Beyond talk: Learning from children and young people experiencing a family health crisis

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Beyond talk: learning from children and young people experiencing a family health crisis

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Introduction

Living with challenging family circumstances has been described as ‘living with an elephant in the room’ where everyone pretends it isn’t there and no-one wants to talk about it (Kroll, 2004). In contrast, and set within wider discussions on children and young people’s participation, it is often assumed that children and young people want, need and have the skills and increasingly the opportunities to talk about their lives (see Chapter 7 by Eriksson and Pringle in this volume). Here we consider how they wish - or not - to talk about personal ‘stuff’ and the implications for policies and practices designed to support them. Participation is a broad and complex theme, as the previous two chapters have discussed, and encompasses how children and young people are consulted on issues of concern to them, how they are listened too, as well as how they choose to express their views, or not. In this chapter we focus primarily on voice.

Ideas about talking and listening are embedded in debates about children and young people’s rights, particularly their autonomy and welfare rights to participate, have a voice and share their experiences. Indeed participation is frequently heralded as the gold standard of research, policies and practices concerned with childhood. Despite the widespread discourse of participation, very little is actually known about the lived experiences of children and young people living with a loved one who is seriously ill. The limited research that is available indicates that a significant proportion are living with a loved one, including parents, grandparents and siblings, who suffer from a chronic or terminal health condition and policies, practices and services to support them are scarce. These children and young people are rarely listened to, their participatory opportunities are challenged by personal circumstances and their experiences of multi-agency practices to support their needs reveal gross inadequacies. Consequently, they may experience distress, anxiety (Kennedy and Lloyd Williams, 2009; Backett-Milburn and Jackson, 2012), depressive symptoms (Holbrook, 2017) and are at risk of becoming disengaged with education, socially isolated and uncertain regarding what the future will hold for them (Bennett et al., 2018).
This chapter shares findings from a recent study which engaged with young people experiencing a family health crisis and reveals participation to be a complex theme. We provide a detailed case study of Hope Support Services (Hope), the only organisation in the United Kingdom which supports those aged 11-18 years living with a loved one who is seriously ill. We focus on many of the assumptions about listening and talk which connect to debates about participation and highlight issues for practitioners. Although the focus here is on the needs of young people experiencing a family health crisis many of the themes resonate with other practice areas in childhood and so will have broad relevance across health, education and social care.

Our research

Studies exploring the impact of living with a family health crisis have often orientated to ‘young carers’ who provide care for a family member within the home (Aldridge and Becker, 2003), as well as studies of parents caring for a chronically or terminally ill child (Brown, 2015) and for children and young people suffering bereavement (Rolls and Payne, 2007; Brewer and Sparkes, 2011). Other research has studied children and young people’s experiences of parental substance use within the home and the strategies employed to endure such challenging circumstances (Hill, 2015). Despite the wealth of research available in the field of bereavement, palliative care and mental health, there is scant research on the needs and experiences of young people living through a family health crisis (Bennett et al., 2018) and the impact that this has upon their lives (Backett-Milburn and Jackson, 2012). This may reflect the complexity of the field, as well as the difficulties in identifying and accessing young people’s (and particularly children’s) views in such a sensitive and highly charged area. In the absence of data our research focused on three key areas. Firstly we wanted to find out how many young people are living with a loved one who is seriously ill; secondly, their experiences; and thirdly, how their needs could be met.

In order to examine the extent of need throughout the UK, we drew upon longitudinal data from the British Millennium Cohort Study (University of London, 2017). The BMCS is one of Britain’s national longitudinal birth cohort survey studies, run by the Centre for Longitudinal Studies (CLS) at the University College London Institute of Education, London. The MCS survey field of enquiry (See http://doi.org/10.5255/UKDA-SN-7464-4) covers such diverse topics as parenting; childcare; school choice; child behaviour and cognitive development; child and parental health; parents’ employment and education; income and poverty; housing, neighbourhood and residential mobility; and social capital and ethnicity. In addition, in-depth case study analysis of existing support—although limited—enabled us to build up a detailed picture of how young people experience living with a family health
crisis and the nature of the services they require based on interviews and field study observations with the charity Hope.

