeting family support needs

Do professionals in health, treatment services and adult services always ask key questions such as “Are there children?” “Who supports you as a parent?”

Do we ask what it's like, what is going on and what young carers and their families say would help them to be a family?

Do we all accept locally there are “no wrong front doors” for young carers who want to talk and do we support this in practice?

Are young carers' needs considered in support planning so that personal budgets can benefit the family as a whole?

Are all local professionals confident about their ability to respond to what young carers tell them and at the right pace?

How well does sharing information and explaining work for young carers?

How can we use learning and development opportunities to underpin Whole Family practice and to share the material from this paper?

Given the importance of “trusted adults” in working with young carers, do we ensure consistency in contact and try to avoid “disrupted relationships”?

Pursuing successful front line partnerships for whole family approaches

Are support thresholds clear? Are we confident that they are not used as a barrier to successful front line partnerships?

Are local assessment mechanisms integrated – how many times has the story to be told?

Are we using the “Key Principles of Practice” [**Appendix F**] and “Whole Family” approaches or concepts such as “family group conferencing” locally?

Are local services within clear care pathways? How well signposted are they and are professionals aware of all services to refer to locally?

How do we approach recording and information sharing? Does it empower?

Are we engaging with third sector partners to widen family choice and control?

What joint learning and development opportunities are in place?

Do front line staff and their managers make use of evidence and best practice to frame improved outcomes for young carers and their families?

Do we promote family resilience whilst still managing risks proportionately and ensuring safety of children?

Is there partnership working between adult and children's services that enables flexibility in the use of resources to support whole families and to support young carers in transition?

Is there managerial perseverance and commitment to overcoming problems?

Building strategic leadership and partnership for sustainable outcomes

What have we done about “Working together with young carers [MoU]?”

What are the barriers to effective partnership working in this area?

Have we shared understandings about boundaries and resources?

What are young carers and families telling us about their experiences and what have we done in response? Are we really listening?

What is the feedback from staff – what would make a difference for them?

How well are local population needs understood and how are they included in our local needs assessments and service commissioning arrangements?

Have we got clear aims and outcomes in mind? Are they shared?

What arrangements are in place to monitor performance results?

Do our processes avoid duplication? Is there a shared care pathway?

Do front line staff and communities know what we are trying to do?

What have we sought to do as a result of the work by SCIE and others?

Do we know what we know? Do we use it in practice?

From Conversations with Young People

“We have a lot to say –the challenge is to really listen to us and then we can all work together to make things better for us and our families”

“Now we know more people will understand our lives and how services can and should work better.”

Young people from Liverpool [Barnardo’s, Keeping the Family in Mind]

“It’s like a stone being dropped into water, the ripple affects everybody.”

Young carer at the Birmingham Regional Conference [The Children’s Society]

“It felt really good when I could talk to people because I felt like a bottle ready to explode and I didn’t want that to happen.”

Young person aged 12 [STARS National Initiative]

APPENDIX A

CHALLENGES TO SELF-IDENTIFICATION

The resource materials for schools developed by The Children's Society and the Princess Royal Trust for Carers [Reference 16] emphasises the importance of professionals understanding the reasons why some young carers may be uncomfortable about coming forward. Young carers may not be easy to identify. Some may not see themselves as "carers" and some may seek to conceal their role. Obstacles to self-identification by young carers include:

- They worry that the family will be split up and taken into care
- They want to keep it a secret and/or are embarrassed about the person who is ill or has disabilities
- They may not realise that they are carers or that life is different to that of their peers
- They don't want to be any different from their peers.
- They believe that the[ir] school will show no interest in their family circumstances.
- School is different; they have a new or different identity.
- It's not the sort of thing that can be discussed with friends.
- There has been no opportunity to share their story.
- They are worried about bullying
- They see no reason or positive actions occurring as a result of telling their story.
- They feel stigma or shame attaches to their parent's drug or alcohol use
- They may be wary about the involvement of outside agencies
- They do not want to "betray" their parents

These factors are similar to more general factors affecting service and benefits take up noted by Arshi Ahmad in 1990²³.

Also relevant to professionals in this context are the factors identified in ***Juggling Harms***. [Appendix C] This material confirms the complexity of the issues that can arise in the context of substance misuse. In families with stress factors such as mental health or substance misuse, parental behaviour is often stigmatised by others due to its illegal nature or unpredictability. Professionals need to be aware, therefore, that young carers may have a sense of "stigma by association" from others which may be in tension with their sense of "loyalty to the family" and the need to talk. How this is handled can be critical to successful identification and engagement with them.

