# ASSURING POSITIVE IMPACTS FROM PARTICIPATION WITH MARGINALISED YOUNG PEOPLE AND THE SERVICES THAT AFFECT THEM

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#### Abstract

Participation has been defined as a 'way of working' rather than an event or a project, and literature demonstrates that the process of participating is as important as the impact on services. Many organisations have developed standards advising on the best ways to engage young people in sharing their voices. There is however, limited evidence revealing the impact of participation on services and on those young people who chose to take part. Where evidence does exist it tends to examine the views and report the outcomes of young people engaged in mainstream services. This study therefore aims to explore the impacts of participation on 'marginalised' young people and the services that affect them.

The thesis is underpinned by a hermeneutic interpretive phenomenological approach and reveals how young people marginalised by society and circumstance can share their voices within the context of their very complex lives. The narrative method enables the capture of the young people's histories and experiences of voice sharing. Key workers' narratives additionally help describe the complexity of the young people's lives and the constraining and enabling factors challenging successful participation.

The research found that whilst participation is important in developing and improving services, young people appear to develop new skills, build confidence and self esteem, raise their aspirations and role model key workers' positive attributes. Young people experience 'therapeutic' effects associated with voice sharing and for key workers the research experience was found to be beneficial and salutary.

To facilitate and sustain meaningful, fulfilling and positive experiences a new model of participation generated from the data is presented.

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**Declaration:** I declare that this is solely my own work.

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#### **Chapter 1 - Introduction**

This qualitative research study focuses on exploring participation work with young people living in Britain, in complex and at times more vulnerable circumstances than the average young person. The author acknowledges that all children's and young people's voices are important, but for the purpose of this study the focus is on young people aged eleven upwards. In the United Nations Convention on the Rights of the Child (1989) the child is defined as all those under the age of eighteen. However, children and young people are different in their personal circumstances, their changing interests and capacities as they grow older (Sinclair, 2004).

Within the study young people and their key workers share their stories and experiences of participation and involvement work across the health and local authority public sectors. The main focus of the research is to expose, through the young people's voices (primarily), the conditions that need to be in place in practice to ensure that marginalised young people and their key workers have meaningful, fulfilling and positive experiences of participatory work.

Within this opening chapter the drivers supporting the development of participation and voice sharing are introduced. Each Chapter hereafter is summarised to offer the reader an outline of the structure of the study.

The National Youth Agency state that;

'Opportunities for participation must be linked to achieving change and improving policy and services. This can take two aspects: changes within organisations and changes in the lives of the children and young people.'

National Youth Agency, 2008, p1

Children and young people's participation has been driven in recent years by numerous British Government policies and directives (DH 1989, 2000a, 2001, 2004, 2006a, 2006b, 2007a, DfES, 2001) aimed at increasing patient and public

voices. Equally important is the United Kingdom's sign up to the 'United Nations Convention on the Rights of the Child' (1989) which has underpinned the development of many of the participation standards that have developed over the past few years (Lansdown, 2001, Kirby & Bryson, 2002, Shepherd & Treseder, 2002, Wade & Badham, 2005, Save the Children, 2005). The 'United Nations Convention on the Rights of the Child' (1989) and specifically in the context of this research, Article 12 relating to the child's and young person's 'right to be involved in decisions that affect them', have definitely prompted action across organisations, possibly driven by their international legal obligations.

However, whilst there are a variety of participation standards stating the practical benefits and processes organisations should consider in ensuring young people can take part, there is limited research exposing the impact and outcomes of such work. Critical discussion of the standards and models ensues in the literature Review, Chapter 2.

The numerous user surveys and high levels of health service consultation across the country, demonstrate a continued push towards public and patient involvement (PPI). More recently, (Office of the Prime Minister, 2007) the emergence of Citizen's Juries demonstrates the Government's attempt to extend participation into politics. In the Prime Minister's speech on 3<sup>rd</sup> September 2007, the notion of listening to public views in an attempt to feed public opinion into Government policy emerged. In Citizen's Juries small numbers of independently selected people are given evidence and can debate issues and come up with realistic solutions, and give policy makers an idea of what informed members of the public think.

In addition, statutory service staff are now more likely to be consulted about policies and guidance that might change the way services are run e.g. National Institute for Health and Clinical Excellence (NICE) regularly send out consultative

documents, thus allowing professionals, who are of course also part of the public, an opportunity to shape future policy.

The notion of people and communities having a greater voice has been driven by legal imperatives placed on statutory organisations, although this in itself may have been partially driven by a rise in patient litigation and strengthening voices of advocacy and campaign groups (Dick & Cunningham, 2000). However, often in an organisation's drive to conform, much difficulty ensues, with Primary Care Trusts for example, concerned regarding levels of inclusivity and representation across communities. Pressure to act quickly to put into place processes or maybe simply misconceptions of 'Participation' as a concept has led to variation in how people are able to share their voices.

The confusion or misconception of participation might be borne out of a true lack of understanding of the concept or it might be linked with an unwillingness to relinquish power. It could be argued that giving people a voice feeds into the consumerist model of healthcare, a movement where patients' interests in health care are promoted. In Williamson's (1999) paper on health care consumerism she speaks of the 'partial redistribution of power' between professionals and patients and the tensions that can exist if the notion of power is not understood. She states:

'Broadly, health care consumerism can be said to be a political movement that promotes patients' interests, joining with health professionals when they act in patients' interests as patients define them but opposing them when they act against, or repress, patients' interests'.' Williamson, 1999, p150

She defines power as the 'ability to take one's place in whatever discourse is essential to action and the right to have one's part matter' (p.150). A professional, in not understanding fully the concept of participation, might inadvertently diminish individuals' rights. For some, representing a patient's or public view which does not concur with their own, may threaten the power relationship as tensions will always arise between patients' and public views and professionals

feeling criticised. The strong relationship between power and participation will be explored in Chapter 2, in relation to children and young people.

There still remains a mixed understanding regarding the purpose of consultation, participation and involvement work amongst organisations and frontline practitioners (Riley & Jones, 2002, Sinclair, 2004), with organisational efforts to meet their legal requirements sometimes driving the agenda without clear and careful planning. The National Youth Agency (2005) concisely exemplifies the reasons for engaging children and young people in voice sharing. The quote clearly indicates the potential impact the child or young person can have on themselves, services and the broader population when given opportunities to share their opinions and ideas.

'Participation is the process by which children and young people influence decision making which brings about change in them, others, their service and their communities'.

The National Youth Agency – <a href="http://nya.org.uk/">http://nya.org.uk/</a>

The National Youth Agency (2005, p. 1) specifically emphasise the importance of young people having equal opportunity to participate, particularly those facing the 'greatest barriers'.

The research presented exposes key workers' understanding of participation particularly for marginalised young people, and has lead to an increased understanding of the differing needs of young people living in more challenging circumstances, who may not be able to share their voices through traditional networks. For public health practitioners responsible for developing services that address inequalities and inequity of access, both PPI and participation is crucial to the successful implementation of policy into practice. The rhetoric of both PPI in health care and public health is often not realised in practice. In children and young people's participation a widening gap between rhetoric and the reality of participation is reported (Badham, 2004).

Within practice the author has been witness to both positive and negative processes of participation through involvement with New Deal for Communities programmes and through the Children's Fund and Sure Start. In leading the development of a Sure Start Programme, and engaging with the local community the benefits of full and effective participation were apparent by working closely with an experienced community development worker in developing services with and for local people. Here the author witnessed visible changes in the self esteem and confidence of local residents of all ages and tangible positive impacts such as increased access to meaningful training and employment. Most important was the active engagement by families in helping to develop a service that would meet their needs within the cultural context of their lives.

During this time through exposure to regular requests from frontline staff for practical advice on participatory methods, the author became aware of the diverse training needs in this area of practice. Many practitioners and managers did and still do not grasp the complexities of 'true' involvement and participation, seeing it as one isolated task, rather than many linked points along a continuum of activities, intrinsic in their practice. These encounters and experiences first inspired the research idea, and prompted the author to learn more about participation and its place in public health practice. Working in an organisation struggling to engage diverse local communities, specifically an expanding asylum seeker population, awakened a particular interest in meeting the needs of more marginalised populations. However, it was a career move to work more specifically to develop services for and with children and young people that finally formalised this research.

#### 1.1 Public health and participation

As a public health nurse consultant ten core competencies underpin the profession and this includes 'Working with and for communities' (Faculty of Public Health, CMO, 2001). Within this public health area of practice work focuses on

improving health and addressing inequalities through the active involvement of communities and key partners, and aims to empower communities to improve their own health and develop their capacity to advocate for health and well being. A range of methods are used to listen to and involve local communities in 'needs assessment', planning, developing and implementing or evaluating community development initiatives. This one core competency is interdependent and interrelated to other key areas of practice seen as implicit to public health work; for example in any partnership collaboration is essential in both understanding and addressing inequalities. Partnership and collaboration with non statutory organisations is important particularly in health policy interpretation and implementation, where an awareness of local communities, their views, beliefs and even cultures is essential. It is only through engaging with the audiences and recipients affected by policy, change and development and who experience services, that sustainable health and well being of the population can be improved.

In working with young people it is important that they too, like their adult counterparts, have an opportunity to influence policy and service development, and that those views are taken seriously i.e. views are respected and where possible acted on, and appropriate feedback is given. This can be challenging in an adult dominated society. Even more challenging is presenting the opportunity and listening to the voices of children and young people living in more complex circumstances. The power relationships are often weighted heavily towards adults as decision makers, and the young person's experiences of adults may not be positive ones. 'Hard to reach' children are often those with the greatest need of good services, but tend to be marginalised in discussions about those services (Hill, 1997 cited in Curtis et al, 2004a p 168).

These public health functions are embedded in the fundamental principles to improve health and well being and address inequalities. It is vital that those developing services for young people are aware of the barriers and constraints that marginalised young people experience, and accept that it is often the service

or the professional that is 'hard to reach' rather than the young people. The research presented highlights the need to strengthen the voices of marginalised young people in helping them to ensure better outcomes for themselves and others.

Research and service development are key components of a nurse consultant's post especially in a public health environment where strong evidence is used to underpin decision making. The researcher's professional position is important to acknowledge in any research, with the potential of one's occupation creating both opportunities and barriers within a research context. Nurses need to take account of both philosophical and pragmatic concerns in order to ensure that all stages of the research process are viewed as robust and credible. The influence of 'self' in biographical and ethnographic accounts is now well documented (Coffey, 1999, Borbasi et al, 2003). The importance of the researcher's positionality and relationship with the participants is therefore highlighted in Chapters 3 and 4.

This research was undertaken with young people and their key workers in Northumberland, a county spanning 502,526 hectares and consisting of diverse population needs. The county is made up of urban and rural communities. Rural areas are reliant on tourism, agriculture, fishing and forestry and associated industries. Rural areas of the county demonstrate different inequalities, inequities and specifically huge access problems to the urban south east corner of the county. Some wards in the urban South East of Northumberland have some of the worst deprivation in England, whilst other county wards are amongst the best. Children and young people live in all communities with 0-16 year olds making 17.6% (54,699) of the population (Research and Information (Infonet), 2007). Marginalised young people live within all areas and the research sample is drawn therefore from across the county. Further detailed debate follows in Chapter 2.

#### 1.2 Research question and objectives

By examining the young people's experiences of participation work in the context of their lives alongside the experiences of the involved key workers, the following research question will be addressed.

'How can marginalised young people engaged in participation be assured meaningful, fulfilling and positive experiences when sharing their voices?'

The following research objectives drive and guide the research process.

- Determine how one Care Trust presently involves marginalised young people in service planning and delivery with their key partners.
- Explore the constraining and enabling factors that marginalised young people and their key workers experience in participatory encounters.
- Explain the role that key workers play in ensuring marginalised young people can share their voices.
- Explore young people's personal narratives for their potential to reveal their willingness or ability to participate and influence services.
- Identify the outcomes of participation for the young people and their key workers which can be disseminated into practice

# 1.3 The chapters summarised

**Chapter two:** a literature review of current policy demonstrates the drive towards more participation and involvement in statutory services. The concept of participation and its varied interpretations is explored through the literature relating to the specific involvement of children and young people in sharing their voices alongside issues of power, rights and responsibilities.

**Chapter three:** the philosophical position of the research is discussed. The researcher justifies why hermeneutic interpretive phenomenology provides a meaningful foundation for the research.

**Chapter four:** the methodology is explained and the sample and research methods are described. The use of purposeful sampling and narrative methods are explored and justified in relation to the research sample and question. Examination of the concept of power is re-explored in relation to the methods used.

**Chapter five:** the analytical framework and methods are explained with regard to the author's dual role of researcher / practitioner. The relationship between the two roles is explored exposing at times the tensions between the academic role and function and the reality and pressures of practice. In doing so the development of an analytical framework emerged.

Chapter six: initial analyses of the key workers' texts expose how key workers understand participation as a concept. The levels of 'participatory and involvement work' described within the narratives demonstrate the diversity of the participatory activity on offer. The data expose variations in the nature of participation depending upon the sample group. Such mapping work although ever changing and not fully complete starts to highlight areas where service

development is desirable. With young people and key workers each describing their own experiences of participatory work, barriers and constraints and potential levels of continued involvement can be debated.

Chapter seven: findings from the key worker's interviews are presented and focus on the role the key workers play in ensuring that their client group can share their voices. The key workers also help to contextualise the complex lives of the young people in the sample leading to a deeper understanding of the barriers and constraints some of these young people experience. Understanding the data in context is important to the researcher's philosophical beliefs and those underpinning this research.

Chapter eight: the young people's personal narratives are explored for their potential to reveal their willingness or ability to participate and influence services. Through the process of analysing their participation in the context of their lives the impact of participation for the young people is established. The role of the key worker in preparing the young people for, and facilitating participation is exposed. The young people's stories start to reveal the impact of participatory work, not primarily to service change but to the young people themselves.

Chapter nine: offers a discussion of the findings in relation to the theoretical models and literature presented at the beginning of this study and how the study builds on the knowledge base. Reflections on the research process, methodological issues and implications for practice are made, exposing the challenges, the impact on organisations and practice. The data exposes a new process of participation relevant to participatory work with marginalised young people and the author is able to conceptualise the outcomes of participation into four main categories, and generate new theory from the data.

**Chapter ten:** the research is concluded with a summary of the key findings, with practice implications reiterated alongside the dissemination strategy. Future research questions arising out of this study are proposed.

#### Chapter 2 – Literature review

#### 2.1 Introduction

Within this chapter the author draws on both published peer reviewed articles, grey literature and experiential learning, to examine participation and involvement work, drivers and responses within the United Kingdom. The review is focused on literature relating to mainstream and marginalised children's and young people's involvement. The concept and models of participation are described and discussed to set the scene. Thereafter children's rights and power are further explored.

The search strategy involved searches on electronic databases including, Medline, EMBASE, CINAHL, BNI; searches of Government and public service websites for grey literature (NICE, DH); additional searches of grey literature such as organisational evaluations and publications were via practice relationships and knowledge, and internet searches of children's charities; retrieval and cross checking of references cited in published articles and reports. Key words searches included public involvement; children and young people's involvement, with involvement supplemented by consultation, engagement and participation, to extend the search. Advanced searches using key words 'marginalised' and 'hard to reach' and 'experience' or 'evaluation' of consultation, participation and involvement work extended the literature search.

Young people's participation has partially emerged out of the initial Government drive to increase public and patient involvement in public and health services and continues to be well supported by policy (DH 1989, DH 2000a, DH 2001, DH 2004, DH 2006a, DH 2006b, DH 2007a). For many the 'United Nations Convention on the Rights of the Child' (1989) has driven the broader participation of children and young people across all services and society. In addition, the social inclusion agenda has played its part in ensuring that organisations consider children's and young people's views and needs alongside other

marginalised groups. This study focuses on the participation and involvement of marginalised young people in and across statutory services as members of the broader public rather than young people as patients and users in receipt of health services. The young people are or have been actively engaged with a broad range of services spanning health, education and social care. This diversity helps capture the broader public health aspects of society, not those just associated with patient care, which impact on young people's abilities and desires to participate.

The initial drive by government aimed at participation in 'health' rather than 'health and social care' potentially limited the broader voice. This resulted in the dominance of patient and user involvement literature. Two literature reviews in user and public involvement in health services (Riley and Jones, 2002; Crawford et al 2002) spanning involvement in individual care through to community development approaches demonstrate the high level of research activity particularly with a patient / user focus and the huge literature base. Limited impacts are demonstrated, leading to the rhetoric of policy not being realised in practice. Crawford et al (2002) specifically set out to highlight the impacts of involving patients in planning and of over 300 selected papers only 12% demonstrated the effects of the involvement work. Children's and young people's involvement is barely mentioned in the literature reviews. This deficit in listening to children's voices even in health care was also exposed in the evaluation of the Patient Advice and Liaison Services (PALS) (DH, 2007b).

The Patient Advice and Liaison Services (DH, 2000b) were established as part of the NHS Plan (DH 2000a) to promote user involvement in health care. Many emerged or were strengthened as a direct result of the Bristol Royal Inquiry (2001), which recommended representation of patients' interests on the inside of the NHS at every level. More recently, PALS have been abolished with a House of Commons Health Select Committee (DH, 2007b) report highlighting their lack of independence, poor communication between PALS and many NHS

organisations, non representative forums, including primarily older retired adults, and bureaucratic expensive systems. The report also highlights the need to reflect a changing health service with increasingly diverse providers, and the need to include social care within public and patient involvement arrangements. The Local Government and Public Involvement in Health Act, 2007 abolished the Patient Forums and the Commission for Patient and Public Involvement in Health and introduced Local Involvement Networks (LINKs) (DOH, 2007b). LINKs are now under development giving local people, organisations and groups a chance to share their views, experiences and needs, and suggest ideas to improve services. It is hoped that children's and young people's views will be taken into account to ensure their voices are strengthened.

The chapter critically considers literature relating to children's and young people's involvement as public and key members of society rather than as patients and specifically aims to review publications that expose the voices of marginalised young people.