Hope works across community and neighbourhood projects and alongside health, social care and education practitioners to provide holistic support services. Hope is unique in the support it provides to those aged between 11 – 18 years (and works with older young people aged 18 years and over who are part of a youth management team) living in the West of England who are experiencing a family health crisis. It supports them from the point of diagnosis through a number of different media, including youth sessions, online support and a youth advocacy programme. Hope already has a number of public-facing case studies. Through interviews (nine in total) we aimed to supplement these further by seeking young people’s (aged 18 - 23 years) stories.

**Children and young people’s participation**

Participation is typically associated with concepts such as listening and voice but is a complex and contested term (Kellett, 2009). Participation can mean much more than listening and has become embedded in debates about children and young people’s basic human rights, including their right to express their views on matters which are important to them, but also their right to have their views taken on board by those in positions of authority, particularly politicians and policy makers, and used to improve their lives (Kellett, 2009). Participation is thus part of a wider dialogue about the capacity, competency and choice children and young people have in when and how they express their views, when they choose to remain silent (Bucknall, 2014), or when they encounter barriers to sharing their views (Cooper, 2015). Many children and young people still find access to participatory opportunities difficult by virtue of their marginalised position, or due to endemic power relations which render them powerless. This is particularly relevant to many including those who are disabled (for a personal account see Chapter 16 by Rix in this volume) or are refugees, those within the care system as well as those affected by parental drug and alcohol use within the home and those who find expressing their views challenging (Cooper, 2017).

Articles 12 and 13 of the United Nations Convention on the Rights of the Child compelled governments to find more effective ways of engaging with children and young people through enhanced listening and more effective consultation processes. A series of policy reforms were enacted in the UK which brought consultation and participation into the heart of childhood and youth service provision. From the *Every Child Matters* Green Paper (DfES, 2003) to integrated services (Kellett, 2014) and multi-agency practice (CSDG, 2018), the discourse of participation remains strong, even if the realities and rhetoric do not always coincide (Cooper and Kellett, 2016).
Our research findings suggest that approximately 20% of all children aged 11-17 in the UK (total = approximately 5 million) have a parent or caregiver who has a longstanding illness and this equates to potentially a million children. Approximately 0.02% of all children have a parent or caregiver who has cancer and this equates to potentially 10,200 children aged 11 and above in the UK. However, it is likely these figures do not reflect the true scale of the problem. For example, an estimated 2,273,200 people who had previously been diagnosed with cancer were alive in the UK at the end of 2013. These figures are increasing year on year, and there were around 357,000 new cases of cancer in the UK in 2014, that’s 980 cases diagnosed every day (Cancer Research UK, 2017). There were 2.5 million people living with cancer in 2016 and by 2040, there will be 5.3 million (Macmillan Cancer Support Annual Report, 2016: 5), many of whom will have a child or a young person living at home. Yet findings from our study indicate that despite the significant number of children young people in the UK that are living with a loved one who is seriously ill their needs and experiences remain somewhat ‘invisible’ (Bennett et al., 2018).

**Listening to children and young people experiencing a family health crisis**

Just someone to listen to you... There was no-one... (Emma).

Although the phrase ‘health crisis’ is typically used in discussions about living with a loved one who is seriously ill, it became apparent during our research that ‘crisis’ – which implies a period of intense difficulty – does not fully encapsulate the enduring extent of children and young people’s shared experiences. Services that are available to support families in the UK are very much dependent upon the age and status of the service user designated as child, young person or adult and their capacity to access and engage with support, as Lisa describes:

‘I was in a weird place in my life. I wasn’t an adult as such. Like I didn’t have a car, I didn’t have a house and I didn’t have a job but I wasn’t a child in school. I wasn’t under 18 when they do offer quite a bit of support. And I wasn’t a parent of the ill person as there is some support for them and I wasn’t the spouse of the ill person as there is some support for them too. There is nothing for someone whose parent is terminally ill who was not really an adult and not really a child.’

Lisa indicates the lack of support for someone in her circumstances. As her mother was diagnosed with terminal cancer, she tried to access support only to find that ‘there is nothing out there’ and very few services who work with young people who have a terminally ill family member. As a young
person at university, Lisa felt that she fell between being an adult with all of the independence and self-sufficiency that it implied and being a young person who was seen as vulnerable and for whom support should be available. Lisa was not alone in expressing frustration at the lack of support for those experiencing a family health crisis and many describe feeling ‘let down’, ‘alone’, ‘isolated’ and that ‘one-one cares’. For service users to be able to access support effectively, they need to be specifically aware of which services are available, have access to appropriate information and, in many cases, being able to engage online support. Whilst there are a number of organisations including Barnardos (https://beliveinme.barnardos.org.uk) and Relate (https://www.relate.org.uk) that specifically address social care, education and mental health issues (see Bennett et al., 2018), there are few that are targeted to support these people experiencing a family health crisis from the point of diagnosis.