The availability of resource materials such as "***Ask me about me***" DVD²⁴ www.starsnationalinitiative.org.uk or the ***Barnardo's Keeping the Family in Mind*** DVD can be important in raising awareness and in informing professional practice. Further resource materials are listed in **Appendix I**.

APPENDIX B

ALCOHOL MISUSE – BARRIERS TO HELP

Swept under the carpet²⁵ estimated that some 2.6 million children in the UK live with parents who drink hazardously. The impact of this will vary from family to family and children will respond and cope differently. The supports available were often important in this context and would include young carers. In general, the impact on children is often significant. Children whose parents misuse alcohol often suffered a range of poor outcomes. Joint working between adult and children's social care was identified as an area in need of both change and improvement.

An earlier report, ***Parenting, alcohol misuse and treatment service provision***²⁶ identified that a family-focused approach has not been widely adopted within the provision of alcohol misuse services. Rather, treatments tended to focus on addictions as the primary problem with much less focus on the demands and responsibilities of family life on the part of the drinking parent. It suggested there were "*concrete and attitudinal barriers*" to providing services for children and families. They were:

- A lack of awareness on the part of children and families that their situation constitutes a problem, which precludes them from seeking help.
- The social stigma attached to parental problem drinking often leads children and families to conspire to keep the problem a secret.
- A lack of awareness of available services on the part of children and families of services available.
- Insufficient service provision for this population.
- Reliance on self referral due to a lack of outreach services.
- The need for parental consent to work with children when parents often fail to acknowledge that there is a problem.
- Insufficient resources, including lack of time, money and appropriate training to meet the needs of this group.
- The many additional demands experienced by parents who have primary responsibility for childcare that make it difficult for them to engage in and adhere to traditional addiction treatment programmes, such as lack of childcare facilities.
- Inadequate interagency communication.
- Attitudes to alcohol where alcohol misuse is perceived as a cultural norm.
- Risk versus need, where children are often perceived as not "neglected enough" and so no action is taken by a professional until actual harm is inflicted.
- Philosophy of care, where treatment approaches are commonly individualistic rather than holistic in their focus, with reasons for this being an "over-emphasis" on confidentiality, a lack of resources and not wanting to "scare people off".
- A fear on the part of professionals, who realise the scale of the problem and the resulting needs, of opening the floodgates and further overstressing resources.

The paper concludes that if this is accepted then agencies coming into contact with children or their parents, including the majority of adult drug and alcohol services, must be seen as having a responsibility to support and protect them. Most parents welcome support. Particular objectives were seen as improving parental functioning and family resilience and removing from children the fear of being split up.

APPENDIX C

JUGGLING HARMS [2011] – KEY MESSAGES*

Unseen is unknown - parents closing doors:

- Parents' damage limitation strategies are mobilised around time and space.
- Many parents engage with the rationale of "that which cannot be seen cannot do harm for it cannot be known".
- Parents invest in denial of disclosure and strategies of ambiguity concerning their drug misuse.
- Parents repeatedly postpone "coming clean" to their children and tend to disclose only once their children indicate that they "know" or when they are about to find out by some other means.

Becoming aware - children opening doors:

- Parents' substance misuse is often sensed before it is verbalised and fully understood.
- Young people's shifting assessment of their parents' behaviour as not "normal" occurs over time.
- Young people's awareness of parents' substance misuse is often accompanied by a sense of shame and embarrassment that their family life is not normal.
- In response, young people invest considerable effort in concealing their family life experiences from the world outside their home, both to protect themselves as well as their parents.

Love, care and family:

- Young people anticipate a norm of unconditional love between parents and children but feel their parents do not always care about them when they are preoccupied with drugs and alcohol.
- The felt linkage between love and "being related" makes it difficult, if not impossible, for children to question the unconditional love between themselves and their parents, even when the relationship is problematic.
- Young people's felt necessity to continue to love their parents and care for the family is linked to the importance they place on "being in a family", and acting according to their expectations about familial love and care.
- Young people learn to explain away or excuse their parents' sometimes lack of care to enable a continued love.
- Overcoming a felt conflict between caring for family and caring for self is important for young people's sense of coping.