#### 2.2 Public health and social inclusion policy

Public health practice is driven by cross government policy, not just that emerging from the Department of Health. The relationship between public voices and public health is vital if the health of populations is to improve and inequalities in health be addressed. Therefore the direct health services related policy development must be considered alongside the broader policy development relating to society, health inequalities and social inclusion. The 'New Labour' Government's clearly stated intention to transform society through economic and social policies to reduce inequalities and poverty, strongly influenced by 'The Acheson Report', (1998) has been seen through the emergence of policies and strategies relating to specific and disadvantaged groups.

The potential to involve the public in service and practice development and change was created through investment in national programmes, such as Sure

Start, New Deal for Communities, and the Children's Fund. Each of these initiatives has, at the very essence of their planning and implementation processes, a high expectation that planners will engage with the public via the formation of partnerships. The partners, in line with Government expectation, are multi-agency and are required to involve local people in helping them meet local needs. Parents, children, people experiencing chronic ill health and other public representatives have been given a voice in effecting the development of future services.

Such involvement can lead to an increase in dialogue and can strengthen links and relationships between previously unconnected parts of the community. Improved and increased dialogue between adults in the community and businesses and young people can result (Matthews, 2001; Shenton, 1999, Seaman & Sweeting, 2004). Putnam (1995) describes the development of these previously distant ties as bridging networks and relationships and suggests they work to build the capacity of both individuals and communities. Furthermore, Seaman & Sweeting (2004), in examining young people's access to social capital in contemporary families found material circumstance to be a greater constraint on access to social capital than family form e.g. one parent families. They identify young people as a resource in the development of community level social capital. This is important for disadvantaged young people, and particularly those with limited or fragile access to the family unit. Opposing views exist between theorists as to the role families play in building social capital. Bourdieu and Coleman (Whiting & Harper, 2003, p 5), locate families at the centre of their conceptualisation, whilst Putnam sees social capital as a feature of larger communities and nations (Edwards et al, 2003 p 7). Measuring the young persons' role in building social capital is problematic. Standard quantitative measures of social capital seen to be irrelevant to young people's lives (Whiting & Harper, 2003, p. 5-6), does not take account of the way young people socialise in non-geographically bounded ways e.g. via internet social networking sites. Defining social capital around geographically bounded areas is even more problematic for those young people who are transient due to personal circumstance or culture. However, the participation of marginalised young people in service design and change increases friendship and social networks, and potentially increases social capital.

The Government initiatives mentioned above have created an emerging picture of participation seen in practice but not always captured through published articles. For this reason the following is not simply a review of published literature, but is interspersed with grey literature and a sharing of expert experience.

## 2.3 Involving children and young people

Heaton and Sloper (2006), studying the 'extent of inclusivity' in PALS for children, young people and parents, found very low use of the service. In addition, early attempts to involve the public in decision making failed to hear the voices of marginalised groups and children and young people (DH, 2001). Webb (2002) highlights the strength of advocacy in local authorities, particularly in relation to children in need, but suggests there is limited development in this area in health services. Webb (2002, p175) suggests that such services could support children in fully participating in articulating their own needs, but suggests children would need to overcome 'cultural and organisational barriers' to be heard in this way.

It is now strongly recognised that young people should have the right to express their voices and that these voices should be taken seriously. Equally important is the need to recognise silence in the context of voice sharing (Lewis, 2008), both in relation to consent procedures and the research or participatory process. Prior to the UK ratification of the United Nations Convention on the Rights of the Child' (1989) and the subsequent promotion of children and young people's voices through policy development, children's voices were often silenced through societal conceptualisation of the child as being 'seen but not heard'. Lewis (2008) discusses whether 'assumed' support for child voice is a good thing, with the

potential of the authentic voice being subverted. Lewis (2008, p16) argues that child voices can be silenced by the very process designed to expose them. Specifically, where the research or participatory process has a 'pre specified agenda, limited developmental time and minimal opportunities for involving 'reluctant' children'. These factors she suggests are often created by organisational or the funder's time and financial constraints. Such limitations can potentially exclude and therefore silence the voices of those children most in need.

Lewis asks us to consider if the facilitation of the child's voice in today's pro voice climate, is overtly promoted as a positive thing without due consideration. There is much evidence to suggest that children and young people want to 'have a say', however, those seeking to ensure such engagement need to ensure that they are involving children and young people for the right reasons and that fair and open processes are in place. Lewis (2008) suggests greater consideration regarding the power of deliberate silences. She highlights the poor extent to which children believe their voices will be kept in confidence, concerns regarding a child's right to withdraw from the process, and therefore a need for more robust evaluation of ethical protocols. She also recommends that researchers should include explicit accounts of why and how children's silences are recognised, noted, responded to and interpreted.

The Carnegie United Kingdom Trust has developed Organisational Standards (Cutler, 2002) and whilst these and other studies (Save the Children, 2005, Kirkby et al, 2003) describe a multitude of methods of engaging with young people, few examine or emphasis the importance of exploring the experiences children and young people have in the participatory event or contact. Some of the guidance suggests active feedback, but this is more about professionals feeding back outcomes, short, medium and long term goals (Sinclair and Franklin, 2000) rather than exploring with young people what the process was like for them. Oldfield & Fowler (2004) also suggest a lack of evaluation through and with young people. Making feedback and evaluation of the experience and the

processes more robust would help expose some of the potentially silenced voices. Maybe the lack of literature in this area results from the value and commitment organisations place on participation and evaluation i.e. no or little investment in evaluation of these types of activities, and / or limited professional's ability, knowledge or time to carry out evaluation of children and young people's involvement work. Perhaps organisations are focused and intent on demonstrating the involvement of the public and the resulting service change in order to evidence that they have met their legal obligations and in doing so forget to ask what the experience was like or further explore the personal impact that the work has had. With a positive Government drive to involve the public and patients implicit in all major policies and initiatives since 1997, one would expect to find a variety of papers highlighting not just the impact of participation on services, but also the impact on those who choose to share their voices. In 'Learning to Listen', core principles for the involvement of children and young people are set out and recommend:

Participation activity should be honestly evaluated: not all approaches will be successful and mistakes will be made, but it is important that lessons are learned, shared and built on'.

Department for Education and Skills, 2001, p. 18

They recommend that children are involved in such evaluation, and that feedback of the impact of their involvement is timely. However, all suggestions of 'impact' appear to relate to the service or initiative being evaluated rather than the real impact on the young people themselves. Kirkby and Bryson (2002, p 60) state that 'there is insufficient theorising about how processes and context inter-relate to produce outcomes'. In addition, Kirkby and Bryson (2002, p24 -27), suggest most evaluation of participation examines the programme outcomes via stakeholder perceptions of change rather than objective measures. They share how the evaluation of some 'good' quality participatory work has highlighted benefits to young people. These benefits include

- Increased confidence and self belief
- An increase in their understanding of equality and diversity

- An increase in knowledge about local issues, and about barriers to change
- An increase in specific skills to include learning how to make decisions, group and facilitation skills
- An increase in educational attainment
- Increased friendship groups and peer relations

These outcomes will be revisited during the analysis of data to examine to what extent these and other outcomes are described.

In a recent systematic review, Cavet and Sloper (2004, p 613) highlight that more evidence is required to capture 'children's views and their experience of participation in public decision-making'. They suggest limited evidence pointing to the improvement of services as a result of children and young people's participation, but 'growing' evidence that 'participating children and young people benefit in terms of personal development'. They also suggest a high need for more evaluation of participatory activity. This support's the author's view that limited studies exist examining the experiences of children and young people in participatory work. One might expect that capturing the children and young people's experiences would be an implicit part of such evaluation. In addition, Kirkby and Bryson (2002) highlight a number of gaps in evaluation and research include the need to examine the impacts on the young people themselves as a result of being involved. They also suggest gaps in assessing the impact on organisations including an examination of to what extent youth participation affects adults' attitudes and commitment to involving young people. With key workers also sharing their experience of involvement work in this study, the impact of youth participation on adults is revealed.

The research presented helps bridge the gaps identified and contextually exposes the impact of voice sharing on the young person.

Whilst there is guidance and evidence on how to promote the involvement of children and young people, limited evidence on the impact on services, and an increasing evidence base over the past few years to demonstrate the impact of participation on the young people involved (Kirby & Bryson, 2002, Cavet & Sloper, 2004, Sinclair 2004), papers primarily relate to less marginalised young people i.e. those in mainstream school. Some of this is driven by the numerous Government policies that have emerged over the last five years promoting much greater public and patient involvement at all levels (DOH, 2001, DfES, 2004a, DfES, 2004b). The National Service Framework for Children, Young People and Maternity Services (2004) places emphasis on listening and responding to children and young people and parents and asks for the views of individual service users and the local population to be sought and responded to. This emphasis on children and their families as members of the public is inherently more inclusive than the previous focus, which has been primarily on health care and people with patient status. Whilst patient views are important they can be limited to meeting patients' own personal needs, rather than broader more representative views encapsulating social care and need.

More recently the legal requirement for local authorities to develop 'Children's Trusts' and 'Children's and Young People's Plans' with their partners has again resulted in explicit instructions to involve children and young people and their families in the development of services and the local plans. The Children's Plan – Building Brighter Futures (DCSF, 2007, p. 4) is based on five key principles; the fourth states that 'services need to be shaped by and responsive to children, young people and families, not designed around professional boundaries'. The number of new ways of ensuring children's, young people's and parents voices are heard include 'parents' panels' where parents help advise on policies affecting children; a strengthening of the complaints procedure for parents whose children experience bullying; and consultation to establish and strengthen the relationship between parents and schools. There appears to be no statement aimed at increasing participation and strengthening the voice of young people

directly, although the new Youth Task Force will improve delivery of young people's services 'designed around their needs'. Participation via the Children's Plan appears to be primarily advocated through parents' voices. Children's rights and power to act are therefore undermined in an arena that set out to strengthen them. Furthermore, Tisdall et al (2008, p. 346-7) debate how courts have not embraced children's rights and how decision making continues to focus on parental rights and a lack of awareness of the limitations on children to take action to fulfil their beliefs.

In the statutory guidance on interagency co-operation to improve the well being of children in the development of Children's Trusts it states 'the voice of children, young people and their families should be heard at all levels in order to inform local design and delivery of the arrangements.' (DfES, 2004a, DCSF, 2008). This is one of five pieces of guidance issued to local authorities supporting provisions set down in the Children's Act, 2004 which underpin Every Child Matters: Change for Children (DfES, 2004b). Local Authorities in developing a single, strategic, overarching plan for all services affecting children and young people must ensure the 'active involvement of a wide range of partners', including consultation with children and young people, parents and carers. Involvement must be at the formative stage and must ensure adequate time for full discussion of available local information about outcomes, the priorities to be addressed and the best ways of working jointly to tackle them.

What is interesting is that the voluntary and community sector are implicated when it comes to the involvement of children who are not or are less likely to be engaged with statutory services. This acknowledges the difficulties that main stream service providers often have in engaging these populations whilst providing universal services. The limited statutory services resources are challenged when time consuming interventions are required for minority communities; and marginalised young people can struggle with the bureaucratic structures and systems of big statutory organisations. Thus the essential role the voluntary and community sector play in such engagement is highlighted.

Whilst all the associated documents use the words consultation, participation and involvement none define them. Thus, as is often the norm, they all intermingle to mean the same thing (Riley and Jones, 2002). For those who do not understand the differences ignorance and confusion can immediately undermine the process of active participation. What is positive is the explicit definition of children and young people who may not be in the mainstream of services and community life. The Children's Trusts: Statutory Guidance in Interagency cooperation (DfES, 2004a) talks of genuine participation of children, young people, carers and families. Even differentiating children from young people demonstrates that they may need to be considered separately. Additionally the involvement of specific groups is clear and the document further highlights the potential 'wide ranging needs' of certain groups and that some will 'suffer complex disadvantage'. There is a strand on equality permeating throughout the text calling for equal opportunity to participate in the development of local plans, and equity in ensuring certain groups of young people are not forgotten. There is evidence that not all parts of the population participate equally, and Kirkby and Bryson (2002, p.29) noted that older young people and girls were most likely to get involved, and Hill (1997, cited in Curtis et al, 2004a p 168) states that children in greatest need are often marginalised in sharing their voices about services that affect them. Curtis (2004a, p. 168) states:

'Disabled children, children excluded from school, and children for whom the discursive nature of conventional interview based research is less accessible have been less well represented in participatory research than children who are easier to interview'.

She suggests that for methodological and practical reasons children who are able to communicate well in English, and who attend school regularly are more likely to be given a voice in research literature. This raises issues about the importance of searching for grey literature, as often there is unpublished literature, such as services evaluations coming out of, for example, Children's Fund Projects that give a voice to those living more challenging lives.

Sinclair (2004, p. 112) suggests that many agencies do not clearly demonstrate who has been actively involved, and states that young children, children with communication difficulties and those with minimum involvement with local agencies are less likely to be involved. She suggests more questions should be asked by researchers and evaluators regarding not just who, but how young people have been selected.

### 2.4 Involving marginalised young people

The following literature relates primarily to the groups of young people represented in the research sample and provides evidence to support their selection in this study.

In this research, five groups of young people have been selected to include young people excluded from school, young carers, teenage mothers, young people in the looked after system and those from the travelling community. There is very little literature exposing the experiences that these young people have in voice sharing about services, and the impact that such voice sharing has had on the young people themselves. There is also limited research that focuses on the experience in the context of the real lives of these young people.

#### 2.4.1 Young people excluded from mainstream school

Children aged between 5-16 years old are of compulsory school age. A statutory duty is placed on Local Education Authorities to make sure that pupils attend school. Government social exclusion policy and strategy aims to raise educational achievements and reduce truancy, as many who miss out on education experience poor future employment and life chances. The Acheson Report (1998) highlights that children excluded from school are more likely to be involved in and be victims of crime and are more likely to face unemployment as adults.

There was a steady rise in the numbers of pupils officially excluded from school between 1993 (11,000) and 1998 (12,300) (Berridge et al, 2001) with unofficial exclusions also thought to have increased. Unofficial exclusions or informal exclusions are cases where schools discourage pupils from returning to school, or encourage parents to remove their children, and is seen as unacceptable practice. Additionally, many pupils self exclude and withdraw from schools. MacDonald & Marsh (2002) found that frequent truancy was likely to support behaviour that contributed to long term exclusion. These, and unofficial exclusions are hard to measure by their very nature but are thought to have also increased. Many pupils are excluded due to behavioural problems, but pupils who disengage from learning can become excluded from education for other reasons such as bullying. This can lead to feigning illness and truancy leading to unofficial exclusions.

Exclusions remain predominantly male, with females making up 17% of all permanent exclusions nationally. The large gender variation may lead to female pupils' needs being overlooked and not prioritised within 'school thinking about behaviour management and school exclusion' (Osler et al, 2004, p1).

Pupils excluded permanently or temporarily, officially or unofficially are vulnerable and may become marginalised for a number of reasons:

- Loss of education;
- Loss of contact with school friends;
- Social exclusion;
- Loss of peer support;
- Home tensions.

Educational alternatives may also reinforce difference and further socially exclude pupils from natural friendship networks, although for many young people attendance in a Pupil Referral Unit offers a positive alternative (Taylor, 2005).

Taylor (2005) set out to explore young people's experiences of exclusion from school and levels of involvement in the exclusion process. The findings were

themed to highlight why young people thought they were excluded, what it felt like, how they thought it could be improved and particularly important to this research young people's experiences of the process. One of the pertinent key messages reported was that:

Young people should have greater involvement in the exclusion process although to do so they may need support and the process will need to be more child friendly' (Taylor, 2005, p. 64).

## 2.4.2 Gypsy travellers

Gypsies or travellers experience the poorest health of any group within the UK and are one of Britain's most socially excluded groups (Kidd, 2004). These communities are an important ethnic group to consider in Northumberland with permanent sites housing people of traveller ancestry; and many more nomadic populations living on illegal sites as they pass through the county. Offering access to services and ensuring that these communities have a voice is more problematic the more mobile they are. However, such groups have the right to equal and non discriminatory access, but are often exposed to discrimination and prejudice.

A literature review of the health of gypsy and traveller families in Scotland (Smart et al, 2003), reports that much of the existing research is out of date. They also found that most of the research related to health beliefs and cultural practice with little emphasis on social exclusion and poverty, despite evidence to suggest that many nomadic families experience considerable hardship due to constant evictions. Travellers also report difficulties in obtaining access to primary care, medical care, screening and immunisations.

It appears that the views of travellers are rarely sought, although in 2001, the Scottish Executive commissioned a study of the views of gypsy travellers regarding housing, accommodation and toleration policy. In Kingston upon Hull, the Gypsy Traveller Participation Group (Scottish Parliament Equal Opportunities Committee, 2001) brought together service providers and travellers with the aim of improving the quality of life for these communities, but this type of work

appears to be fairly unique. Also, accessing children within these communities directly appears to be rare.

In 2002, the Young Traveller Action Research Team in Northumberland, produced 'Gypsy Joe from Mexico' a study commissioned by NCH in partnership with Wansbeck Council (Northumberland) for Voluntary Services (Wansbeck Council for Voluntary Services, 2002). Eight young travelling people in Northumberland from permanent sites aged between 7-16 years old were trained to undertake the research to answer four questions.

- What do children from families of Travelling People need to make their lives better?
- · Do children of different ages need different things?
- What kinds of things do travelling families need so they can care for their children?
- What kinds of things could be done or provided to make the lives of travelling families better?

A principle recommendation from this study was the employment of a worker to help the communities 'have more say' and help them take action on things that concern them. This research marked the beginning of an on-going dialogue with the traveller community in Northumberland, which continues to be strengthened. With many travellers living in or moving through the county it is important that the young people in these communities are also given on-going opportunities to share their views, alongside their peers.

# 2.4.3 Young carers

According to the 2001 census there are 175,000 young carers in the UK; 13,000 who care for more than 50 hours per week, with almost a third caring for someone with mental health problems (NCH, 2007). NCH also state that the average age of a young carer is 12 years old. Many children and young people, who care for relatives, miss out on opportunities to play and learn. They may struggle educationally, and are often bullied at school (Barnardos, 2007). Some

groups of children are disproportionately represented in school exclusion figures; young carers are one of those groups. This may be related to the difficulties they experience at school or concerns regarding the parent or sibling they care for.