In terms of listening to the needs of children and young people, the discourse of multi-agency working where everyone who is concerned in providing support consults with the child or young person and works across sectors to provide support, is clearly stated (Nicholas, 2015) and yet so often falls short of meeting such objectives (Bessant and Broadley, 2014; Cooper and Kellett, 2016). Joining up services to ensure integrated practice works around the needs of the child or young person not only relies on collaboration between professionals following referrals, targeted intervention and open channels of communication (Nicholas, 2015; CSDG, 2018) but fundamentally rests upon an initial recognition of need. Professionals are likely to come from a wide range of services and each will have their own professional and organisational structures as well as preferred ways of working (Brown, 2015; and see Chapter 10 by Souhami in this volume). Our research highlights that targeted support for children and young people living with a loved one who is seriously ill is both inconsistent and inequitable (Bennett et al, 2018). Hope is currently the only service in the UK that provides such support and the lack of awareness and funding means that the scope for such services remains limited. Furthermore, our findings reveal the emotional challenges that children and young people face when their needs remain unmet.

The most common presenting issues for young people accessing Hope are mental health problems, including anxiety, panic attacks and depression. Issues with relationships, experiences of loneliness and problems at school and university are also frequently reported:

‘When you get such devastating news it’s hard to continue on with life and turning up to school to learn everyday and being told the news ... it sticks in your head’ (Bill).
Challenges at home and a lack of support can make it difficult for young people to maintain a social life and educational experiences either at school or university are typically problematic. Friendships are often hard and time for socialising limited. Young people describe the inadequate support they received until they had discovered Hope and the impact of their circumstances on their daily lives, but without having any sense at all, at the time, that their lives were far from typical for their peers.

It felt normal. Looking back on it now, it still feels normal because that's all I've known. But it wasn’t really normal because all of my mates would be going out on a weekend and I couldn’t because I had to help my sister with her homework or I had to do the washing or had to do the gardening or... I struggled ...I’d have to help mum in the morning, then I’d have to go to school, come back from school and then helping her. It was like I was going to school, but like I also had a full-time job if you know what I mean... I’d have to give my mum her meds, I’d have to clean the house, I’d have to cook for the family, I’d have to sort my sister out and get her to bed, I’d have to help mum in the shower, help her get to bed, help her get up out of bed if she needed to go to the toilet and help her to the toilet... I was 7 or 8 when I started caring. (Brian)

Although the family member diagnosed with a chronic health condition is characteristically defined as the ‘victim of illness’, Brown (2015) notes how other family members become partners in the same experience. Children and young people are likely to experience a host of emotions including fear and anxiety as they grow up in an environment shaped by the circumstances of a family health crisis (Bennett et al., 2018). Families may undergo significant changes during a family health crisis and young people may experience a shifting role within the family from dependent to carer.

Following a family health diagnosis, children and young people enter a world marked by confusion, often anxiety and distress, and where their rights to welfare and autonomy are compromised by their challenging life circumstances. For our study we interviewed young people all of whom had been living with a loved one who had been seriously ill over many years and in many cases had since died. Partial knowledge about serious, complex illness is a daunting prospect to come to terms with, emphasising the value of regular information for young people in forms appropriate to their levels of understanding throughout their childhoods and adolescence. Young people find it difficult to understand not only the health problems their parents and/or grandparents or siblings faced but also to understand their own situation within that. They described the sporadic and inadequate support they received until they discovered Hope and which typically relied upon the assumption
that they want, need and have the skills to talk about their experiences at a time when they are trying to make sense of these experiences themselves.

‘You see, this is where Hope is different, because I just wanted them [school] to understand that there is something going on that maybe I didn’t want to talk about, but they should just accept the fact that there is something going on. They should understand why I was acting the way I was sometimes or why I was quiet sometimes. They should have looked past the fact that I was acting out or looked past the fact that I was quiet and realised that there was something further and realised that maybe if I didn’t want to talk about it, they should still be there. In a way that maybe they didn’t understand, but at least they could try to understand, if you know what I mean. The schools just don’t have the time of day for it because it’s not what they’re there to do’ (Amy).