Caring for siblings:

- Sibling order matters; when younger siblings are parented or protected by older siblings they may not develop the same levels of knowledge or skills to manage parent's substance misuse.
- Siblings often move at different paces in how they feel about their parents' substance misuse and in their attempts to cope.
- Older siblings often struggle to give up their role as primary carers and in consequence often down-prioritise their own needs

- Siblings often share their parents' substance misuse in silence. This may be linked to growing up with their parents' substance misuse together as their "normal".

Practices of friendship:

- Many young people do not talk to their friends about parents' substance misuse. This needs to be understood within a context of fragile friendships and uncertainty around ongoing trust.
- Friends often become aware of parents' substance misuse in the same way as young people themselves – through environmental exposure. This often makes explicit disclosure unnecessary.
- Young people appreciate the conversational space that their friends give them to talk or not talk about their experiences at home: trusted friends don't ask direct questions all the time.
- Friends who are aware of parents' substance misuse and have a nuanced understanding of what is going on may be allowed to talk about parents in a way which others are not.

Engaging with professionals

- In the absence of early identification young people's disclosure tends to happen at crisis points.
- Professionals' awareness of parents' substance misuse does not necessarily, from a young person's perspective, translate into "knowing" what this involves or how it is experienced.
- Young people appreciate professionals who give them space to build trust as well as the choice to talk, what to tell and at what pace.
- Young people's repeated experiences of disrupted relationships with professionals may result in resignation and lack of engagement.

Juggling Harms - Children and Young People Speaking

This study includes all lot of direct comments by children and young people. Here are three relating to the section on engaging with professionals. [See also: **Appendix D**]

Um, when, they don't tell you what to do. Like they listen to you. That they take things slowly and don't rush you into doing stuff.

-Lauren – what makes a good social worker [p.59]

She [key worker] knows if I say I don't know then I don't want to talk about it yet, and that's OK.

-Jamie [p.60] [space for non-talk that creates trust and respect]

And I didn't want to have to keep repeating myself...and it were getting on my nerves. But then like, with [support service] it's like the same person every time I come and see her. So, I don't have to keep like, repeating stuff all the time.

-Sarah [p. 62] importance of continuing relationships

* **Houmoller Katharin, Bernhas Sarah and Rhodes, Tim, *Juggling Harms – Coping with parental substance misuse*, London School of Hygiene & Tropical Medicine, 2011.**

APPENDIX D

ENGAGING YOUNG CARERS

Barnardo's Keeping the Family in Mind [Liverpool] resource pack²⁷ contains 10 key messages from children and young people for professionals coming into contact with parents with mental health difficulties. They are:

- Introduce yourself. Tell us who you are and what your job is.
- Give us as much information as you can
- Tell us what is wrong with our parents
- Tell us what is going to happen next
- Talk to us and listen to us. Remember it is not hard to speak to us we are not aliens.
- Ask us what we know and what we think. We live with our parents; we know how they have been behaving.
- Tell us it is not our fault. We can feel guilty if our mum or dad is ill. We need to know we are not to blame.
- Please don't ignore us. Remember we are part of the family and we live there too.
- Keep on talking to us and keeping us informed. We need to know what is happening.
- Tell us if there is anyone we can talk to. Maybe it could be you.

In their own words:

"If staff and workers don't really understand how we feel then things just won't change." Louisa, young carer

"They look at me and think "She's young, she won't know anything, but just because I'm young doesn't mean that I don't know everything about my mum." Cait

They say things like "we only work with your mum" but my mum lives with me so it's all connected." Young carer, aged 12 talking about professionals

"It's difficult enough living with mental health problems but it feels like me and the kids have all our problems separated out and then no one gets the whole picture and sees how we are all affected." Mother with mental health issues talking about services and professionals

"To me it needs those people at the top to say we are going to really work on the things in the guide because it will help families." Cait, young carer

Finally, Sue, a young carer from Liverpool [See DVD] whose comment sparked the idea for the title of this paper:

"Can you hear me, can you see me ... then why did you ignore me?"

APPENDIX – E

WHAT WORKS - SUCCESSFUL FRONT LINE FAMILY SERVICES

SCIE “*At a Glance 09*”²⁸ summarises the messages from the main “*Think child, think parent think family*” report of 2009. This suggested that a successful service for families with a parent with a mental health problem would:

- Promote resilience and well being of all family members, now and in the future.
- Offer appropriate support to avoid crises and will manage them when they arise.
- Secure child safety.