Action for Children (previously NCH), define young carers as;

'Children and young people under 18 who care for a sick or disabled relative. This includes children caring for parents who have mental ill health and/or severe drug and alcohol problems'. (Action for Children, 2009)

There are a number of charities now actively engaging with young carers and their families, with publications and website support and advice available, for example, NCH, Barnardos, and The Children's Society Young Carers' Initiative. The voluntary and community sector appear to provide a high level of support, and statutory services appear to be heavily reliant on the services provided through these networks. This study provides opportunities to directly link with young people, the service provider and the statutory organisations, and will help expose the strengths and weaknesses of the systems.

## 2.4.4 Young people in the looked after system

The National Statistics First Release document (2007) reveals the following statistics.

- In March 2007, 60,000 children were looked after in the UK.
- The main reason why social services first engaged was due to abuse or neglect (62%).
- 74% were of white British origin
- 360 mothers aged 12 years and over were looked after

The Government has a Public Service Agreement to narrow the gap in educational achievement between Looked after children (LAC) and their peers, improve educational support and the stability of their lives. Over the past five years the percentage of LAC children now aged 19 years old who were in education other than higher education increased from 15 - 26%, with numbers in

training and employment also increasing. Most children who were looked after at 16 were accommodated into independent living (National Statistics, 2007).

In Northumberland, 320 children were looked after by the local authority in January 2007, some of these are also teenage mothers and have experienced school exclusion, emphasising the multiple vulnerabilities they live with.

#### 2.4.5 Teenage mothers

In March 2001, the Teenage Pregnancy Unit produced guidance relating to the involvement of young people in teenage pregnancy work (DH, 2001) and emphasised involvement work with young people as an important component for the success of the Teenage Pregnancy Strategy. The Government action plan had four main themes as follows:

- A national campaign to improve understanding and change behaviour
- Joined up action to co-ordinate action at both national and local levels
- Better prevention of causes of teenage pregnancy
- Better support for pregnant teenagers and teenage parents

The involvement of young people in the implementation of this action plan was seen as important to:

- Develop credible approaches to awareness raising and service provision
- Ensure that support services for pregnant teenagers and pregnant parents are accessible to those who need them most;
- Communicate effectively with those groups most at risk

DH, (Teenage Pregnancy Unit), 2001, pp. 1-2

It will be important to see if by having an explicit statement of expectation that young people should be involved in the implementation of the action plan, whether participation is more advanced in this area.

In giving young people and their key workers a voice through this study, the impact of voice sharing will be demonstrated. Those taking part will be able to highlight how effective involvement opportunities are in providing better opportunities for teenage mothers.

#### 2.5 Barriers to involvement

A number of studies highlight the barriers to participation with children and young people. Cavet and Sloper's (2004) review of literature of the involvement of children and young people in public decision making highlights barriers to taking part to include:

- Bureaucratic organisations and internal politics;
- Adults retaining power and control over young people;
- Adult training needs, and;
- The short term nature of thinking and funding.

In examining the impacts and outcomes of pupil participation in school, Davies et al (2008, p. 32), demonstrate the constraints in participation:

- The need for whole school structures and activities enabling participation beyond provision of school councils. This will help ensure an increase in diversity of types of involvement, address issues relating to low numbers of involvement and representation. There is also a need to strengthen weak feedback links to pupils, teachers and governors
- Tokenistic participation, disregarded views, slow pace of change, suppression of democratic school dissent, and lack of funds to support activities all act as potential barriers for ongoing engagement
- Pressure on staff, timetables and curricular activities means time constraints do not promote good quality participation
- Adult-student relations such as responsibilities versus rights can impact on participation with discourse of rights and political literacy not always popular in school.

 Power issues are complex but include pupil power seen as further undermining teacher authority, teachers feeling uncomfortable about participation of pupils in some activities e.g. interviewing for staff. There needs to be high level support and vision and this needs to be embedded in the ethos of the school to ensure greater empowerment rather than pupil control.

Furthermore, and very relevant to the research presented, school councils tend to attract articulate, resourceful middle class young people (Tisdall et al, 2008), and therefore the views of those who potentially would gain the most from voice sharing is lost.

In an evaluation of the impact of involving young people through a hospital based youth council in developing children's services Coad et al, (2008) highlight several barriers, although not all were directly due to the youth council itself. For example, not all young people felt taken seriously, an issue that is relevant to children in society generally, but in this case decreased their self esteem and stopped them getting involved again. Final decisions about issues raised did not materialise into actions due to budget constraints and although senior people communicated this to the young people, the young people involved felt the power was firmly with the senior managers. This raises questions regarding honest and realistic involvement and participation, and the importance of setting clear guidance on what is or is not possible. In addition, feedback was often poor post consultation, leaving the young people frustrated.

Curtis et al (2004b, p. 155) suggest that consultation results are often not acted on in health services which potentially undermine young stakeholder's future willingness to take part. They suggest four reasons for the lack of action against findings as follows:

- Children tend not to have the lobbying power of adults;
- Re-structuring of health services can lead to 'Organizational memory' loss, and often high level concentration on strategy detracts from small scale improvements;

- The patient involvement part of the NHS Plan did not specify 'children',
   and therefore with a huge agenda children are often forgotten or ignored;
- There are few rewards for individual practitioners who re-structure services based on young people's views and no real disincentives for conducting business as usual.

The papers referenced above are relevant to mainstream young people. Whilst the types of issues are also relevant to marginalised young people many experience different barriers. Instigating access and finding methods of engagement that are acceptable to young people who have by choice or circumstance found themselves outside of the normal systems can pose challenging barriers to ensuring meaningful involvement. Key workers and the young people in this study build on this thinking.

Equally important to participation programmes is the need to consider how young people's views are interpreted. Sinclair (2004) suggests there is still work to be done in finding ways to be true to what children say and mean in their voice sharing. She believes that learning across practices and disciplines needs to take place e.g. in social science research, youth participation and community development. Sinclair rightly points out that the time and resources afforded by a researcher are rarely available in practice, yet the importance of representing the views of children and young people is just as relevant. Care needs to be taken to ensure those being asked to share their voices are clear what has been asked of them and equally the listener has properly interpreted the shared response. Sinclair (2004, p. 113) suggests more research is necessary to find ways of remaining true not only to what the child says but what he or she means.

#### 2.6 The impact of participation on young people

Kirkby and Bryson (2002, pp. 24-27) in their review of literature evaluating and researching young people's participation in public decisions evidence the benefits of participation. They state that young people build their confidence through the

assertion of views, challenging issues and asking of questions, and self expression to adults and their peers. Young people can develop their knowledge base, understandings and attitudes and specifically develop greater understanding of diversity issues. This can also lead to a greater understanding of the young people's own competence. A variation in skills development is seen depending on how the young people are involved.

Bugge et al (2008) demonstrated the impact of a 'Family Support Program' for families where one parent had incurable cancer. They examined, through indepth interviews, children's experiences of the programme and focused on how it met their needs and supported their coping. The impacts shared by children and young people aged between 5-18 years old consisted of increased confidence to talk about the illness situation with someone outside of the family (because often families have many things to deal with). Children were able to talk freely to workers who respected their wish not to tell others what they had discussed. Children were better informed about cancer and specifically the prognosis of the ill parent. The experience of the 'Family Support Program' helped them understand what a 'valuable' family member they were, and gave them the ability to talk about their emotions and ways of coping. Project workers helped them raise difficult questions with parents opening the communication pathways. Bugge's study highlights the importance of voice sharing and of the impartial listener and advocate to children and young people who find themselves in difficult circumstances.

In a literature review of seventy five studies Davies et al (2008) in searching for evidence of the impact of student participation in schools and colleges highlights personal outcomes for students to include:

- Increases in self esteem, motivation, ownership and empowerment through ability to influence;
- Development of interpersonal and political skills helping them better navigate formal organisations, take part in volunteering, and reduce risk taking behaviour;

- Development of democratic skills (listening, speaking, negotiating, team work and taking responsibility);
- A greater sense of agency and efficacy.

Whilst there appears to be an increasing evidence base demonstrating the impact of participation on the young people involved (Kirby & Bryson, 2002, Cavet and Sloper, 2004; Sinclair 2004), Sinclair, (2004), points to a lack of evaluation. She states that there is little evidence that participation is impacting on major policy and resource decisions, and less is known about how that participation can bring about change. Equally, as there are few evaluations, the details behind the impacts are often not shared in context, and often do not reveal the nature of those engaged in participation. Observing the impacts on mainstream children is important in promoting and resourcing future participation but does not necessarily help us understand the impacts for more marginalised groups. One impact of participation might be for example an increase in social networks. The importance of this impact may be far more profound for a homeless young person or a looked after child than a high achieving middle class girl in mainstream school. For some, simply taking part is a huge step but viewed against participation leading to increased academic attainment in the mainstream may be undervalued. Any impact must be viewed in context and therefore clarity in evaluations regarding the temporal, material, familial, geographical and emotional backdrop of studies is essential. In Chapter 7 (key workers' narratives) and Chapter 8 (young people's narratives) the context is made clear, which allows the reader to consider the broader impacts, for example an increase in confidence against the challenges of everyday life.

#### 2.7 Exploration of participation as concept

In order to address the research question the author originally felt a strong need to underpin the research with a clear working definition of 'participation'. This was borne out of personal frustration and exposure through articles and practice to the regular use of consultation when referring to all participatory activity. Many practitioners do not grasp the complexities of 'true' involvement and participation, seeing it as one isolated task, rather than many linked points along a continuum of activities, intrinsic in their practice. Undertaking a 'concept analysis' might lead to a clearer understanding of a vague term as academics and professionals, and might even provide 'a precise operational definition' (Walker, 1995), but what really matters in the research presented is how the young people and their key workers perceive participation, and how it affects them.

The researched and the researching of the topic will lead to a better understanding of what the concept means in practice. How it may be used and interpreted through the real lives of people will emerge. Key workers were asked direct questions about participation and their responses have helped frame the contexts behind the shared concept. It may not ever be possible to have a precise definition, as the concept may change according to the context and temporal issues. However, what is important at this stage is recognition that participation, involvement and consultation are terms that are often used interchangeably in literature and professional accounts. This fluidity can cause confusion in trying to make sense of policy and act on it. In Chapters 6 & 7 the issue is re-visited and meanings of participation in public health practice are presented.

## 2.8 Models of participation

Examination of models of participation has further enhanced understanding of participation as a concept and as a method. Participation frameworks have assisted the author in understanding the key workers' definitions of participation (Chapter 6). Hereafter some of the models are discussed.

The PPI movement is seen as an initiative of the late 1990s and early new millennium, but even as far back as the late 1960s Arnstein's 'Ladder of Citizen

Participation' (1969) demonstrated the eight stages or degrees of participation through 'rungs on the ladder'. Whilst some of the language appears dated the concept remains the same, i.e. there is a huge difference between 'manipulation' in the participatory process and true participation described as 'Citizen Control'.

'The idea of citizen participation is a little like eating spinach; no one is against it in principle because it is good for you.' Arnstein (1969, p. 216)

In reading the quote above the author is always tempted to add her own cynical second sentence — 'organisations taste it because they feel morally and legally obliged to, but often spit it out with fear of the outcome'. Of course some organisations and individuals working in them are committed to participation, but many remain fearful of it. By exposing current practice and outcomes, and a better understanding of systems and structures which need to be in place to ensure positive participation with marginalised young people, this fear may be allayed.

Arnstein describes the first two rungs of the ladder labelled as 'manipulation and therapy' as 'non participatory'. Power holders are described in 'educating and curing' roles, and may 'engineer' support through the guise of involvement in planning programmes. On rung 3 (informing) and 4 (consultation) Arnstein suggests that participation smacks of tokenism and allows for little transference of power to the public. 'Have-nots' she suggests are allowed to hear and have a voice, with further humiliation at level 5 (placation) where 'have-nots' are allowed to advise at a slightly higher level of tokenism. Arnstein states that the typology is designed to be provocative and sets out to expose the relationship between power and participation.

In Arnstein's (2004) electronic commentary on her work she acknowledges that at an information-giving level, ensuring citizens are aware of their rights, responsibilities and options is an important first step toward legitimate citizen participation. However, she argues that all too often this is a one way process with little room for feedback and negotiation. Additionally, individuals must want

to engage, with often endless fruitless efforts resulting in further apathy or disaffection. Again consultation can be a positive step towards a more fully engaged form of participation but can be simply a 'window dressing ritual', where people have "participated in participation" and power holders have gone through the motions. To placate, means to pacify or appease, and at this level although participants may be allowed to plan, they will not make the final decision.

It is only when the public reach levels 6, 7 and 8 that a degree of citizen power emerges. At level 6 (partnership) people can 'negotiate and engage' at a meaningful level, with ground rules established at the start. Power is redistributed according to agreed criteria and is not subject to unilateral change. It is suggested that having an 'accountable body' in the community strengthens the position and bargaining power. At level 7 there are degrees of delegated power, and negotiations may lead to citizens having dominant decision-making authority over officials. With this increased power comes increased responsibility and accountability. On the top rung labelled 'citizen control' the public have a majority decision making function. What is important of course is not that a person holds the power to act, but more importantly how one uses that power, and whether one remains inclusive in taking and making decisions.

Arnstein's model has been reinvented and modernised many times. Since its first publication the vocabulary has been updated and the model made appropriate to new audiences such as those working with children and young people. The pictorial use of a ladder (the higher up the ladder the more power one has) adds strength to her underlying message about the relationship between participation and power.

Arnstein's model of participation, originally aimed at examining the adult power of the 'have nots' and 'nobodies', or what might be labelled today as the 'marginalised' adult society, has been modified with a youth focus. Hart's ladder of children's participation is recognisably based on Arnstein's ladder of participation.

The ladder (Figure 1) previously used by Hart (1992) to illustrate the different 'degrees of initiation and collaboration children have when working on projects with adults' can also be used by adult facilitators to help them establish the conditions that enable groups of children and young people to work at whatever levels they chose and for adults to consider the capacity particular children have and how they might contribute. Avoidance of the bottom three rungs of the ladder are recommended, each rung is explained below.

On the first rung 'Manipulation' is where adults consciously use children's voices to carry their own views and messages. Deception occurs where adults with good intentions deny their own part in a project with children as they believe it would carry more strength to be seen as child led, e.g. where children have been involved in collecting data but the adult chooses to analyse alone.

On the second rung 'decoration' is where children are used by adults to advertise and promote a cause by wearing T-shirts and costumes carrying a message which they do not fully understand, or where children are present but do not know why, and are seen as a symbol of involvement rather than truly being involved.

At level three 'tokenism' is where young people appear to be given a voice, but in fact have no or little choice about what they do and how they participate. In essence at these levels the power remains with the adult and the child has little choice and poor involvement and understanding.

From rungs 4-8 the degree of power relinquished to the young people increases where adults initiate the participation and involvement work but share decision making with children and young people to the ultimate child initiated activity and where children share their decision making with adults.

The top two rungs remain controversial with the degree of adult influence not clear. Sharing decision making with adults may be crucial to ensuring an adult response in an adult dominated world. Many believe that shared decision making is beneficial, whilst others believe that young people are most empowered when they make decisions without the influence of adults.

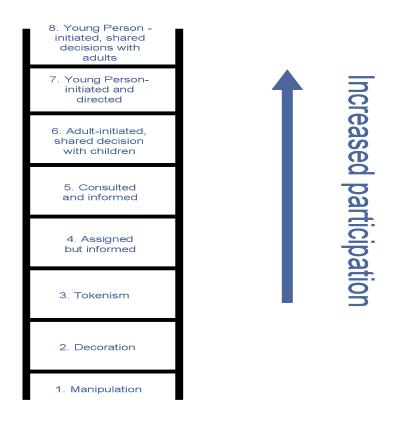


Figure 1 Ladder of children's participation (Based on Dr. Roger Hart's Ladder of participation, 1992)

Participants in the final seminar of a series of meetings aimed at challenging social inclusion (Davis M & Edwards R (2004, p. 98) raise some important questions. They question whether 'children and young people's participation always means taking power from adults (zero sum) or whether both can be empowered (variable sum'), and suggest consideration be given to 'the conditions that lead either to mutual empowerment or to redistribution of power'. Participants in the final seminar also suggest further investigation of participation of certain social groups to include those who are experiencing poverty.

A number of contemporary models of participation for children and young people have emerged over the past few years, and these consist of: core principles, (DH 2001); standards for the involvement of children and young people; (Carnegie Young People's Initiative, Cutler, 2002; the National Youth Agency, 2005, Shephard C & Treseder P, 2002, Save the Children, 2005) and Charters (Children's Society, 2003). Although the Department of Health has provided some good guidance, it is primarily the children's charities that appear to be driving this work.

With each of the publications come the organisations' own definitions of participation with children and young people, for example:

The National Youth Agency (2004) states:

'Participation is the process by which children and young people influence decision making which brings about change in them, others, their service and their communities'.

This definition positively promotes participation as a means towards service change whilst also acknowledging the impact it should have on those participating and others.

The Children's Society (2003) states:

'For The Children's Society, participation means creating and promoting positive opportunities for children and young people of all ages and abilities, to get actively involved in all areas of our work'

This definition emphasises participation for all as one would expect from an organisation that strongly promotes the rights of children with disabilities. The Department of Health (2001) defined participation through the Teenage Pregnancy Strategy as follows:

'It can simply mean taking part in, or being present; or it can mean a form of empowerment – having a real say in decisions'. DH, 2001, p. 5

Participation is emphasised here as a range of possible levels of engagement and appears to place value on all aspects of participation irrespective of the role one chooses to take. In Shenton's (2004) practical guide to youth involvement participation is seen as an ethos, 'a way of working' embedded in organisations.

"Participation is a way of working, rather than an event, a project, an unachievable dream or a tick box... [it is] a culture of participation from top to bottom and side to side." Shenton, 2004, p 6

The Department for Education and Skills in 'Learning to Listen' (2001) state that children and young people should be involved at a number of levels as follows, and that a range of approaches might be used:

- Where individual decisions are being taken about children's own lives (Involvement in decisions about their own care);
- Where services for, or used by, children are being developed or provided locally (Children and young people involved in decision making and may help run services);
- Where national policies and services are being developed or evaluated (Children and young people's consultation to stimulate thinking and ideas).