There are many young people, and children, who are not able to express their feelings or views for a whole host of different reasons, including denied rights, few participatory opportunities (Kellett, 2009) as well as those with communication difficulties (Bligh et al., 2013), lack of confidence (Cooper and Kellett, 2016) or, as in the case of young people living with a loved one who is seriously ill, confusion, partial understanding and often anxiety (Bennett et al., 2018). Good quality information and guidance that can help them make sense of their family situation as well as provide pointers for support are vital and yet present issues for practitioners and service providers in how they reach out to diverse groups. How children and young people understand concepts such as ‘health’, ‘disease’ and ‘palliative care’ for example are socially and culturally defined and likely to be perceived differently across different ages, faiths and languages (Gatrad and Sheikh, 2002). There is also the danger that the very notion of listening may be conceived as somewhat stable and assumes that merely being afforded the opportunity to talk will facilitate participation. This overlooks a number of important issues: firstly, how listening is very much an active process which is negotiated and constructed in complex social situations. Listening takes time and is a process that typically depends on relationships of trust and respect. The extent to which the experiences and views of children and young people are listened to and acted upon to improve services also remains in question (Cooper and Kellett, 2016). One cannot therefore assume that listening necessarily equates with participation and very much depends on when, where and how practitioners listen as much as how children and young people choose to express themselves.
**Talking about difficult ‘stuff’**

Chronic and terminal illness as well as death and dying are taboo subjects in the UK. The idea that either young people or children wish to or have the skills, emotional maturity, understanding and confidence to share their experiences somewhat overlooks the difficulties that talking about highly sensitive issues can present. Furthermore, such assumptions risk, as Wade and Smart (2002, p. 43) suggest, ‘creating culture where children are expected to talk’. In her research exploring young people’s experiences of living with a parent with alcohol problems Hill (2015) notes how the majority of them do not choose to talk about personal experiences openly outside of the family. Hill goes on to argue that when given the opportunities to do so they will adopt a variety of different ways to share their experiences.

Our research suggests that talking about their personal family experiences is an ambivalent experience for young people who, whilst recognising the importance of ‘being listened to,’ found this so very difficult. For a significant number of the young people interviewed, their parents had been diagnosed with a serious illness while they were very young and the effects of that diagnosis were felt not only then, but over long periods of time throughout their childhoods as illnesses progressed. Brian, for example, described how his mother developed Crohn’s disease and aplastic anaemia when he was eight years old, had had continuing severe health problems over the years including an amputation and had recently, when Brian was 18, had a stroke. Throughout that time, Brian had taken on the role of carer for his mother and siblings. Molly’s mother had been diagnosed with stage 3 kidney cancer when Molly was 14-yearsold. Now 17, Molly had spent the last three years in a caring role alongside her father. Amy’s mother was diagnosed with multiple sclerosis while Amy was at primary school in year 6 (approximate age: 11 years) and had experienced continuing poor health as a result over subsequent years. ‘In year 5, my aunty was diagnosed first and then my mum a year later. So my aunty was diagnosed in 2007 and my mum in 2008’ (Amy). Now aged 20, Amy’s late childhood and teenage years had been spent in the context of her mother’s illness. Similarly, Bill’s mother had been diagnosed with breast cancer when he was in year 4 at primary school (approximate age: 9 years), which had subsequently been diagnosed as terminal when he was 14 years-old.

Clearly supporting young people to make sense of their family circumstances and help them to manage the roller coaster of emotions that typically accompany these circumstances is especially important and yet many young people reflected on the difficulties of knowing who to talk to and where to get help;
‘I haven’t found a single other organisation who work with young people who have a terminally ill family member’ (Lisa).

Amy found that school did not really understand her situation and where she was ‘labelled a problem child’ and ‘sent out of lessons’:

‘I was made to sit in the head teacher’s office and stuff like that. Mum and dad had to come in quite regularly for meetings and stuff but no-one could quite pinpoint what was causing it and stuff. When we look back now, coz obviously it was the time that mum was being diagnosed as well, they don’t think I knew how to cope with what was going on, didn’t know how to process it...then it just got a whole lot worse in secondary school.’

Reasons for her behaviour were sought by the school, e.g. testing for ADHD, but there appeared to be a lack of understanding that her behaviour could be the result of the family health situation:

‘The school knew about my mum, but they just didn’t do anything about it. They just labelled me as a naughty child and put me on report, stuff like that’ (Amy).