A high quality service that incorporated a “*Think child, think parent, think family*” approach would:

- Respect an individual's wishes and recognise their role and responsibilities in a family.
- Incorporate a resilience led perspective building on a family's strengths.
- Intervene early to avoid crises, stop them soon after they start and continue to provide support once the crisis has been resolved.
- Be built upon a thorough understanding of developmental needs of children, the factors that impact on parenting capacity, the impact of parental mental health problems on children and the impact of parenting on a parent's mental health.
- Address the potential impact of parental mental health problems on children over time and across generations.
- Support the empowerment of people who use services through sharing information and knowledge and ensure their involvement in all stages of the planning and delivery of their care.
- Respect the right of the child to maintain contact with both parents, except if this is contrary to the child's best interests.

The Islington *Think Family* evaluation²⁹ confirms many of these messages. It indicates:

- Staff from the trust and LA do want to work in partnership but need support from managers
- The Joint Working protocol³⁰ can be used to address concerns of confidentiality, safeguarding, referral pathways & legal process
- To embed the ethos of *Think Family* will require further management initiative and the delivery of audit recommendations across services
- Whole family assessment can be used to assess families with multiple needs and can be shared. This can avoid repeat assessment.

- Families responded positively to the *Whole Family* assessment and to the joined up work of the team around the family.
- The ethos of *Think Family* does reduce risk in families including crisis/relapse in parents and children being put at risk.
- Voluntary agencies are often best placed to support families and families respond well to their needs (Islington Families/Epic and Family Action, CSV).
- Staff appreciate, and learn from, joint training on mental illness and child protection.
- Young carers benefit from tailored assessment and support, identification of who is a young carer needs to be improved throughout all services.
- Difficulties and problems between services can be overcome with managerial support and perseverance.
- Children enjoy a creative response to their needs and want to tell their stories.
- Children and their parents can be supported to have happy, healthy lives and contribute to the community they live within.
- The Social Return on Investment [SROI] indicates that the project has produced significant cost savings per family seen.

APPENDIX F

THE CHILDREN'S SOCIETY - KEY PRINCIPLES OF PRACTICE 2008

Six Key Principles of Practice²

- 1 Children's welfare should be promoted and safeguarded by working towards the prevention of any child undertaking inappropriate levels of care and responsibility for a family member.
- 2 The key to change is the development of a *whole family* approach and for all agencies to work together, including children's and adults' services, to offer co-ordinated assessments and services to the child and the whole family.
- 3 Young carers and their families are the experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.
- 4 Young carers will have the same access to education and career choices as their peers.
- 5 It is essential to continue to raise awareness of young carers and to support and influence change effectively. Work with young carers and their families must be monitored and evaluated regularly.
- 6 Local young carer's projects or other targeted services should be available to provide safe quality support to those children who continue to be affected by any caring role within their family.

Using these ***Key Principles*** will help ensure the best use of resources to deliver support to the whole family. Threading them throughout local practice will also:

- influence change and clarify lines of accountability
- support interagency joint practice and vital joint working between adults' services and children's services
- encourage young carers and families to come forward and self-refer at an early stage
- make the identification and assessment of any needs more holistic and more effective
- support disabled parents' entitlements to assessments and services, including any parenting support needs
- work towards ensuring that young carers and their families receive the same high standards of support and services wherever they are in the country
- work towards ensuring that children do not take on inappropriate roles and responsibilities.

² **Frank, Jenny & McLarnon Julie**, *Young carers, parents and their families: key principles of practice- supportive guidance for those who work directly with, or commission services for, young carers and their families*, The Children's Society, 2008

APPENDIX G

STRATEGIC LEADERSHIP & PARTNERSHIP

“Working Together to Support Young Carers” outlines an administrative mechanism to secure a vision for improved partnership working between adult and children’s social care; better outcomes for young carers and their families and a platform for working with health and schools. In relation to young carers and their families, it is clear effective partnership working is often a very productive way of achieving more efficient and effective use of scarce resources.

Joint working between health and social care and others is, of course, an established policy priority in England. There are a number of formulations about what makes partnerships work and principles for partnership working³¹. A recent review by Jon Glasby and others of progress³² confirmed the importance of a shared vision, clarity of role, a sharp focus on outcomes and a shared understanding of the nature of the partnership required to achieve the aims it has set. The review includes a partnership readiness framework³³:

- Building shared values and principles
- Agreeing specific policy shifts
- Being prepared to explore new service options
- Determining agreed boundaries
- Agreeing respective roles on commissioning, purchasing and providing
- Identifying agreed resource tools
- Ensuring effective leadership
- Providing sufficient development capacity
- Developing and sustaining good personal relationships
- Focusing on mutual trust and attitudes

Partnership approaches are a key mechanism for joint responses to joint problems and seamless ways of working with families with complex needs. The Glasby paper makes the point that health and social care have to work together if they are to respond effectively to people with complex needs. The reframing of resources is seen as making this even more important.