The document states that no one focus or method is appropriate in all cases.

Each document clearly indicates that children in more marginalised groups may need specific attention and thought to ensure that their voices are heard. The Department of Health (2001), in referring to marginalised groups and those with quiet voices, state:

'Children and young people are not a homogenous group. There is no single way to ascertain their views. The most excluded are, almost by definition, the hardest to reach. No one body can bring the full range of children's views to any one table. Departments will have to decide which specific groups of children and young people to involve, and whether there are particular organisations that can help to identify children and young people willing to take part.'. (DOH, 2001, p16)

Readers are also advised to consider children and young people 'with previous adverse experience of government services', and suggest that they may present significant challenges for organisations wishing to engage with them, and as such advocate partnership working with organisations with 'expertise in reaching out to disengaged children and young people'. What is evidently different in the contemporary models is the acknowledgement that children should operate at which ever level they so wish, and that in order to do so various levels of support need to be in place.

The following 'Standards Framework' is from the 'Hear by Right' publication (Wade and Badham, 2005) and pictorially demonstrates the different elements essential to a structured approach to participation within organisations.

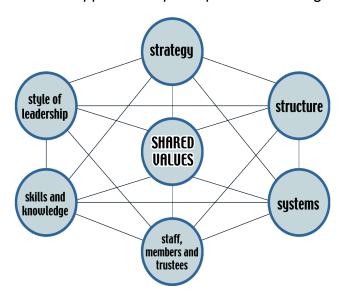


Figure 2: The 'Hear by Right' standards framework: The National Youth Agency (2005) (Reproduced with the kind permission of the National Youth Agency)

The structure (Figure 2)<sup>1</sup> is reliant on 'shared values' in the centre of the matrix and on transparency as to how much power can be devolved to children and young people in the context of organisational constraints.

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<sup>&</sup>lt;sup>1</sup> The Hear by Right Model is based on the work of Tom Peters and Robert H Waterman, In Search of Excellence (1982).

Establishment of the shared values (at the highest level through a 'Charter of shared values' used to review performance in an organisation) ensures that the notion of power aligned to different types of participation as with Arnstein's model is removed, and instead is embedded in the matrix. The shared values embedded in this model ask that children and young people's participation is a visible commitment, is well resourced and is valued. It asks that children and young people have an equal opportunity to participate and that participatory policy and standards are in place, are evaluated and improved.

In essence it is the 'structures' and 'systems', the capacity of the children themselves to take part (skills and knowledge), the commitment of the organisation, senior managers and the children and young people themselves (style of leadership) and having dedicated people supporting the 'active involvement strategy' to challenge those less willing to relinquish power that will result in a successful model of participation and engagement.

The commitment and support of organisations to ensure positive participation will be examined through the key workers' narratives in chapter 7 and is discussed in chapter 9.

Furthermore, this framework comes with resources to evaluate progress and clearly indicates that the standards need to be used to establish what has been achieved. In 'What's Changed' (The National Youth Agency, 2008) results of young people's participation from across the country demonstrate tangible effects of young people sharing their voices, e.g. involvement in community consultation has led to the provision of youth facilities and space for young people.

The Hear by Right model moves participation from a disjointed, ad hoc activity to one embedded in organisations. Implementation is still however fraught with difficulties, with implementation of effective and meaningful participation dependent on an organisation's participatory motives as discussed below.

## 2.9 Implementing participatory practice

There has been much criticism regarding the way in which organisations have responded to their legal obligations to involve patients and public. Kashefi and Mort (2004, p 290) refer to the 'bureaucratic pre-occupation' of health agencies in attempting to involve the public in decision making and are critical of the predominantly 'consultative' methods in use. In their paper on Citizen's Juries they contrast the effects of the consultative i.e. the bottom end of Arnstein's ladder, with the more grounded approaches such as community development approaches. They suggest that the 'consultation industry' is:

"...primarily interested in the use of fixed models to generate the public view as a standardised output, a product, developed to serve the needs of an established policy process, with little interest in effecting change."

Kashefi & Mort (2004, p 290)

They argue for the adoption of more 'grounded' approaches, a movement from consultation carried out in the interests of the agency rather than the public to discussion that 'arises from within communities.' They also suggest increased involvement of commissioners in the process and increased collaboration. Recommendations, they state, should be:

'Context specific and developed within the framework of existing community assets and expertise, and most importantly, opportunities are provided for longer term involvement of local people, retaining the skills developed through the process'. (Kashefi and Mort, 2004, p 292)

This is a particularly important point in considering the investment that is required to help children and young people share their voices and views. Building young people's knowledge and skills through the process of participation not only has the potential to increase an individual's capacity but also a community's and organisation's capacity.

Kashefi and Mort (2004, pp 296-6) suggest four principles that underpin their 'grounded model' of Citizens' Juries, namely deliberation, integration,

sustainability, and accountability. Whilst these principles are linked to the use of citizens' juries, they could be linked to any 'grounded' method.

They argue that deliberation is crucial to decision making initiatives, and consultation without deliberation is not legitimate. They state;

'Deliberative democracy has rightly been described as a 'politics of transformation' because the process of being engaged in deliberation can and does lead to transformation of values and preferences of those involved'. (Kashefi and Mort, 2004, p.296)

This has been important to consider in examining the ways that the young people in this study have been involved in sharing their views, and whether any transformation of values and preferences occurs.

Integration as an underlying principle refers to participation of communities from 'inception to realization', with recommendations implemented through existing networks for credibility and workability. The process must be embedded within the community where the issue under scrutiny exists. Again, within this study the nature of participatory work and its focus will require scrutiny. It will be important to see whether young people are involved from inception to realisation.

Whilst there is acceptance by most community development workers that participation needs to be underpinned by sustained work within communities, Kashefi and Mort argue that development work is also needed to help policy makers and professionals to *'listen strategically'*, thus increasing chances of sustainability through capacity building in communities and within organisations. Moreover this will lead to the effective translation of outcomes into practice. From a public health practice perspective the author would argue that often although the views of the public are used as valid evidence it is the systems and structures between frontline work (consultation, research etc.) and strategic thinkers and implementers that need strengthening. The middle managers are often the ones most in need of skills development to increase their understanding of the role of participatory work and its links to change management and service change.

These limitations are evident within the research presented and are discussed in Chapter 9.

Kashefi and Mort (pg 297, 2004) also suggest that accountability becomes an important principle with evidence supporting the continued existence of one off consultations with no visible change. Local commitment to act on findings and results, they suggest, should be secured from the beginning. In essence, Kashefi & Mort (2004) describe a community development approach to participation with communities. The use of community development methods and the principles described are appropriate particularly for more marginalised communities and the young people who live in them, particularly where the capacity and continued engagement of community members is sought. Openness and honesty about the role community members can play, and choosing the right method against the purpose of the activity is important. Whilst it is possible to demonstrate power imbalance through the hierarchical ladders, such models are not helpful in promoting community engagement. In any sharing of voices and views there are responsibilities and rights. Not all members of the public will wish to engage in decision making; they may simply wish to be consulted. What is important is that individuals and communities are given a choice, and that a choice of methods and levels of engagement are on offer, and that the purposes of these are clearly stated. It should be acknowledged that 'choice' does not present an equal playing field where some individuals will always be in more powerful positions than others. However, community development work and approaches offer increased access to participate in voice sharing often through diverse routes. Additionally important is that action or new learning occurs as a result of this engagement.

Within this study one defined model of PPI was selected to help practitioners describe and place their participatory activities along a continuum. The 'Framework for public and patient involvement' was developed through a joint initiative between the National Assembly for Wales and the Office for Public Management (OPM) (2001). The publication offers strategic and operational guidance to NHS organisations to develop robust PPI frameworks and strategies.

The model was developed and based on the findings of a qualitative research study undertaken by the OPM and incorporates six dimensions of PPI. It can be used as a diagnostic tool for mapping present activities across a whole organisation or specific service. Organisations can map and audit the differing types and levels of activity with a view to 'broadening and deepening activities'. The model is explained further in Chapter 6 (Level of Participatory and Involvement Work) but in essence it allows the completer to map out activities at an individual or collective (group) level along a continuum from information giving to a level of influence.

Whilst not perfect, this model has allowed the key worker participants in this research to think through and reflect on their present and changing practice. It has also allowed the author to have a clear framework from which the key workers' understanding of participation can be established and present practice can be mapped.

## 2.10 Children's rights and power structures

The participation of children and young people is also underpinned by the 'United Nations Convention on the Rights of the Child' (1989). These Rights are regularly mentioned in the proliferation of guidance, including standards, directing professionals on how best to involve children and young people within a quality framework.

Standards for the active involvement of children and young people have been set by the National Youth Agency. The 'Hear by Right' publication (Wade and Badham, 2005, pg 7) states five reasons for active involvement, as stated below, and suggest benefits for the organisation, the children and young people and the wider community. Children's rights emerge, giving an indication of the recognition of children as citizens.

 'It is children and young people's right to be involved in decisions that affect them (Article 12 of the UN Convention on the Rights of the Child, UNCRC.

- Services will be more effective, better targeted and received. This saves money.
- The health of our democratic community depends on the active involvement of children and young people.
- Children and young people will benefit from being involved in decisionmaking.
- Local and National policies encourage and require it and our performance will be evaluated on how we do this.'

Hear by Right, 2005, page 7

However, even with a legal obligation to involve children and young people in decisions that affect them, adults often struggle to do so. John (2003, p2) examines the relationship between participation and power:

'...In a world characterised by rapid explosion of communication of various forms, we are still largely deaf to what they [children] have to say and teach us about the world as they see and experience it. We are deafened by dissonance. Is this inability to listen related to a reluctance to relinquish our view of what children are and, in doing so, to relinquish our own power?'

People experience differing childhoods and may exhibit at times childlike behaviour and may crave the limited responsibility that childhood brings. People can also recount experiences of feeling disempowered or not listened to. However, adults are unable to directly experience what a child or children are currently experiencing in this new and changing world. Often adults only view the world through an adult lens, with children's and young people's views only important if they influence the adult world. An ethos is needed that recognises the importance of children as people, with rights to voice their views and experiences, for those views to be listened to and taken seriously. Prejudices and views deciphering the shared voice of the child need to be appraised with regard to bias and adult interpretation to ensure that where the child is unable or chooses not to share that view, that adults do not misrepresent them.

The challenges emerging from poor understanding and misinterpretations are further compounded by negative expressions. The media's construction of youth

specifically is often negative. Television and the tabloid press tend to demonise and regularly represent young people as 'out of control' and 'disrespectful'. They rarely share good news stories where young people have helped communities, and are helping shape the world in a positive way. Such constructs only assist in closing down adult communications with young people and vice versa. Even where there is the will, practical and sometimes financial resources may impinge on an adults' ability to involve young people appropriately and effectively. Equally important are young people's perceptions of the opportunities presented. O'Toole et al (2003, p. 353) studying the engagement of young people in politics highlighted that contrary to the belief and research evidence suggesting that young people tend to be apolitical or politically apathetic, many are committed to the democratic process, show high political interest, but suggested that 'politics was about being able to express one's views and demands, but felt there were significant constraints on their opportunities to do so'. These views were strongly evident amongst marginalised young people, (in this case homeless young people living in hostel accommodation). Even the young people in more privileged circumstances felt that no-one in authority was listening to them.

The 'United Nations Convention on the Rights of the Child' (CRC) (1989) and specifically in the context of this research, Article 12 relating to the child's and young person's right to be involved in decisions that affect them, has definitely moved this agenda on. Hart (1997) suggests that the CRC results in countries and its citizens rethinking the extent to which children have the right and responsibility to be involved in shaping their own future.

The convention focuses on participation, protection and provision, and as such provides a framework and set of universally accepted standards from which agencies should act. Combined with the more recent legislation placed on health and social care providers, the framework highlights and places specific responsibility on everybody. It is important not to see the three foci as separate entities, but to consider how each affects the other. There must be assurance that young people can share their voices in a safe and secure environment and in

meaningful ways, and this involvement may lead to the provision of services or opportunities. To simply listen and not acknowledge or act may result in disempowerment. John (2003) highlights the importance of a fourth 'P', the notion of power, which she argues is often omitted when talking about children's rights. The argument returns to the debate on whether children are treated as people, whether in establishing the needs and desires of children and young people adults are prepared to relinquish power to enable them to act and think autonomously. Hart (1997), in discussing the involvement of young citizens in community development and environmental issues, suggests children need to be both reflective and even critical. Such sentiments are easily stated but not easily executed in an adult dominated world, where critical thinking and the voicing of such critique is not always accepted by the adult audience.

John (2003) states that:

'The fourth 'P' is not about satisfying needs for protection or provision but rather about realising aspirations – and aspirations which can only be, unlike 'needs', self defined'. (p. 46)

Adults as professionals and parents often struggle with the notion of power, and tend not to talk of children's rights and responsibilities but of care and authority. Bugental and Happaney (2000), talk of parent-child interactions as opportunities for 'socialization and protection of dependent children from harm', and highlight how parent power assertion serves the long term interests of both parents and children. However, in their paper focusing on the power contest in the parent-child interaction, they talk of power in some cases serving to meet the needs of parents. They highlight that parents with low perceived power often exercise abusive and coercive behaviour, including insulting and humiliating behaviour and 'heavy handed power assertive control tactics'. They conclude:

'In response to potential threat, they [parents with low perceived power] showed an increase in child derogation.' (Bugental and Happaney, 2000, p 280)

It is worth noting that many of the children in the sample groups selected for this research have been exposed to inconsistent and negative parenting. This is especially true of those in the looked after system, who may have been removed because of a breakdown in their relationship with a parent or because the parent is deemed unable to parent at that time.

Child power feels threatening to many adults as power may be viewed as something that is divided and not shared. Where power is divided, i.e. 'the more you have the less I have', parents can feel vulnerable with potentially children demanding more and more. If viewed as a share rather than a divide, then each person respects each other's position and power is not rebalanced but changes in nature. Griffith (1996, in John, 2003, p. 51) identifies two forms of power worth consideration, namely 'invested' and divested power.

'Invested' power presents itself in a hierarchical and competitive environment seen in Government and Educational establishments. Where the organisation is steeped in ritual, specified dress codes, initiation ceremonies and depersonalised language is used. Individual success and economic status is rewarded.

Both Hart (1992) and John (1995), share their concerns of, and contradictions in the education system. Information and education are acknowledged as essential components in the empowerment agenda, yet conventional educational practices operate in a less than democratic way. Democracy is taught in a pedantic way, where citizenship lessons take place in an environment where a child or young person is not treated like a citizen. For some of the young people in this research, not conforming and openly voicing their views has led to exclusion from the very establishment that should be helping them develop and learn.

Conversely, divested power fits more comfortably with personal empowerment, where realities are open to negotiation and are not fixed.

'Divested power is characterised by being corporate and distributive in that it diffuses and gives to the periphery with an organic, regenerative and dynamic view of society that regards change and celebrates diversity. This sort of power is based on an ethical rather than economic democracy, is non-hierarchical, based on participation in citizenship in an open society

enthusiastically embraced as changing, adapting, growing and transforming.'

Griffith, 1996, p 215 in John, 2003, p. 50

Divested power is particularly important in this research as the young people in this sample do not always fit into the norm or feel comfortable in the environments where invested power is experienced. Promoting divested power may lead to the young people feeling more included and listened to. A less rigid power framework allows for the child or young person's complex life circumstances and changing expectations and capacity to be accepted, it also importantly allows for the young person to be aspirational and not fearful of failure.

#### 2.11 Conclusion

Such conventions and legalities do not change mind sets, the ways in which adults treat and speak to children, the way the media portrays young people, the ways services are set up to care for children, it is these realities which influence how young people are socialised. Children's consciousness will be influenced by their observations of the systems and structures around them, of adult behaviour towards them. Where adults constantly treat children's views as less important than their own, they start to treat children as something other than people. John (2003) in her book on Children's Rights argues throughout her book for children to be treated as people regardless of age, circumstance or context. The young people participating in this research who willingly consented to share their accounts are symbolic of John's emancipatory position. These young people are individuals in their own right, share experiences from within the context of their everyday lives. Children's voices are not stationary accounts of children's views but moving and evolving stories, seen through the eyes of developing and maturing individuals – people in their own right.

The following study design has developed as a result of the

- Apparent deficit of evidence in examining the experiences of marginalised young people in participation and specifically the limited evidence of impacts of participation on these young people
- A lack of evaluation of those involved
- Insufficient evidence (or theorising) about the process and context and how they inter-relate to produce outcomes
- Clear evidence suggesting that those children and young people in greatest need are often excluded or marginalised from voice sharing.

### Chapter 3 - Establishing a philosophical position

#### 3.1 Introduction

Within this chapter the development of hermeneutic thinking is described together with a critical discussion of the relevance of hermeneutic interpretative phenomenology in the context of the research. The importance of 'lay language' in developing understanding is discussed.

### 3. 2 Understanding the development of hermeneutic thinking

This qualitative research study is primarily underpinned by a hermeneutic interpretive phenomenological approach. The research is undertaken with an acceptance of Martin Heidegger's work that all human existence is shaped by and cannot be disassociated from past experiences, culture, history and even future intentions (Koch, 1995). Hermeneutic interpretive phenomenology is used when 'the research question asks for meanings of a phenomenon with the purpose of understanding the human experience' (Crist & Tanner, p 1, 2003).

Hermeneutics, an area of interpretive methodology, focuses on the interpretation of the experience of others and on empathetic understanding. It is the art of interpreting hidden meaning. The word is derived from 'The Messenger' and Greek God 'Hermes' who interpreted and translated messages from Zeus to human beings (Gadamer, 1979 p147). It literally means 'making the obscure plain' (Blaikie, 1993 p28).

Early hermeneutics in Germany was focused around the understanding of texts, specifically biblical interpretation of text. Schleiermacher modernised this limited use and saw it as 'a science for understanding any utterance in language'. His work focused on two main understandings, grammatical or linguistic which set the boundaries in which thought operates, and perhaps better known is his psychological understanding, which led to the process known as the 'Hermeneutic circle' (Blaikie, 1993 p29). He argues that to interpret the world of the social actor one must place oneself in the mind of the author and 're-

*experience*' their mental processes or conversations, thus reversing the process which produced the text.