Not only did Amy describe the limited recognition of her needs but also the inadequacy of the provision for support where she felt pressured to ‘have to sit and talk’ before she had developed any kind of relationship or trust:

‘It’s just so individual, isn’t it, Hope, and there’s not really many charities like it out there. Just that it is totally unique in how it supports young people. I know with other charities it is quite formal. So you go there and you have to sit and talk. Whereas at Hope they can talk about as much or as little as they want. So they can find their feet before they talk about things that are going on. Making friends before you have to talk about anything, like finding trust before you have to talk about anything. In other places you have to talk about it before you’ve built the trust, if you know what I mean? I think that’s quite important’ (Amy).

For many of the young people talking was highlighted as ‘hard’, not only as this was often expected when they were young and at a time when they hadn’t necessarily made sense of their own experience, but during an emotionally turbulent time in their life. How both children and young people articulate experiences that are characteristically hard to know and tell is complex and has more recently become an area of interest within the field of childhood studies (Cooper, 2017).
The extent to which children and young people can fully and with a clear intention articulate their feelings, has been called into question (Horton and Kraftl, 2006; Jones, 2008), as well as the very idea that they should be expected to do so. There are things that children and young people experience that do not always make sense to themselves or others (Cooper, 2017) and, like adults, they cannot always rely upon language to share their views (Thrift, 2008). Indeed Thrift (2008, p. 7.) describes his deep suspicion of claims that lives can be ‘known and understood’, and such ideas cast doubt on many of the assumptions associated with aspects of participation, particularly the emphasis upon listening and talk which not only favours verbal accounts of experience but also places great faith in the articulation of feelings and experiences which are so often beyond words.

Our research draws attention to the importance for practitioners to try to understand young people and their experiences in ways which sometimes look beyond talk and what is said (or not), and find ways to engage with children and young people that allow them to say as much or as little as is right for them at that time and in ways which reflect their needs. This might entail, as Hill (2015) suggests, young people reflecting on the past from a space or place in the present, talking in the third person, drawing and using metaphors – all of which might be incomplete and partial and yet provide glimpses into complex and personal lives. We might further add that such approaches provide spaces and places which recognise children and young people as individuals with diverse needs and different ways of sharing their experiences. There are countless ways of expressing oneself and more recent developments in childhood and youth research have explored different ways of engaging with them through the use of pictures (Flewitt, 2008; Plowman and Stevenson, 2012; Kullman, 2012), photographs and map-making (Clark and Moss, 2001), for example, and concede that there is no one way for children to convey meaning but a number of different expressive modes (Flewitt, 2008).

The focus on participation is much broader than listening and talk and encourages much greater debate amongst researchers, practitioners and policy makers on the different ways in which adults can engage with children and young people. The young people in our study describe how sharing their experiences and feelings need not rely predominantly on talk but on other forms of participation. In the next section we examine the participatory model which underpins the work of Hope.

**Hope**

In 2006, Sue Trevethan was diagnosed with cancer. She set out to find if there were any services available for her three children, who were 13, 16 and 19 at the time. She soon found that no such service existed. Sue decided something had to be done to help the thousands of children and young
people every year who experience the trauma and uncertainty of a family health crisis. With her background as a therapist with young people, Sue set about starting Hope Support Services (‘Hope’) from a coffee shop. The first-ever youth management team (YMT) was established in 2009 as a group of young people who were experiencing or who had been through a family health crisis themselves and wanted to use their past experiences to help others, as Amy who is part of the YMT describes,

‘Everyone in the team has gone through a family health crisis themselves, so we know what the young people might need. I know that they might need support during school because there isn’t always support available in school. We can understand what people are going through. We decide where we (Hope) spend the money.’

Hope is described by Amy as a service which works ‘around the young person’ and is evident in the way in which the services are managed in consultation with the YMT ‘who sit round a table and share the money out and organise events’ which are ‘designed by young people for other young people’. The value of improving childhood and youth services by engaging young people to contribute to decision making and practices based on their personal insights is widely acknowledged (Kellett, 2014; Bessant and Broadley, 2014) and was recognised by Amy as a far more effective approach ‘than a group of adults making decisions’ who don’t fully appreciate what it’s like for children and young people.