The Glasby paper makes clear that to succeed a strategic partnership approach needs to work at three levels: individual/front line, organisational and structural. The way people behave will reflect, in part, the different priorities values and ways of working. Leadership, vision, shared understandings, ownership and benefits are all vital components of change and achievement. That this is the case, was very apparent in the network’s workshop presentations and discussions of May 2011.

The Carers Policy Network workshop reviewed the messages from SCIE ***“At a Glance No 32”*** This highlighted seven messages for senior managers. They were:

- Promote and support *Think child, think parent, think family* approaches to improve outcomes for parents with mental health problems and their families.
- Take a strategic multi-agency approach to implement the guide’s recommendations.
- Lead cultural change by challenging practice that does not support families and by collaborating across agencies.

- Ensure your organisation listens to parents and children, including young carers.
- Embed *whole-family* approaches into performance and quality systems such as supervision, performance management and internal audit.
- Provide opportunities for staff to improve their skills. This includes formal joint training and informal opportunities such as shadowing.
- Ensure that information about families is recorded and accessible. This is essential for individual care management, child protection and to build up population information for commissioners and managers.

The SCIE *Think child, think parent, think family: interim evaluation report*³⁴, published in August 2011, emphasises the need for senior management sign up. This was linked to a range of other factors including an impact on: awareness of the project across the organisation; ensuring links are made to other initiatives; the effectiveness of intra-agency working; and, ensuring that staff are released for training. Senior management sign up was important for:

- **Leading** the work at senior level
- **Modelling** multi-agency working
- **Facilitating** relationships within and across organisations
- **Allowing** other staff to make time for and prioritise this work

Pre-existing approaches to and experience of inter-agency working together with the strength of relationships between key players were also relevant to the development of these projects. The SCIE report outlined some emerging solutions:

- quick wins – relatively quick and low cost actions that help people to work together and adopt “think family”
- linking to related initiatives such as *Hidden Harm*
- building capacity in the voluntary and community sector on screening, assessment and onward referral of parents and families.
- practitioner champions
- building on the Common Assessment Framework[CAF] and Team Around the Child [TAC] can provide a good basis for taking a whole-family approach

A SENIOR MANAGER SPEAKING

“... we have much to learn about how to “Think Family” in practice and meeting the needs of families effectively does not lie within the gift of a single organisation or service”

Clare Mahoney, Head of Integrated Mental Health Commissioning
Liverpool PCT/Liverpool City Council

APPENDIX H

WHOLE FAMILY WORKING

PRIORITIES FROM 2010 INCLUDE PARTNERSHIP REGIONAL CONFERENCES

At each of these regional events workshop participants were asked to identify two key priorities. The priorities for “whole family” working compiled from all five events as set out in the published conference summary are set out below:

Whole Family Working – Tools and Solutions*

- Promote good working relationships that are backed by inter-agency agreements and strategic agreements from senior level.
- Consider interagency and peer training requirements
- Be realistic about what you can do/provide and signpost to other agencies
- Young carers training should be embedded within training for students studying to be GPs, teachers, social workers etc..
- Develop real partnership between voluntary and statutory sectors.
- Embedding joint commissioning between adults and children’s services.

“Acknowledge the time for relationship building for sustainable solutions”

Regional Conference Participant

***Note:** From page 5 of the summary. The summary conference report also outlines priorities for Parental Substance Misuse, Parental Mental Health and for the Department for Education Whole Family Working Programme. [For full reference see endnote 11]

APPENDIX – I

Sources, References and Additional Resources

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⁴ **HM Government**, *Recognised, Valued and Supported: next steps for the Carers Strategy*, Department of Health, 25 November 2010. Gateway ref:15179

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¹³ **Houmoller Katharin, Bernhas Sarah and Rhodes, Tim**, *Juggling Harms – Coping with parental substance misuse*, London School of Hygiene & Tropical Medicine, 2011.

¹⁴ **Princess Royal Trust for Carers/Mental Health Foundation** *My Care, The challenges facing young carers of parents with a severe mental illness*, December 2010, Foreword p 2.