'It starts with the finished expression or activity and goes back to the mental activity by which it was produced. It consists of a laborious process of endeavouring to construct the life context in which the activity has taken place and in which it makes sense. This process is known as the hermeneutic circle, of endeavouring to grasp the unknown whole in order to understand the known parts. (Blaikie 1993:29)

In essence, the aim was to gain understanding from the text or social activity. Ricoeur (Blaikie, 1993 p 30) suggested that the psychological interpretation

allowed for a subjective understanding of the speaker and the spoken word, whereas, the linguistic interpretation was more objective. Schleiermacher (Blaikie, 1993 p 30) argued that the outsider was in a better position to

understand and describe the totality than the social actor.

The basis concept of hermeneutics was developed by Dilthey (Holloway, 1997, p 87), the German Philosopher, who moved the psychological interpretation to the socially produced systems of meaning. He endeavoured to establish an objective understanding of history and social life above and outside human existence. He insisted that the foundation for understanding (*Verstehen*) human beings was in life itself, the human world, the social and historical reality. This reality he argues provides concepts and categories needed to produce understanding. Whilst Dilthey rejected the natural science methods as inappropriate in the study of the social sciences he strived to produce objectivity and validity. Both Schleiermacher and Dilthey felt that the interpreter's own lived experience and prejudices could distort thinking, and developed strategies to remove their subjective thinking from the process of understanding. In essence they struggled to think outside of the positivist approach (Blaikie 1993 pp 30-31). The author rejects this approach in the belief that social interaction between the researched and researcher aids mutual learning and personal development, creating new not

distorted thinking, and that this close relationship is essential to individual and collective understanding.

Another early contributor to hermeneutic thinking was Husserl. Husserl's phenomenology was a descriptive detached analysis of consciousness, in which objects as its correlates are constituted (Blaikie, 1993 p 33-34). He developed the procedure of 'bracketing', freeing philosophers from prejudices and helping to secure a purity of detachments as observers, allowing people to encounter things as they are in themselves, independent of presuppositions. The researcher struggles to understand how one can suspend external knowledge and thinking in one's efforts to understand a social issue, where interaction with others helps develop one's thinking and experience of the world. It was Heidegger who moved the thinking forwards.

Martin Heidegger (1889 – 1976) was strongly influenced by Edmund Husserl's phenomenology and became his assistant when Husserl was Chair of Philosophy in Freiburg. In the 1930s in his own publication 'Being and Time' Heidegger, produced a powerful critique of Husserl's work. His change in thinking was known as 'the turn' (die Kehre). Influenced by Kant and Nietzsche amongst others, he philosophised about 'the essence of truth'. He became pre-occupied with language and poetry. He believed that Husserl's phenomenological attitude of consciousness was only one possible way of thinking. Heidegger regarded hermeneutics as a philosophical 'exploration of the nature and requirements for all understanding and regarded objectively valid interpretation as impossible' (Blaikie, p34 1993). He believed that 'understanding' was an integral part of human existence and could not exist outside of one's history and culture. He believed that interpretation was not an elite thing that an 'outsider' did, but an everyday part of our lives located in space and time.

One of the best known modern proponents of hermeneutics is Gadamer (1976, 1979). Gadamer asserts that the interpreter of the data constructs and

reconstructs history through the strong relationship between the text, and the reader, and the context in which the data sit. The basic tenet of hermeneutics is to clarify the conditions in which understanding takes place. Gadamer highlighted the importance of the context of data. Understanding is developed through consideration of the context in which the data were generated. He believed the researcher to be an important part of the hermeneutic circle entering into it with his or her own lived experience, thus impacting on how the data are viewed.

Gadamer was interested in the human experience of the world and focused his work on the process of understanding. In doing so he posed three philosophical questions:

- How is understanding possible?
- What kind of knowledge can understanding produce?
- What is the status of this knowledge?

Key to understanding was one's 'historical tradition', understanding in time and place, and exposing these world views or cultures within the text. He was interested in not hearing the mere words, but in revealing the meaning behind them, not just 'what they say, but of what they bear witness to' (Gadamer, 1979 p 300). Heidegger and Gadamer moved the thinking away from an objective and scientific act to an understanding that was context bound, where data are inextricably linked to the past, present and future, and the interactions one has with the world. Gadamer recognised that language, understanding and interpretation are inextricably bound. It is this view that underpins this research. The researcher believes that it is not possible to disassociate one's own background, professional and personal understanding of the world from the interpretation of data. The researcher will build on pre knowledge to form new understandings of the phenomenon.

In this short history of the development of hermeneutic thinking one can see that the research therefore goes beyond the descriptive accounts of the participant's original text. Exploration of the meaning beyond the literal, where the meaning is not immediately understood, can mean going 'behind the text' and requires a 'comparison with other data which allows us to estimate the historical value of the text from the past' (Gadamer 1979 p 301). The researcher's own interpretation of the text through the analytical process (Chapter 5) generates a more in depth interpretation or understanding, integrating the participants and the researcher's interpretation to create meaning in context. The interaction between the young person and the researcher creates opportunities for interpretation. Within the research accounts presented the young people constantly interpret and reinterpret their position, views, feelings and experience. The researcher is in an enviable position, able to interpret both within and across stories, thus able to view the bigger picture.

Hermeneutic interpretive phenomenology primarily focuses on the meaning social actors place on their subjective experiences and places great emphasis on the use of language both written and spoken. As previously stated, Gadamer was interested in not hearing the mere words but in revealing the meaning behind them. Phenomenology and hermeneutics have a reflexive stance. This approach has been called the *'narrative or discursive turn in human disciplines'* (Lindesmith, Strauss & Denzin, 1999), where language, discourse and discursive practice, and meaning viewed in context are all important.

## 3.3 Philosophy in the context of this research

Porter (1996, p 113-122) describes qualitative research as being founded on four levels of understanding:

Level 1: Ontology – What is reality?

Level 2: Epistemology – What counts as knowledge?

Level 3: Methodology – How can we understand reality?

Level 4: Methods – How can evidence be collected about reality?

The reality in this research is viewed from the perspective of the researched. Placing the focus on the individuals who choose, or choose not to be involved in service development is essential. The young people and the key workers, who

share their stories in this research, do so through their own experience of the world, the meaning they place on things, and through their own individual experience and understanding of participation. As will be discussed in more detail in Chapter 4, the story telling process allows the participants to share their own story and views in a fairly unstructured way. Through this process they in essence are the primary sense makers and interpreters. They, through their stories, expose their lives and the meanings they place on them. It is their lived experience and their understanding of the world which the researcher must seek to understand. The researcher's own reality and understanding of the world will inevitably impact on how she views their worlds. As such, interpretation of the experiences shared creates understanding at a number of levels. The subjective nature of this research, through the direct personal contact during data collection and through the interpretive processes essential to understanding may be open to criticism from those in support of context free laws and generalised explanations. However, it is the interpretive thrust, the shared exploration of time and place and personal experience that is the value of narrative and phenomenological research.

The researcher's epistemological position is therefore an important one to consider. What counts as knowledge? In this research the knowledge of all those involved, the young person, the practitioner and equally the knowledge of the researcher, all count. To exclude any would limit the understanding of the process towards the outcome, and thus lessons would not be learnt. The researcher's position as a researcher and a practitioner is important to consider here. Operating as a pure academic without the everyday interaction with colleagues, would alter the researcher's ability to interact with the world of participatory practice. Whilst this research has provided an opportunity to engage directly with young people, it is primarily the researcher's colleagues who sustain the direct interactions with these young people. Researcher/ practitioner connectivity with colleagues therefore provides an on going opportunity for discussion and debate. It is this debate that leads to the continued interpretation

of data at a number of levels, and that partly constitutes what counts as knowledge. This interaction between academic study and practice relies on a strong 'dialogic' relationship as described by Habermas (in Blaikie, 1993 pp 52-53). He stated that the hermeneutic sciences opposed the natural sciences by using 'communicative experience'. In the natural sciences reality is based on 'universal facts' and 'independent observations' as a disengaged 'monologic' being who stands in a subject-to-object relationship to the subject matter. In hermeneutics, the constant and evolving dialogue and communication through data leads to understanding of meaning. The researcher accepts that social and cultural reality is already pre interpreted by the young people and the key workers, and that through their continued interaction with the world, these meanings may change. The researcher is both a 'reflective partner' and a coparticipant, in that the practice cannot be clinically and clearly separated from the research. This researcher / practitioner relationship will be described in Chapter 5.

In studying the 'involvement and participation' of young people in practice development and service change, it is important to understand the social worlds of the social actors. Goodley (1996, p 342) reminds us that 'dangers exist in overlooking the social aspects behind the stories'. For example, in doing so the political narrative and the unseen pressures of economic and structural change may be missed. Getting involved and sharing one's voice for the confident, well educated person may seem a human right, and a natural thing to do. For the young people in this study living relatively complex lives, ease of access is not so straight forward. It is important for the stories to be viewed in context for them to be truly understood. In Interpretivism there is an acceptance that people are constantly involved in interpreting and re-interpreting the world around them. The constant interaction of people with the environment, behaviours and social situations help individuals create meanings and an understanding of their world. Interpretive hermeneutic phenomenology allows the voices to be heard without decontextualising them which is important in practice and organisational

development where services need to meet the real needs of those they are created for.

# 3.4 Lay language and understanding

Researchers using interpretive hermeneutic phenomenology gather data as stories, verbal discourse, conversations. This research is focused around 'participation and involvement' through the sharing of voices. The data provide a picture of people's everyday accounts, of their experiences and their unique knowledge. Language and social activity are inextricably linked. Human existence is based on communication and everyday discourse. People understand each other through utterances and actions. Lay language shared through story telling allows the tellers to express themselves and maintain control and power. Where language is not shared or understood due to for example, cultural differences, conversation can lead to a better understanding.

Subjective knowing requires exploration of personal experience of self or others with the aim of developing an understanding of a phenomenon. Objective knowing and understanding assumes one can stand outside of the experience and understand it. Inter-subjective knowing relies on the sharing of experience or knowledge with another. Narrative methods rely on subjective and intersubjective knowledge and understandings of life experience (Denzin, 1989, p27-28).

In this research listening to lay language as a shared experience allows for researcher interpretation to be context bound which results in the interpretation of meaning on the subject matter being more robust. Analysing the way people speak and express themselves, considering silences and pauses allows for an emotive element of interpretation. How passionate does this person feel about this? Why have they emphasised this particular point? Is this silence significant? This therefore requires the researcher to interpret the lay language.

In adopting an interpretive approach, where it is legitimate to go beyond the description of the social actor's accounts to produce explanations, the data

become practical and useable. If methodology is a theory and analysis of how research should proceed, in researching public involvement it is important to theorise in a way that allows understanding of the public's views of social life.

Drawing on elements of participatory research and Interpretivism research allows for inclusive and joint learning opportunities for the researcher and the researched. Emerging actions can be taken 'en route' to ensure that change can occur. The relationship between researcher and practitioner is an essential consideration in this research, where experiences and views are shared and interpreted within a practice setting, thus allowing the research to lead to service improvement prior to completion of the thesis. This close relationship between practice development and research in its own way requires a methodology and methods that are inclusive of the participants themselves. Doing research 'with' and 'for' rather than 'to' or 'on' the key workers and young people is central to the approach adopted. It should however be noted that the idiographic method i.e. a method which attempts to understand people and social situations in relation to their unique characteristics, does so without attempting to make generalisations. In hermeneutics clarification of the conditions in which understanding takes place, underpinned by dialogue and communication through data, leads to understanding of meaning. The movement from an objective understanding to one embedded in social and subjective reality as described in this chapter, is important in exposing the hidden meanings. The philosophy is strongly linked to the research methodology chosen in the study presented and the successful gathering of and interpretation of data is reliant on both. In Chapter 4, the research methodology is presented and alignment with this philosophy is demonstrated.

### Chapter 4 – Research methodology

#### 4.1 Introduction

This chapter, whilst deviating from the normal presentation, begins with a discussion of the research sample to ensure the reader appreciates the subsequent research design. The sampling strategy and structure will be justified within a debate on purposeful sampling and its significance in the project. Integrity, ethical positions, and safety of the participants underpin the sampling framework. The process of consent and criteria for selection will be made clear. Finally, the research methods will be explained and justified in relation to the sample and the research aims.

Feminists and phenomenologists specifically assert the importance of the relationship between the researcher and the participants. Accounting for, and justifying one's own position, is essential in a methodological environment where one's own experiences are deemed worthy of consideration. Throughout this chapter the researcher will therefore demonstrate how one's positionality and shared decision making will minimise the potential power differentials between the researcher and the participants e.g. through the consent process, the narrative method and the chosen research interview environment.

# 4.2 The research sample discussed

The research is based on principles aimed at addressing inequalities, which are key drivers in public health practice. Statutory organisations need to ensure they have in place robust systems to ask those marginalised by society and circumstance for their views. People, who fall into this category, have the same human rights as others whether an adult or child. The children in the research sample in this study are often deemed to be 'hard to reach', a term which can imply poor health outcomes experienced by this group are of their own making Carr, Matheson & Tipene-leach (2001). Within the research young people will be referred to as 'marginalised' because of the external factors suggested hereafter

that impact on their lives. Marginalised young people do not fit into the norm that many services are built around and based on. Their health, education and social needs therefore are less likely to be served. At times it is the systems and structures in and around services that lead to the more 'vulnerable' in our society becoming marginalised. Any label, including the terms marginalised and vulnerable, can lead to further isolation and feelings of difference and exclusion. Carr, Matheson & Tipene-leach (2001, p226) suggest that the use of the term 'hard to reach' however, can 'subtly reinforce a political system that denies certain groups or individuals access to wealth, opportunities, health care, and knowledge'. However, there are political drivers which can benefit some groups who are thus labelled. Often recognising the differences or placing people into categories can lead to service providers highlighting areas of need and concern and with those raised issues come specific resources to support change. However, 'labeling' groups of people can create a vicious circle, with labeling pulling in resources, but also further marginalising groups by depicting them as different from the norm. This in itself can lead to social tensions, misunderstandings and further isolation.

## 4.3 The sampling strategy

The research is undertaken in partnership with the local Children's Trust which consists of employees drawn from and through the health and local authority communities. Education and children's social care employees remain employed by the local authority through children's services, whereas health staff remain employed through the Health and Social Care Trust. These arrangements enable young people and key workers to be purposefully selected from across health, education and social care thus broadening the research from a health care, patient perspective to encapsulate additional social aspects of life.

### 4.3.1 Purposeful sampling

In quantitative research the logic and power of probability sampling depends on the selection of a random or statistically representative sample if the results are to lead to generalisability to the broader population so that inferences can be made (Patton, 1990). Conversely in qualitative inquiry such sampling methods will not be used or even deemed appropriate to the research, with sample size numbers much smaller and random selection unlikely. The purpose of most qualitative research is to provide insight and depth of meaning to the subject under scrutiny. Sometimes atypical cases can reveal the most useful data, as can small intense in-depth scrutiny of a few specific cases rather than a reduced level of investigation of many more cases (Patton, 1990). Most important in this debate is the correct selection of a sample to help answer the research question and illuminate facts around the inquiry.

Qualitative sampling is usually purposeful or purposive, with 'information rich cases' selected.

'Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research'. Patton, 1990, p.169

Patton (1990) suggests that these 'information-rich cases' will illuminate the question under study. He discusses 15 strategies of qualitative sampling in qualitative research. One such strategy is known as 'intensity sampling'. Here the focus is not on cases that are 'extreme or special' as in extreme or deviant sampling, but on 'information-rich cases that manifest the phenomenon of interest intensely (but not extremely)'. This research aims to establish how statutory services can ensure 'marginalised young people' have positive participation experiences. It therefore seems appropriate to study individuals who have had experience of participation, who fall into the appropriate age category under scrutiny and who are perceived as marginalised in some way. Whilst the author believes that marginalised young people might have different needs than young people more aligned with, accepted and accepting of main stream services, she would argue that they are neither deviant nor extreme. Whilst those

young people chosen may provide 'rich examples of the phenomenon of interest', that is they are young people who have been potentially disadvantaged in some way and have been able to share their voices with and through statutory services, whether they can be described or categorised as an intensity sample is not clear. Patton (1990) suggests the possibility of picking a small homogenous sample, a sub group that can be studied in depth. Studying a sub group of specific young people is crucial to this research. Homing in and scrutinising participation activity and the outcomes for services and the young people themselves, in some ways makes them both homogenous and an intensity sample. However, although all the young people chosen are marginalised in some way, by the very nature of their complex lives they are not homogenous, although as previously discussed, the labelling of such individuals as 'vulnerable', 'marginalised' or 'disaffected' might immediately categorise them as such. In some ways, the group of young people desired for selection are homogenous in that they must have been involved in sharing their voices in some way, and they have all experienced difficulties in their lives. Equally the aim of this research is not to examine participatory practice in the broader population or for all children and young people, but to investigate through their stories what participatory practice is like for those young people marginalised by society. It is however hoped that by understanding children living complex lives then services will also improve for children in less challenging circumstances. Does this then make the sample a 'critical' sample? Patton (1990, p. 174) describes the focus of data gathering as understanding what is happening in critical cases, picking a group that 'would yield the most information and have the greatest impact on the development of knowledge'.

It could be argued that marginalised young people are a critical group. Their needs will vary because of the instability of their lives, and because of other economic and social factors. Patton suggests that dimensions must be set that define critical cases 'cases that make a point dramatically or are ... particularly important in the scheme of things'. He suggests that the existence of critical

statements such as 'if it happens there, it will happen anywhere'. Patton (1990, p. 175) gives examples of working with communities around implementing legislation and decision making, and speaks of working with either educated or less educated people. He states 'one might consider the critical case to be the community consisting of people with quite low levels of education: "if they can understand the regulations, anyone can".' Patton suggests that this does not 'technically permit broad generalizations' but that logic suggests the argument is weighted towards generalisabilty.