‘I think that’s important because if it were run by adults who haven’t been through it and they’re just going on what they learnt in uni, it might be completely different. It might not be what the young kids need as such’ (Amy).

Amy describes the value of Hope as much more than just about coming together with other young people and with practitioners, but a service which provides flexible layers of support which service users can choose to engage with in very different ways to suit their own needs. Being able to ‘dip in and out’ of the different youth sessions and events to suit their needs at particular stages in their lives was identified as very important and which recognises the value of service flexibility in relation to age and stage in life and the changing nature of children and young people’s experiences at any given time.

‘For the young person it’s such stressful time at home that a flexible service that you can dip in and out of and you want to have full commitment or you don’t is really important because everyone is different and they handle it differently. Some people
will want to spend their whole time with Hope and that’s what they’ll do. Others might want to be a little bit disconnected’ (Bill).

The extent to which Hope facilitates flexible support to meet individual needs builds upon the commitment to establishing an environment where children and young people are accepted without judgement and where ‘they’re all going through the same sort of thing’ and ‘you don’t really have to explain anything’.

‘And I like that about Hope because like you accept everyone for who they are. You don’t judge them on what they’ve been through or what they’re going through at the time and I think that’s good’ (Amy).

This participatory approach utilises young people’s experiences, which can help develop a service that recognises what others in similar circumstances may be facing and creates a culture of understanding, and where they are not expected to explain their circumstances or ‘have to divulge personal stuff’ unless they choose to do so. But instead they design a service where they can engage in a number of different ways; where they can just ‘hang out’ and ‘be a normal child’. Furthermore, for many of the young people, accessing the service at Hope meant they could go to a session or attend an event with the confidence that they would not be judged and could use the service in ways that suit their own individual needs perhaps to just ‘chill out’ as Brian describes:

‘It means that if you don’t want to be doing anything when you get to Hope, you can just sit down and chill out and do nothing. I’ve gone to a Hope session before and just slept. So you’ve literally got a couple of hours where you can do what you want ... without worrying about what you’re doing...’

Youth sessions are organised and led by the Hope team of youth development workers. These sessions are designed to provide a safe space for young people experiencing a health crisis to come together. All the young people talked about the value of the youth sessions, days out and events, in enabling them to make friends and have some fun and take some time out from many of the challenges at home, which can allow the young people to step away from their home situation for a while.

‘The days out, they are essentially that, there are not really points at which we sit down and talk. It’s just very much enjoying the activities’ (Bill).

Our research suggests that, for many young people, having the time, space and opportunities to just have some fun and forget about their family circumstances for a short while was invaluable. These
insights come from young people who themselves know what it’s like to live through a family health crisis. Furthermore, this participatory approach provides them with a sense of ‘belonging’ to a service they can ‘contribute to’ but also gives them a sense of ‘purposefulness’. The YMT not only have a key role in making decisions about the management and delivery of services at Hope but are part of a much broader research and dissemination strategy to promote the work of Hope nationally; voice the shared experiences of other children and young people living with a loved one who is seriously ill and lobby politicians and policy makers for change (see http://www.hopesupport.org.uk/hope-highlights/). This approach to participation not only can help design services which are better matched to the needs of others but also provide opportunities for children and young people who have experienced a family health crisis to ‘use’ their experiences to do something positive for others and as Bill, one of the YMT who lost his Mum to cancer so eloquently describes:

‘Obviously it’s a very tough experience but being able to actually use quite a sad and emotional period of my life to actually benefit people, I think, for me, is quite self-rewarding and knowing what I went through to then help and develop and shape a service ... it’s what my mum would have wanted me to do ....’

**Conclusion**

Our research reveals that participation is a multi-faceted concept and one that rests upon many assumptions, particularly in relation to how practitioners and policy makers listen to children and young people, as well as assumptions about the positioning and status of ‘talk’. Participation can take many forms and children and young people can share their experiences and express their views in different ways, from articulating how they feel, to being quiet, from ‘hanging out’ and ‘having fun’ to ‘decision making’ and ‘using personal experiences to make a difference’. This has implications for both policy and practice in recognising complex needs and findings ways to engage and listen to children and young people and for them to express themselves which may sometimes go beyond talk. It also raises questions about the stability of participation as something easily achieved, afforded to children and young people without fully considering how participation is a practice which is negotiated and constructed within fluid and changeable contexts which involve complex relationships.
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