¹⁵ **Princess Royal Trust for Carers/Mental Health Foundation**, *My Care, The challenges facing young carers of parents with a severe mental illness*, December 2010, Foreword p 2.

¹⁶ **Princess Royal Trust for Carers and The Children's Society** *Supporting Young Carers: A resource for Schools*, 2010.

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Additional resources to help you locally

The following additional resources complement this paper. They are all very practical and help to bridge the “theory-practice” gap.

- **THE CARERS HUB (for Listening, Learning and Leading section)**

The Carers' Hub, a project by The Princess Royal Trust for Carers and Crossroads Care is a developing showcase of successful interventions for carers and young carers and a ‘ready-made’ evidence base from which to draw from. See:

<http://www.carershub.org>

- **MANUAL FOR MEASURES OF CARING ACTIVITIES AND OUTCOMES (for Listening, Learning and Leading section)**

The Manual for Measures of Caring Activities and Outcomes contains a range of outcome measuring tool relevant for assessment and evaluation work with young carers: <http://professionals.carers.org/young-carers/assessments,3063,PP.html>

- **THE INCLUDE PARTNERSHIP RESOURCES FOR LOCAL AUTHORITIES (for Building Strategic Leadership and Partnership section)**

Toolkit for local authorities and young carers’ services: The Include Partnership Project – a partnership between The Children’s Society and The Princess Royal Trust for Carers was originally funded by the DCSF and then the DFE, to deliver training, information and best practice examples to local authorities in England. The project developed a range of resources to aid local authorities and services with their development of strategy and service provision for young carers and their families:

<http://www.youngcarer.com//showPage.php?file=200813131330.htm>

- E-LEARNING: PARENTAL MENTAL HEALTH AND FAMILIES [SCIE]
- E-LEARNING: PARENTAL SUBSTANCE MISUSE [SCIE]
(for **Successful Front Line services section and Conversations**)

These e-learning resources launched in 2011 are freely available to all. They provide audio, video and interactive technology to assist in exploring the nature of parental mental health and its impact on families. It covers: introducing the family model, Think child, think parent and think family; Working together with parents; Working together with professionals; Care planning and review; Interventions, Managing complexity and leading practice; Communicating with families.

The e-learning resource on parental substance misuse is similar. It provides resources for exploring parental substance misuse, its effects on children and parenting capacity and the implications for social work practitioners: recognition, referral, engagement and assessment, supporting children and families, roles and responsibilities across agencies.

<http://www.scie.org.uk/publications/elearning/parentalmentalhealthandfamilies/index.asp>

<http://www.scie.org.uk/publications/elearning/parentalsubstancemisuse/index.asp>

- **SUPPORTING BLACK, MINORITY AND ETHNIC YOUNG CARERS AND FAMILIES (whole paper)**

‘The Children’s Society Engage toolkit is a hub, drawing together understanding, policy and best practice from a wide range of sources, including national and local experts, to support adult and young carers in Black Minority Ethnic families, including Gypsy and Traveller communities.

<http://www.engagetoolkit.org.uk>

- **PREVENTION THROUGH PARTNERSHIP -IMPROVING OUTCOMES FOR CHILDREN, YOUNG PEOPLE AND FAMILIES WITH MULTIPLE PROBLEMS (for Listening, Learning and Leading)**

The Children’s Society free online resource bank and free workforce development events to help all agencies working with vulnerable families where a parent is experiencing mental ill health or substance misuse and maybe relying on a child to provide care.

<http://www.youngcarer.com/ptp>.

HEALTHY SCHOOLS MODULE – CHILDREN’S SOCIETY (for Identification, engagement and successful front line working)

A Healthy Schools young carers e-learning module is now available to help school staff who work with young carers. The aim of the module is to increase understanding in schools of particular issues and challenges facing young carers and their families. The module is designed to help all school staff identify and support young carers throughout their education. Based on a set of questions, it provides insight into young carers and practical ideas about how to support them directly and within the wider school setting.

www.childrenssociety.org.uk/what-you-can-do/resources/school-resources/supporting-young-carers

STARS NATIONAL INITIATIVE (for whole paper)

This web site is an excellent hub for information for those people working with families affected by parental drug and alcohol misuse. It contains a wide range of resources in different media. It includes a section on Children’s Voices, DVD gallery, information on web sites and has separate pages for adults and professionals and children and young people.

<http://www.starsnationalinitiative.org.uk>

OTHER RESOURCES/YOUR NOTES:



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