Patton then takes 'critical case' sampling a step further by discussing snowball or chain sampling – an approach for locating critical cases. He suggests asking 'well situated people' to identify information rich people with 'the snowball getting bigger and bigger as you accumulate new information-rich cases'. Certainly, within this research, the researcher is reliant on front line workers to highlight young people, and in essence they are the 'well situated people'. The variation here is that as an ethical researcher, the selection of young people in this study was determined by the 'well situated' person, to ensure the safety of the vulnerable young person, but one selection did not lead to the next. Each key worker selected one or two individuals they felt fitted the criteria for selection. It was therefore essential that key workers had clear criteria for selection. In identifying the key workers, it was professional knowledge and networks which led to their selection, and here the snowballing effect was evident particularly across health and social care professionals where individuals appeared to have strong professional bonds.

Finally, Patton discusses one other variation which is worth consideration, 'Criterion sampling'. Here we are guided to review all cases that meet 'some predetermined criterion of importance'. He states:

'The point of criterion sampling is to be sure to understand cases that are likely to be information-rich because they may reveal major system weaknesses that become targets of opportunity for program or system improvement'.

Patton, 1990, p. 176-7

This tends to be a quality assurance method and has important considerations in research aimed at improving practice. Whilst cases are chosen in this research to highlight through experience good and poor practice, not all young people falling into the criterion for selection would be interviewed. Patton suggests looking at data systems and identifying all people who fit the criterion for in depth qualitative analysis.

No one sub set of purposeful sampling fits perfectly the approach and method used within this study. Certainly criteria for selection were clearly stated (see section 4.33) from the onset. Sample size was limited due to the in-depth nature of the methods used and deemed appropriate in establishing participatory experience in the context of the young person's life. The cases in some ways are 'critical', they are important in exploring different more complicated lives, and may help improve participation and understanding of the systems and structures around participatory practice in a focused way. The snowball effect of identifying cases applies here with 'well situated' people essential in offering access to people often deemed inaccessible. Care should be taken in relying on snowball sampling. Individuals may simply select a like minded person who will reiterate that which has previously been stated. In this research clear criteria are explained and key workers were given assurance that the research was not a judgement of their practice. The cases are also 'homogenous' due to the 'labelling' of such groups, and because they have 'taken part' and because of their age range. Finally, they are most definitely 'information-rich' or have the potential to be so.

#### 4.3.2 The research sample

The aim of the research is to engage with young people living in less straight forward circumstances, who may be marginalised because of their social circumstances, and who need additional support beyond the mainstream and universal services.

Health and local authority services often employ specific workers to engage people who are vulnerable. This is primarily to ensure communication is maintained and service provision is understood and needs are met.

Those employed to work with vulnerable young people in this sample were an important source of access to the young people. The research also aimed to examine the role that such workers had in helping these young people engage with services and share their views. As such the research sample is split into two main groups, key workers and young people. The characteristics of each group are discussed hereafter.

The aim was to interview 10 -12 frontline practitioners, key workers from health, education and social care working with marginalised young people in the following areas:

- Young people excluded from mainstream school
- Teenage mothers
- Young carers
- Looked after young people
- Young people in the travelling or gypsy communities

The same key workers would purposefully select the sample of 10 -12 young people invited for interview, with each key worker selecting a young person each. The five groups of young people were selected based on the strong relationship between health and education needs that these young people have. Each has a strong correlation with the other with poor health potentially leading to barriers to education and poor education potentially leading to poor health outcomes for these groups, particularly as life chances are reduced (Acheson, 1998, Badham, 2004).

#### 4.3.3 Selection criteria

- Young people who had experienced a level of involvement or participatory work within the trust or with key partner organisations within the past year.
- Young people (male or female) aged between 11-18 years old at the time
  of the involvement work, and who had been deemed safe and suitable to
  take part.
- Young people who had been informed about the research and who had consented to take part (or who have a parent or carer who has countersigned the consent where the key worker has deemed that an adult should be involved in the consent process).

#### 4.4 Ethics and consent

NHS and University Ethics approval was obtained prior to data collection in line with research governance arrangements. In order to approach and request access to local authority staff as a potential sample, letters were written to the Head of Education and Social Services. Formal permission was granted in writing.

It was important to ensure that the young people selected understood the nature, aims and objectives of the research, were willing and comfortable about taking part, and had formally consented to do so. Purposeful sampling was primarily used to ensure that the key workers could assess the suitability of the young people to take part at the time of asking. Young people living in complex circumstances often have very unpredictable and challenging lives. Most of the key workers had regular contact with the young people and therefore were well placed to ensure that their lives had not changed too dramatically between the time of asking and the interview taking place. They also had a close relationship with the young people and were therefore able to sit down with them and explain the research to them and work through the young person's 'Information sheet' to gain 'informed' consent (Appendix 1). As noted by Lewis (2008, p18), 'an opting in to voice is simultaneously an opting out of silence'. The researcher therefore

took time with key workers to help ensure young people were not coerced into taking part and asked key workers to ensure that young people knew they could opt out at any time. The predominant aim of the epistemological researcher is to ensure that the young people's voices could dominate the interaction by ensuring the young people could choose the level and length of participation to engage in. The researcher undertook interviews with all the key workers before they selected the young people from their area of work. At each interview the young people's selection criteria was explained and each key worker was asked to read through the information sheet with the young person and ensure that they could ask questions and clearly understood what they were consenting to. The researcher was aware that bias could be introduced if key workers selected individuals who had all participated without difficulty or individuals who would only present a positive view of the participatory experience in fear of compromising their relationship with their key worker (Holloway, 1997). The researcher directly discussed these possibilities with the key workers to ensure they understood the purpose of the research; did not feel professionally compromised and felt able to select young people who would be honest in their representations. The process is discussed further in section 4.41.

The positionality of the researcher is important to consider and has the potential to influence all stages of the research process, not least the process of consent. Borbasi et al, (p. 495, 2003) states that 'researchers should account for self in the field, and be aware of and able to justify their own position'. Research information sheets and consent forms (Appendix 1) clearly stated that the researcher was also a practicing nurse. This may have influenced the participants' decisions to consent with the profession often described as a 'caring profession'. Additionally, the positive promotion of the nurse / researcher by the key worker could have potentially influenced the young person's decision to take part. Whilst it is not possible to determine why all young people chose to take part, the openness and honesty about one's position and reasons for undertaking the research were ethically and professionally essential to the consent process.

# 4.4.1 Children's and young people's competence

Issues relating to children's competence need to be considered alongside the increasing expectations and recognition, that children and young people have rights and abilities to contribute to society. Alderson (1992) argues that assessing children's competence to consent to medical treatment is not simply about assessing a child's ability and maturity, but also requires an assessment of the child's social context. She suggests we consider external and internal influences on competence. Competence related to genetic factors such as intelligence and ability are problematic in their measurement. In Alderson's research professionals measured children's intelligence in numerous different ways. Parent's estimates of their children's competence to consent to medical treatment are always easier, where a parent and child agree. Competence is usually only called into question when a conflict occurs. It is now widely recognised that a child's intellectual ability is only one facet of competence and that a child's emotional development, their relationships with others, practical, social and imaginative talents can all help an individual in their decision making. One's social world and experience of race, class, poverty, illness and disability may all impact on how a child perceives a given situation (Bradley, 1989). Within this lived experience children and young people are often very capable of weighing up risk and benefit, by using imaginative thought and searching for explanations. Adult reasoning may not concur with that of a child, but adults can help assist in the process of decision making without retaining the power. Home and family, friends and significant others can and will influence a young persons perspective. Key workers in this research are asked to measure a young person's competence to take part against different non life threatening, but equally complex circumstances. They also measure competence either overtly or covertly, when deciding which young people will share their voices in practice based participation. It might be argued that it is the young person who should be the prime decision maker, but professionals may be influenced by many issues not least those associated with safeguarding. This may result in a scenario where a key worker feels a young person would be vulnerable in a participatory environment but where the young person wishes to take part. The key worker potentially silences the voice of the young person in doing so, but equally may be ensuring their safety. Avoiding discussions can be convenient for adults; ensuring discussion can often allay fears and concerns. As Alderson (1992, p.123) states 'Competence is more than a skill, it is a way of relating, and can be understood more clearly when each child's inner qualities are seen within a network of relationships and cultural influences.'

#### 4.4.2 Process of consent and structure of research interview

Consent was undertaken in accordance with the terms agreed through the ethics committee and the debate (See Figure 3: Summary of consent process). The key workers were contacted directly by the researcher via telephone and / or letter. This contact was either due to existing professional contact, or a contact made during the promotion of the research idea. Each key worker was informed of the nature, purpose and design of the research study, and before agreement to take part each key worker was asked whether they had undertaken any work which involved young people sharing their voices. This was to establish whether they would be able to link the researcher with a young person who could be considered to take part in the research.

Each key worker was then sent a formal letter, information sheet and consent form and asked to formally consent to take part (Appendix 1). Thereafter a mutually convenient appointment was arranged. All key workers were happy to be interviewed in the researcher's office.

At the beginning of each interview the aims and objectives of the research were reiterated and the consent re-checked to ensure that the professional was happy to continue, and had consented to the interview being tape recorded, and subsequently transcribed.

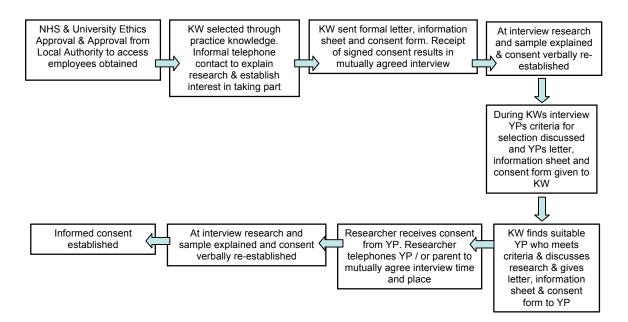


Figure 3: Summary of consent process

For key workers the process of data collection was slightly different to that used with the young people. Each key worker was shown a blank 'Public and Patient Involvement proforma' (Appendix 2). This was explained by the researcher (see chapter 6), and the key worker was encouraged to share participation and involvement work undertaken in their field of work, and where possible the proforma was completed by the researcher as they spoke. The purpose was to establish the nature and level of involvement work presently being undertaken, and secondly to establish the key workers' understanding of participatory work. From this initial debate most professionals were able to highlight a young person that they felt would be suitable and willing to take part in the research.

Key workers were then asked to share one positive and one not so positive experience of participatory and involvement work relating to their specific group of young people. Strengths and weaknesses, successes and problems were explored, with an emphasis on what they might do differently next time. During the course of the interview each participant was encouraged to share information

about the nature of their client group to help contextualise the participatory activity.

At the end of each key worker interview, each professional was informed of the criteria for selecting young people into the research project, and was given a copy of the young person's information sheet, and consent form. Each worker was asked to select an individual who had shared their voice. It was emphasised to the workers that the researcher would welcome young people who would be 'straight and tell it how it is', rather than simply picking young people who would tell the researcher what she wanted to hear. The researcher emphasised that this research was aimed at improving what was presently being done and was not aimed at criticising practice, and that most benefits would come from young people who would feel able to be open and honest about their experiences. The key workers were also informed that the young people would each receive a ten pound voucher of their choice once they had shared their stories. The researcher asked the key workers not to share this fact with the young person until they had consented to take part. This arose out of the discussion and debate during ethics committee approval, where issues of coercion were discussed. Some group members were in favour of payment for taking part, others were not. In order to ensure that young people were not coerced into taking part it was agreed that the payment information should be withheld until consent was established.

Once the purposefully selected young people had agreed with their key worker to take part, and had returned by post in the stamped addressed envelope provided the signed consent, each young person was then telephoned by the researcher on the contact number provided. This was the first point of contact between the young person and the researcher. At this stage the researcher ensured that the young person understood what the research aims were and that they remained happy to take part. A mutually agreed date, time and place were established. Two young people chose to come to the researcher's office; six young people were interviewed in their own homes, and the final two were interviewed in a

public place (one children's centre building and one community centre). All young people were interviewed on their own, although one mother of a young man in the travelling community was present for a small part of the interview, and one grand mother of a young woman excluded from school was present during some of her interview. This was attributable to the nature of the venue, where living space was limited, but may also have been due to intrigue and interest of the adults regarding the nature of the research. Additionally, the young people were in the main able to claim space for themselves, which was potentially empowering.

At interview the researcher again explained the research aims and objectives to each young person and verbally re-established consent. The researcher was honest about why each individual had been selected, and each young person was informed of the nature of the sample, and why young people living more complex lives had been chosen. The young people were informed of their right to silence at any stage of the process, their right to opt out or stop the interview either temporarily or permanently, and that this would not affect their present or future care. This was also clearly stated on the information sheet for the young people (Appendix 1). Lewis (2008) states the importance of recognising the right to silence and also the need to clearly note this within the accounts. As such all silences were explicitly noted within the transcripts and were considered in the interpretation of texts. When the young people were silent during the interview, the researcher needed to determine whether the young person was struggling to understand or whether they were exerting their right to silence. This was difficult to manage and required concentrated effort to prevent undue pressure being placed on the young person.

Each young person was asked to tell their story to include if possible some information about their background, childhood and family circumstances, and then to share how they had been involved in sharing their voices. A prompt card

was available for the young people to refer to, to help them keep focused (Appendix 2).

At the end of the interview each participant was offered a copy of their interview once transcribed, to provide an opportunity to call should they wish to amend or add to their story. This, it was felt, would help to contribute to the validity of data. Some but not all of the young people requested their interviews; no young people chose to alter their accounts.

#### 4.5 Justification of research sample characteristics and size

From this research sampling strategy the following key workers and young people consented to take part in the study.

<u>Number of key workers</u> – 12 including one pilot interview (11 transcripts used within this research – pilot interview not used). All the key workers were female.

Number of young people – 11 including one pilot interview (9 transcripts were used within this research with the pilot interview not used and a young carer interview unusable due to poor sound quality.) Two young people were male; one young man excluded from school and a young person from the travelling community.

Young people were selected from eleven years up to eighteen to ensure that the young people themselves could reflect on their earlier childhood in relation to their participatory experience. The aim of the study is not to look for differences across these groups but to explore the experiences of participation for these young people and explore how these experiences can help to improve services and outcomes for these young people.

#### 4.6 Research methods

The interpretive biographical method requires the researcher to study and collect personal life documents. In this study the life documents are the stories told by the participants. This research is embedded in socio-cultural theory, where the social and cultural contexts of lives shape human learning and development (Vygotsky, 1978). The study examines how key workers and young people relate contextually with participatory activity. Story telling provides the method of enquiry; narrative analysis exposes the hidden meaning within the stories.

# 4.6.1 Narrative enquiry through story telling

Narrative interviewing provides the main method of data collection in this interpretative study. During the design stage, in considering appropriate methods of collecting data, narrative enquiry emerged as a method that would meet the research objectives without compromising the position of the research participants (Bruner, 1984, Riessman, 1993, Cortazzi, 1993, Riley and Hawe, 2005). As Cortazzi (1993, p 28) states 'Narratives give speakers strong rights to hold the floor' and place them in a position of power. With a research focus on the experience of participation for marginalised young people, to find an exemplary method of data collection was imperative. The method must demonstrate best practice in relinquishing power and allowing free speech and at the same time must be comfortable with the participants.

'Self stories' position the teller at the centre of the story and focus on a specific set of experiences in the context of the life of the teller. As Denzin (1989) points out:

'It is literally a story of, and about the self in relation to an experience... the self story is made up as it is told' (p.43).

Narratives are in essence familiar to us all. They form part of our communication and conversations with the world. Most people tell or hear an account of

experience everyday. The personal narrative, from being thought through to being spoken, is an account, a personal interpretation of the lived experience.

'A life lived is what actually happens. A life experienced consists of images, feelings, sentiments, desires, thoughts and meanings known to the person whose life it is.... a life as told, a life history, is a narrative, influenced by the cultural conventions of telling, by the audience and the social contexts.' Bruner, 1984, p. 7

Although many people use the term 'narratives' and 'story telling' interchangeably, some researchers view the terms differently. The 'story' is described as the told account, with the 'narrative' sitting beneath the story available for analysis by the researcher (Frank, 2000, Riley and Hawe, 2005). Riessman, (1993, p1) defines stories as 'first person accounts by respondents of their experience'. A primary way individuals make sense of experience is by casting it in a narrative form. This is especially true of difficult life transitions and traumas. As such the storyteller provides data, either verbal or written, that can be interpreted and made sense of in line with the research question or issue under scrutiny. Where participants feel comfortable and able to share, the story telling technique produces a huge amount of powerful data (Riessman, 1993). However, making sense of it and making it useful and meaningful to those in practice requires some complex research strategies. Ensuring that personal experience stories and the thick description of the lived experience are not lost in their translation into meaningful data for practice and service development can prove difficult. Development of an analytical strategy to prevent distortion, improper or under representation has become an important personal and research outcome (See chapter 5). Consideration turns to how sense of the world is made. Meaning is interactionally accomplished at a number of levels. As Bruner (1984) states, the storyteller will be influenced during the telling by many things, culture, knowledge, social context and importantly who is listening. As a listener, the researcher in this study may be perceived as a white middle class woman, a researcher and/or a nurse, a person with authority. In using narrative enquiry the teller has the potential to be in a position of power, being able to

control what they want to share and when they wish to remain silent. They may be able to guide the interpretation by placing specific emphasis on certain issues and parts of the story. However, it is important to acknowledge that both researcher and the researched may use silence to their own ends (Lewis, 2008, p19). The young person may require time to consider how to answer and what to share. The researcher must be careful not too interrupt such silences too quickly, thus interrupting thought processes. Equally, the lengthy silence protracted by no researcher interruption may place pressure on the young person to share.

Each person makes sense of the world by conversations with themselves. As stories are told people internally shape and consider how to act and what to say. These internal shapers are known as 'internalised soliloquies' (Atkinson, 1997, Ezzy, 1998). Stories may be vocalised. These vocalisations or descriptive accounts may develop into explanatory stories, where people start to justify actions and beliefs. Movement into comfortable conversation may result in an emotional reliving of the story and a movement into 'narrative flow', where the barriers of the research situation are forgotten and the teller is primarily focused on the story (Denzin, 1989).

Through this process of sharing or indeed through any participatory event, the power relationships as detailed in Chapter one cannot be ignored. If direct structured questions were asked to gain specific data, then the researcher is in a position of power and control. Potentially only the researcher's a priori interests are explored. The questioning can suppress the respondent's stories and produce modified, reduced understanding. However, by asking individuals to tell their story, rather than answer a set of prescribed questions, the power is relinquished to the individual. However, the researcher will still need to set the scene guided by the research focus.

The narrative method of data collection seems appropriate given the central theme of participation. It is important in any participatory work that the power is

shared, and that participants feel able to offer honest and open accounts to establish true beliefs and understandings. The sharing of power should be demonstrated in practice, especially when researching and engaging young people. Goodley (1996, p 334) argues that life histories act as an 'agency through which historically marginalised individuals may account for their own lives'. Many of the young people within this sample have rarely been in positions of power. Their lives have often been very public and controlled by others. The use of this method is therefore justified in ethical terms and in the richness of the data it produces. It is also an accessible method because as Riessman (1993, p3) suggests 'Telling stories about past events seems to be a universal human activity, one of the first forms of discourse we learn as children.'

The nature of story telling allows the researcher to uncover, describe and interpret the meaning of experience. The teller can reinforce the insider's subjective understanding. This Goodley (1996) argues, prompts the reader to challenge their own often generalised understandings, both professionally and personally. It is a method therefore that sits comfortably with the researcher's philosophical thinking.

There are both tensions and affinities between narrative as a method and the phenomenological position. Individuals tell stories of their lived experiences, and as such a single and individual account is produced. Phenomenological researchers focus on the meaning of several individual accounts, with the aim of describing a phenomenon, as a composite description across accounts; 'to grasp the very nature of the thing' (van Manen, 1990, p 177). By asking marginalised young people to share their individual lives and experiences of participation through story telling, the phenomenologist is able to interpret data and build understanding iteratively. Thus the researcher exposes hidden meaning in the participant's narratives (Maggs Rapport, 2000, p 220).

These individual and subjective accounts are important in developing deeper insight into human nature and consciousness. Equally important is the positionality of the researcher. In moving the data from individual accounts to create a deeper collective understanding of the phenomenon requires a high degree of openness of the analytical process (See Chapter 5). This research is underpinned by hermeneutic phenomenology; as such there is an acceptance that the researchers' understanding and position can influence interpretation. The researcher, therefore, never totally disassociates with her own subjectivity. According to Gadamer (1989) the unity of understanding between the researched and the researcher creates innovative thinking and guides interpretation. In phenomenology, striking a balance between participant dialogue and researcher interpretation is challenging.

As Webster (1966 p. 1503) states narratives are 'a connected succession of happenings". Riessman (1993) describes a variety of types from 'Habitual Narratives' which are routine events and actions recalled into stories; 'Hypothetical Narratives' that describe events that did not take place - an imaginary story, and importantly in this research 'topic centred narratives' – a story of past events connected thematically by the storyteller. She suggests narratives are useful for studying 'transformations and transitions' in people's lives, an important fact in establishing the impact that participation has on the lived experience of the young person sharing their voice. She states:

'Individuals construct past events and actions in personal narratives to claim identities and construct lives.' Riessman, 1998, p. 2

In this study both the key workers and the young people will be asked to tell their stories of participation. By studying oral accounts of personal experience the teller's representations and explanations of experience can be examined.

According to Cortazzi (1993 pp 6-12,) who studied the use of narratives in studying teaching and teaching culture, narrative research is a method of hearing teacher's voices to begin 'to understand from the inside the thoughts,

perceptions, beliefs and experiences of teachers, and in doing so can learn more about aspects of people's culture'. He describes three trends of research important in teachers' narratives which could be transferred to other groups.

- Reflection
- Knowledge
- Voice

He suggests using reflection or deliberation, as a method of learning, through the keeping and examination of journals, logs and personal histories. For the young people and key workers in this research, reflection of their text is not directly possible (although all transcripts are offered to each participant as part of the research and validation process). However, the story telling naturally encourages personal reflection, as one speaks and considers the shared accounts. In nursing and public health work reflective practice is often used as a method of continuing professional development. Within the context of a professional doctorate where learning application to practice is important, these accounts can be used in training and professional development circles as well as within the context of this research. It is possible to look at narratives and examine to what extent personal and professional knowledge is expressed in the account / story. Certainly, this is one method and aim within this research particularly in attempting to decipher how the sample use and understand the terms 'participation, involvement and advocacy'. Finally Cortazzi suggests that narratives can be used as a method of empowerment allowing teachers to speak for teachers, sharing experiences and using this as a method to ensure change in education comes from those most involved in delivering services. He suggests that researchers using teachers' narratives are more likely to see the classroom reality in terms of the teacher's voice (from an insider perspective). For this research, gaining the samples' direct experiences through their personal stories is more likely to generate robust evidence than the researcher observing practice would attain. With a research objective aimed at better understanding the impact of the participatory

experience on the young person a method that empowers them to share and reflect is important.

Through this method of 'empowerment' it is possible that new skills and experiences emerge for both the researched and the researcher. This emancipatory enquiry approach of listening and learning through conversation and debate leads to new understandings for all concerned.

# 4.6.2 Strengths and weaknesses of the method

Story telling is accessible as an everyday activity. It empowers the individual, allowing him or her to be in control of what is shared or not shared, what information is accentuated or minimised. The method produces a large amount of data for analysis which is positive in gaining in depth insight but is problematic in research data management, and therefore requires a systematic method for data handling which is described in Chapter 5. As detailed accounts are produced, the researcher must be focused to prevent exploration and interpretation of data unrelated to the focus of enquiry.

What ever the story told, there will be an interaction between the teller and the listener. Each time the story is told it will vary. It will vary because of the chosen emphasis the teller wishes to place on the story and the response the teller receives from the audience. The questions asked and the interruptions made will take the story down different routes each time it is recounted. Importantly as time passes, more reflection by the teller will have taken place, new issues may have emerged which in turn shine new light on the experience. Conversely, memory recall may blur some of the tellers' ability to fully relive the story. In Riessman's (1993, p15) words the meaning will be 'fluid and contextual, not fixed and universal'. In the narrative research environment, it is important to emphasis the contextual nature of the data, that each story is a 'limited portrait' (Riessman, 1993, p 15). Whilst generalisabilty is not the aim, researchers may speak of the representativeness of concepts (Strauss and Corbin 1990), where new

knowledge of concepts, instances and conditions is produced. Understanding and accepting these issues are important but are often the weaknesses exposed by positivists (Riessman, 1993, p5). Importantly, whether as a research method or a method employed in participation work, the process of sharing one's voice through story telling creates an important personal learning environment where, self reflection of the experience helps reiterate or challenge the teller's own experiences and beliefs through constant reflection and interpretation. This happens at the level of the teller and the listener.

In Chapter 5, the analytical process is discussed, demonstrating how the researcher has analysed the data from the stories and each of the sample groups; and how the research analysis relates to practice.

# **Chapter 5 - The analytical process**

#### 5.1 Introduction

There are tensions between the dual role of a practitioner / researcher engaged in formal academic study whilst employed as a public health nurse consultant. The joint role requires the post holder to build research capacity and improve practice whilst actively researching. The research process and messages, and the personal learning through research activity and academic input, hugely impact on each other and with day to day work. The practice and research activity are at times separate worlds but invariably link at key points in time. The more advanced the research stage as the data shared builds up, the greater the need to feedback into practice. Evidence generated from the research is not always available for sharing when required in practice and conversely, research evidence may be available when there is no practice audience responsive or ready to hear it. Practice targets and research timescales are often therefore the primary drivers in the analysing and sharing of data.

The analytical framework described in this chapter emerged as a response to these sometimes opposing and sometimes converging worlds.

Inductive analysis is used to understand the data emerging from this research.

'Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis.'

Patton (1990, p. 390)

The inductive process 'of finding a single case and observing a relationship, then observing the same relationship in several more cases and finally constructing theory to cover all the cases' (Gilbert, 1993, p. 22-23) moves the analysis from single story to cross story analysis, and assists the researcher in applying the learning to practice.

Consideration and justification of the multi-method approach to the analysis and its connectedness to the participatory project ensues.

# 5.2 The process explained

The analytical process is explained through a series of flow charts. Similar processes were used in analysing the key worker's and the young people's interviews.

The key workers' interviews were undertaken in advance of the young people's interviews as it was at the initial interview that the key worker would identify young people who could be approached to take part in the research. It was not possible to analyse in depth the key workers' narratives in advance of all young people's interviews for practical reasons e.g. time shortages between interviews. However, once a key worker was interviewed initial notes were made on the observed behaviour and issues that stood out from the story told. The researcher also re-listened to the tape recording, made initial notes about issues important to the research question and objectives. Tapes were transcribed by the practitioner's secretary and once the transcripts were received these were reread and again notes were made on the transcripts, highlighting emerging themes and text which illuminated the theme. This was a very basic initial analysis, but importantly started to highlight issues of interest that the researcher / practitioner could take into practice and to subsequent research encounters. This was important as new issues emerged that required further exploration.

Within the practice arena there was a formal 'Participation Operational Group' (POG), and a strategic 'Empowering Children and Young People Group' (Now the Participation Strategy Group). The POG consisted of multi-agency frontline professionals who were engaged in participatory practice on a day to day basis (some of the sample were drawn from this group). The strategic group was made up of more senior managers who acted as a resource to further debate the issues raised in the POG, and who could help ratify the annual plans of the group and the standards of good practice being developed. These groups were the researcher's main form of workplace professional supervision. It was in the POG initially that many of the themes and original findings were taken, as it was thought that the research could directly influence the writing of the Families and

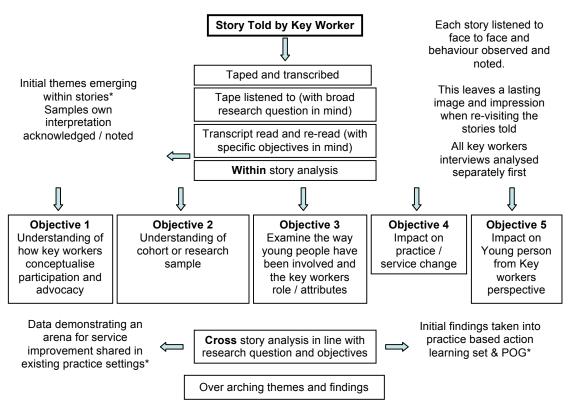
Children's Trusts (FACT) Participation Standards (Appendix 4). The strategy group members were more likely to instigate formal sharing of data through conference presentations. In addition to these formal groups the researcher through her role as public health nurse consultant instigated an Action Learning Set (McGill & Beaty, 1992) to support practitioners who took part in the research to reflect on practice and further debate the themes (and problems) raised through the initial research analysis. In practice this provided an opportunity to reflect on past actions in order to learn from experience and explore current issues (Johnson, 1998, p297). Within the context of this research it provided an arena where some of the initial themes could be debated in a group setting, where the researcher's interpretations could be checked and clarified, and where practice participants could gain peer support and consider suitable actions. They were not used as direct research evidence within this project, although they have been used to clarify the researcher's understanding of the problems faced by both key workers and the young people as a form of validation.

# 5.2.1 Process of analysing key worker stories

Figure 4 represents the process of analysis undertaken when analysing the key workers' narrative interviews.

All initial analysis was 'within' story analysis (Lieblich et al, 1998), where the researcher read each transcript with a key research objective in mind. For example, 'How does the key worker describe participation and advocacy, and is that contradicted or advanced within the main text?' This structured process was important in focusing the analysis to the research question. Each story was read independently, and thereafter the main themes and areas of interest were considered together in 'cross' story analysis. The researcher constantly returned to the research objectives as a guide. The huge amount of data shared at interview could have resulted in a tendency to stray down paths of interest that were not directly relevant to the research questions.

Once each individual story had been examined in line with the five key objectives shown in Figure 4, cross story analysis took place to examine similarities and differences within the data.



<sup>\*</sup>As the data builds and analysis commences selective data are taken into the practice arena for further debate advancing the researcher's thinking and often resulting in additional analysis

Figure 4: Process of analysis for key workers' interviews

An initial issue that became apparent across the stories was the huge amount of preparatory time key workers spent on building relationships with the young people, improving skills and preparing the young people to share their voices. The researcher considered that the extent of this preparatory work may be more relevant to work with marginalised young people. This is a good example of how the research impacted on practice development, with the idea of extended time being required for some young people built into the developing Participation

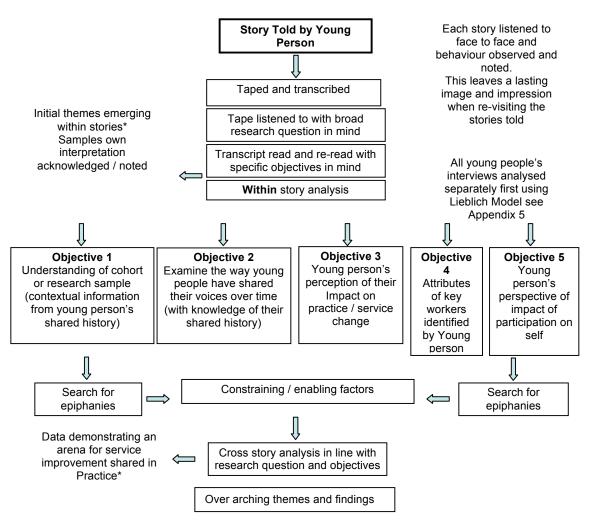
Principles (Appendix 4). It became possible therefore to share selective data 'en route', where the researcher felt the evidence was robust enough to share.

# 5.22 The process of analysing the young people's stories

The young people's interviews were far less structured than the key workers with the participants simply asked to tell the researcher about their experience of growing up, home life now and how they became involved in sharing their voices. The lack of structure resulted in immensely detailed and rich stories, but made the analysis more difficult. It was therefore very important for the researcher to have a clear structure in analysing the data. As with the key workers' interviews five key areas of focus were established in advance of the analysis in line with the research objectives (Figure 5).

These were slightly different from those shown for the key workers, but again allowed for 'in story' analysis to take place in a structured way, and then subsequently cross story analysis to occur. Often the young people share key moments in their lives within their individual accounts. These are referred to by Denzin (1989, p70) as epiphanies or 'interactional moments and experiences which leave a mark on people's lives'. These were exposed within each story and help reveal key drivers and barriers to voice sharing.

'In story' analysis was undertaken using a model devised by Lieblich et al (1998). With the huge amount of data generated the researcher needed to follow or devise a systematic process of analysis to ensure that the focus remained clear. Lieblich et al (1998, pp 12-14) describe two main dimensions in analysing narratives in their 'Model of Classification and Organisation of narrative analyses' to include 'holistic versus categorical' and 'content versus form'. The holistic approach refers to the life story or narrative account analysed as a whole, with sections of the story interpreted in the context of the rest of the story. This approach lends itself to observing the development of a person through their life, or the aspect of their life under scrutiny e.g. what factors in the person's life have led them to share their voices?



\*As the data builds and analysis commences selective data are taken into the practice arena for further debate advancing the researcher's thinking and often resulting in additional analysis

Figure 5: Process of analysis for young people's stories

In the categorical approach the original story is dissected into categories by single words or sections, these are then shared across stories. This can be a useful approach if the researcher wishes to examine a problem that the whole group may experience. This method would be useful in taking explicit issues of interest into practice pertinent to 'marginalised' children as a homogenous group. This is not dissimilar to thematic or content analysis. Holistic analysis has been used and is particularly useful in examining the individual stories in this research, with the categorical analysis useful in the cross story analysis. For example, the life course is exposed through holistic analysis, and categorical analysis will

expose variations in the methods of engagement used which may or may not be replicated across stories.

In the second dimension, the 'content' might be the focus of analysis, for example the 'explicit content' might refer to what happened, why, who participated, all from the standpoint of the story teller. In analysing the 'implicit content' the researcher may observe the meaning of the story, the motives and traits of the teller, and what the images narrated portray or symbolise. For some the 'form' not the 'content' becomes the point of interest: The plot, the structure of the story the sequencing of events, style, and the choice of metaphors. Lieblich et al (1998, p 13) suggests that this can 'manifest deeper layers of the narrator's identity'. The author also suggests that researchers may draw on aspects of both dimensions. Certainly in the context of the study presented the researcher needed to draw on each dimension depending on the reasons behind the analysis. For example, when sharing the nature of participation in the key workers' accounts, (who, how, and for what purpose), the content dimension is important and allows for the sharing in practice. For academic purposes and for in-depth understanding of the way young people share their stories, observing the form is important.

Holistic: Search for 'in story' epiphanies across whole life story e.g. bullied at school and presently shares carer's voice in community support group, but not in school environment

Content: Would not seek support nor voice share at school (explicit). Bullied by peers / poor support from head teacher (Implicit) — has made her stronger, independent and driven.

Categorical: Support and voice sharing via school rejected for self. In analysing across stories did others feels uncomfortable participating at school? Do others mention bullying?

**Form:** Sequencing of events – early childhood event leading to present view of voice sharing in school. Very eloquent reflective speaker.

Figure 6: Example of analysis of YP YC1 narrative using Lieblich et al (1998) two dimensional framework

In Figure 6, one aspect of a young carer's story is presented to demonstrate the different ways a story can be analysed using the analytical method described.

Within the broader analytical process the researcher primarily uses a 'Holistic-Content' perspective from the two by two model (Lieblich et al, 1998). At times the nature of the analysis moves into and draws on other elements of the framework. According to Lieblich et al (1998), this is not uncommon.

'The reader should bear in mind that these fine distinctions are not always clear-cut in the reality of conducting narrative research and interpretation. Form is not always easily separated from the content of the story. In fact, the word 'idea' in classical Greek refers to both content and form. Some may view the form of a story as an embodiment of its content, a more subtle manner for conveying a message...' Lieblich et al, 1998, p.14

The researcher developed a process of analysing each stage from Lieblich's work. The initial 'in story' analysis is summarised in Appendix 7, with each young person's story analysed individually following a structured approach (Figure 7).

Stage of analysis	Young people's Stories
Stage 1	Initial Analysis of Young Person's Transcripts – Read through / re-listen to tape and highlight:  • Brief background
	<ul><li>Epiphanies</li><li>Initial impression / assessment</li></ul>
	<ul> <li>Self-descriptions</li> <li>Personal outcomes / impacts</li> <li>Service outcomes / impacts</li> </ul>
	<ul> <li>Relationship with Key Worker and significant others</li> <li>Aspirations</li> </ul>
Stage 2	Analyse epiphanies or key issues in relation to rest of story (holistic Content approach), also consider 'Form' (tragedy or comedy) – how individual deals with or describes and reflects on event e.g. solution focused, stoic.
Stage 3	Examine findings across stories – similarities or differences between young people's stories (Categorical approach)

Figure 7: Stages of analysis of young people's stories

In stage 1 each young person's story is broken into sections to assist the researcher in understanding and summarising the account. The following is an illustration of stage 1, and captures the key elements of the story told by one young person excluded from school.

#### Stage 1 EX 1 is a 15 year old girl who has had a turbulent home life. She has a mother, sister and 2 brothers. Her biological dad is gay and she has Background lived with her mother and step father in violent circumstances. She describes a happy childhood but difficult teenage years. **Epiphanies** Difficulties in managing her emotions moving into her teenage vears Relationship with mother (mum could not choose between violent partner and daughter) Step dad's domestic violence and unpredictable behaviour Being hit by step father (also offensive verbally) Biological father's sexuality Intermittent residential care and movement between different carers School changes / change of friendship groups and bullying Overdoses (specifically final attempt) – Wake up call School Exclusion Being able to stay permanently with her Nana Initial impression / This young woman has matured through exposure to very difficult and assessment challenging circumstances She takes responsibility (on reflection) for previously poor behaviour She recognises that pressure from her peers has lead to at times her own poor behaviour She has strong negative feelings about the use of illicit drugs and alcohol (having lived with a step father who used cannabis and alcohol) She is non judgemental and is accepting of her dads sexuality but expresses difficulties associated with this. She has experienced residential care, movement between parents and schools. She has built an incredible amount of resilience over time, although in low times overdoses were the chosen option Makes friends easily Self-descriptions Quick Tempered Feels 'stupid' having taken overdoses Felt 'stupid' getting excluded 'It's hard to know that I have been so evil'. Now – 'Happy go lucky 15 year old teenage girl who wants everything and is very demanding. I don't get everything I want but I like to try'. Personal Outcomes / Very little participation around exclusion or even later decisions in her impacts life around her care – feels she could share her views one to one with re integration officer. Through previous peer support training feels she could help others (has supported cousin regarding suicidal feelings). Service outcomes / None revealed as very little opportunity to share voice impacts Close to girl in residential care (similar experience to EX2) Relationships and Residential care officers (2 specific people mentioned as important) significant others Nana and granddad are straight with her and praise her and have

	provided a stable and permanent home life after many moves.
Relationship with Key worker(s) – links to support needs	Very positive view of Re integration Officer (key worker link for this research) even though she has not had a huge amount of time with her – trusts her.
Aspirations	To get GCSE's To get E2E (Education to Employment grant) and move to A levels at Newcastle College. To be a Residential Care Officer
Additional researcher commentary	The fact that her mother could not choose between her daughter and her boyfriend (now regrets the way she has treated her mum!) Endless moves / fraught and uncertain home life Knew overdoses would lead to an action (reaction) and an offer of support. However, got a 'wake up' call when finally hospitalised and very ill on last attempt Regrets being excluded from school Feels she and her family should have been given more chance to discuss exclusion
Stage 2 – Analysis of epiphanies within story	Many of the negative family relationships and circumstances could be linked to her behaviour at school, and her subsequent exclusion. Very little opportunity to express her feelings and state her views which may have sequentially worsened her behaviour and impacted on the next negative event.  Living with her Nana has introduced some stability and a first opportunity to properly reflect on her circumstances.
Stage 3 - Examine findings across stories	Limited opportunity to share her views and thoughts particularly regarding her exclusion and also her social placements. Limited opportunity to share and debate collectively with others in similar circumstances.

Figure 8: Analysis of young person's transcript (YPEX 2)

Each young person's narrative has been broken down in this way (Appendix 6). Finally, an analysis of the epiphanies, and cross story considerations are made. In stage 2, analyses of epiphanies within story are important in relation to the rest of the story (Holistic Content approach). Denzin (1989, p. 33) defines experience as 'the individual meeting, confronting, passing through and making sense of events in their lives'. Expressions of experience come in many forms and problematic experiences are called 'epiphanies or moments of revelation in a person's life'. He suggests as these are shared and expressed, data are formed.

They are often moments of extreme experience and he suggests that they come in many forms as stated below:

- A major event, which touches the very fabric of a person's life
- A representative event, which signifies eruptions or reactions to experiences which have been going on for a long period of time
- A minor epiphany, which symbolically represents a major, problematic moment in a relationship or a person's life, and
- Those episodes whose meanings are given in the reliving of an experience.

Narratives are useful for studying transformations and transitions in people's lives. Analysing epiphanies, these significant moments, has been important in analysing the young people's stories in this research. They have enriched the accounts, and have firmly contextualised the stories told in their real worlds.

It is also important to consider the 'Form' (Comedy or tragedy) (climax or turning point in story) – both may be relevant to the content and analysing the way the young person tells the story. Such analysis also highlights relevant personality traits which may increase young people's ability to participate, e.g. tragic events told but turned into positive experiences. An example is shared in Chapter 8 as a Young Carer speaks of her negative childhood experiences of school and how she has the ability and resilience to reflect positively on the experience.

Many of the young people describe very difficult circumstances but are stoic and resilient, and in many ways expose a drive which is unexpected. This drive to change, help others, move out of one way of living into another, are all factors which enhance their likelihood to share their voices and take part. Key events or epiphanies expose changing points. These are often both emotionally and sometimes physically needy times and may create drivers for action. Analysis of the epiphanies, whether words, phrases or sentences forces the researcher to explore the concept or issue and challenge assumptions and assign meaning to them (Strauss and Corbin, 1990).

Most important in this analysis was making lateral links between the five main objectives or areas of analysis, for example, considering the context of the young person's life in relation to the impact the participation had on their lives. The

simplified linear process moving from individual analysis of stories to cross story analysis (Stage 3) is demonstrated in Figure 7. In reality the analytical practice was not straight forward, and required a great deal of re-reading and cross checking.

# 5.3 Using a mixed method approach

Within this research narrative analysis is primarily used to make sense of the data generated through the story telling method. Development of an analytical strategy to prevent distortion, improper or under representation of the data was an important personal and research consideration. However, as a direct result of some of the research / practitioner tensions shared above a mixed method approach was originally adopted. Initially thematic analysis was used to broadly analyse the text. In essence 'thematic analysis' involves open coding of data, it builds a set of themes to describe the phenomenon of interest (Strauss, 1987). Those themes may emerge from the researcher's a priori interests, from the data itself or a mix of both. In this research the latter was applicable with specific areas of focus dictated through practice needs and naturally emerging themes important to practice exposed through the data. For example, many of the key workers have highlighted both a lack of managerial understanding of the nature of their work and the high level of professional and emotional support required but generally not available to them. This emerged during their sharing of a broader experience of participatory work. When Key Workers are asked prior to telling their stories how they would describe 'participation' and 'advocacy', some have struggled. However, they naturally define both terms through their stories, but their stories sometimes contradict their definitions or the views given to the direct question. In essence the researcher is able to answer the initial question posed, but a new set of data emerges i.e. the lack of clarity of the role of some of the workers. These broad themes can be taken into practice and may well make a difference.

As a practitioner / researcher thematic analysis provides a fairly prompt analytical method. It allows the researcher to answer very specific questions and gain a broad understanding of issues, and then provides data in a way that is useful and easy to report in practice. Adopting this method originally extended the analytical process but allowed some key concepts to be shared in practice which provided an arena and focus of debate when developing children and young people's participation standards in practice.

However, given the researcher's philosophical stance and value base to preserve where possible the accounts and to expose the true human face of the stories, the limitations of thematic analysis were considered. Thematic analysis can lead to data being decontextualised by 'cutting and pasting' themes together and thus producing 'broad' categories and therefore a broad understanding of the issue in question. By decontextualising the data it is possible that the original meaning is lost. As the researcher was committed to keeping the data as true to the original source as possible, advancement of thematic analysis was essential.

Figure 9 demonstrates the complex nature of analysis where competing tasks exist. The researcher is in the centre with the raw data available for analysis and with a personal interpretation already underway. As a researcher in practice the real lives of these young people are exposed through the research itself and the key workers and young people's accounts coupled with the contact the researcher / practitioner has with professionals in day to day work. The researcher's interpretation is influenced by many external factors, none more important than the context of the research itself. Where has the interview taken place? Does visiting the person's home rather than the young person attending the researcher's office impact on the impression and interpretation made?

Within the story telling process many levels of analysis are evident. As a researcher aiming to collect data in context, value is placed on the language of interaction. The personal and social meaning the storyteller shares is considered

within each account. The context of the lives exposed and how these are shared forms a backdrop influencing interpretations and understandings.

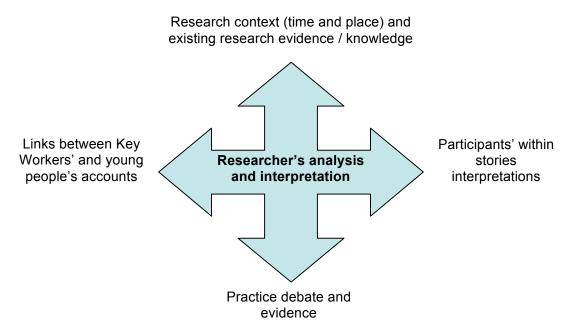


Figure 9: Expression of the relationship between practice and research

There is an acceptance that the story told is an interpretative account, and that the individual is the primary sense making agent. Within the process of telling and listening there is a convergence of the researcher's and the teller's understanding through the dialogue. What he or she shares in the next telling might be different and may be interpreted differently, and will be dependent on the audience and the recipient's position.

The words narrative and story telling are often used interchangeably but both Denzin & Lincoln (1998) and Frank (2000) argue their difference. Denzin and Lincoln (1998, p. 155) states that 'Narrative is both phenomenon and method', and that whilst people 'lead storied lives and tell stories of those lives' it is the researchers who 'describe such lives, collect and tell stories of them and write narratives of experience'. Frank (2000, p. 354) suggests that people tell stories

but that narratives come from the analysis of stories. To a certain extent this is true as the researcher has a particular focus in analysing the story to help answer the research question. However, it is the researcher's belief that as stories have been retold in this research, interpretations are evident at numerous levels. Often the tellers informally attempt to analyse their own stories en route, before the researcher has a chance to contemplate doing so. This appears not to be calculated and deliberated but a natural part of speech, self analysing and justifying comments made, and giving further meaning to the information shared.

By using the additional method of narrative analysis, a new set of data emerges. For example, in analysing the young carer's story, the pause demonstrates difficulty in discussing aspects of her dad's illness initially. She also starts to highlight the stigma society places on individuals with mental health problems as a justification for his actions.

"He does not work. Em, I don't think he can now. But I think he could of [have] done, even when he was not [long pause]. Do you know what I mean? Like em, I think he kind of doesn't want to, and I know there are loads of stigmas in society that these people who kind of live off benefits because they cant work, well that's basically what my Dad did. Em, he thought because, like he had a mental health problem that he would not be able to work, do you know what I mean?" YP YC Lines 122-127

Narrative analysis begins from the standpoint of the storyteller and helps contextualise the sense making processes by focusing on the person rather than on a set of themes (Riley & Hawe, 2005). This helps provide an in depth understanding of the key events which may have impacted on an individual's desires or ability to participate in and influence services. Riley and Hawe (2005, p. 227), suggest that the 'Researcher's role is to interpret the stories in order to analyse the underlying narratives that the story teller may not be able to give voice to themselves'. Within the stories people tell are stories within stories, each one often organised in terms of an 'epiphanal moment'. The researcher actively searched for epiphanies within the young people's stories. During the listening

and active engagement with the young people it immediately became apparent that key events and experiences had often influenced their decision making.

Within the story telling method complex levels of interpretation and analysis occur for both the teller and listener. Some views, feelings and interpretations are held (internalised soliloquies). As individuals move into comfortable conversation, they emotionally relive the story and move into 'narrative flow'. At this stage specifically for the story tellers a huge amount of clarification and justification takes place (self interpretation), and these act as an informal but highly important first level of 'in story' analysis, which will and has impacted on the researcher's own interpretation of events.

Narrative inquiry provides in-depth understanding of the issues from the stand point of the teller and highlights the complexity of lives. This is particularly important to capture when researching marginalised / vulnerable children and young people. These young people's lives do not fit the 'norm' and therefore presenting issues in context is essential in order to fully understand them.

The benefits of narrative analysis are that it allows one to make sense of the data in context – through the storyteller's interpretations and subsequent actions. Story telling techniques allow the person (the researched) to tell what is important to them. The researcher can then analyse what is discussed? What is left out? How people talk about events? What changes in time? It may reveal tensions, epiphanies (key drivers or events influencing the individuals thinking / actions), past histories and future possibilities. For example, the young man who was excluded from school had no concept of participation and involvement work. His inability to share any examples demonstrated that he had not been involved in sharing his voice at any meaningful level throughout his experience of being excluded.

Narrative methods give the teller the freedom to express 'what you want when you want', which may lead to some unanswered questions where no boundaries or guidance are given. As an analytical model there are limitations, the time and effort in analysing individual stories often restricts studies from going beyond reconstructions and comparisons. This results in strong 'in story' analysis, and weak 'cross story' analysis (Lieblich, 1998).

The process and model offered by Lieblich (1998) as described earlier in this chapter have offered a direction and process useful to this research and have prevented the researcher from losing her way through the huge amount of data generated.

#### 5.4 Validity

Determining whether the data and the interpretation are valid is a difficult and problematic task with the potential for stories told to be recounted differently each time. There is a gap between the experience of the person and the communication about it. The longer the time between the experience and the telling, the more reflection and interpretation of events is possible. Questions regarding whether the stories are 'truths' arise. A basic claim underpins narrative research, that there is no static or everlasting truth. There are different subjective positions from which the world is experienced and interpreted (Moen, 2006, p 7). Denzin (1989) suggests that during the telling and the interaction between the teller and the listener, the real life event moves to fictional statements about real lived lives. What is important is not what is told, but how that story is interpreted, and to what extent that interpretation is a true reflection of one or many stories.

Riessman (1993) suggests that there are no one set of rules for interpreting narratives, but recommends that the researcher describes how interpretations are produced, and makes visible the analytical process. She also suggests that primary data should be made available for others to view.

Giorgi (1992, p. 119 -135) suggests that it is legitimate to return to the 'subjects themselves for confirmation or denial of the authenticity of the data or using

external 'judges' to test the validity of findings'. In this research the participants were offered a copy of their transcripts and an opportunity to add to, retract or modify utterances. Some but not all of the young people requested their interviews; no young people chose to alter their accounts.

The key workers were asked to join together through practice based action learning sets to consider some of the researcher's initial and early interpretations of the data. Although these deliberations are not reported within this research they did have an influence on the final interpretations, as data were further debated, and discussion increased the researcher's understanding of the issues. Without a co-researcher to assist in the analysis, the practice based Participation Operational Group (POG) discussed in section 5.2, acted as a form of external validity as it was here that many of the researcher's interpretations were taken and discussed. In addition, members of the POG sub group writing the participation principles helped verify and discuss findings. The Trust's Research Manager also helped confirm selected findings prior to conference presentations.

In sharing the practitioner / researcher issues in this chapter alongside the process it is hoped that the reader will understand how the researcher has made sense of the stories within the context of this research.

In Chapter 6, the levels and methods of participatory practice are exposed and the first stage in analysing the key workers' narratives is described. Early findings are presented which assisted the researcher in understanding how the concept of participation and advocacy was understood by the key workers.

# Chapter 6 - Level of involvement and participatory work

#### 6.1 Introduction

In helping to understand 'How marginalised young people can be assured meaningful, fulfilling and positive experiences when sharing their voices through participation' it was important to map and analyse present practice. The research objective to determine how the Care Trust presently involves marginalised young people in service planning and delivery with their key partners' was explored through the key workers' interviews. The key workers are involved in a wide range of participatory activities with marginalised young people and are therefore in a good position to reflect on present practice and methods, and can highlight positive and negative outcomes through direct experience, and alongside the young people can expose constraining and enabling factors.

Within this chapter findings of the level and methods of involvement and participatory work are presented through

- the direct completion of the Public and Patient Involvement Proforma with key workers
- the key worker narratives, and
- the young people's narratives

Initial analysis of the proformas and narratives also expose how the concepts of participation and advocacy are understood by the key workers, although this is explored further in Chapter 7.

# 6.2 Mapping model explained

The researcher needed a simple method of capturing the key workers' experiences of participatory work with their particular marginalised group, which could be quickly explained and completed during the broader interview. Prior to the study, the researcher had been involved in helping a Trust within the same region map present participatory and involvement work. At this time the Office of Public Management produced a useful practical guide to public and patient

involvement called Signposts (Office of Public Management, 2001) with the National Assembly for Wales. The document offered a useful tool to map out (baseline assessment) and 'performance manage' involvement work in and across agencies including local authorities. The tool once explained to completers helps offer a common understanding of what the term involvement means. The interviews with key workers in this research started by establishing what they understand by the terms involvement and participation. Completion of the tool thereafter helps them further understand the concept. This proved useful in ensuring that both interviewee and interviewer were working from the same broad understanding as progress was made through the narrative interview.

The tool seemed appropriate for use in this research because it spanned public and not just patients' involvement, was useful for NHS, Local Authority and voluntary sector organisations and was fairly straight forward and easy to understand.

In the signpost document the 'main dimensions of public and patient involvement' are described. The 'individual' dimension relates to discussions and decisions concerning the person's own care or service requirements. The collective dimension relates to the public's decisions concerning delivery or planning of services. At both an individual and collective level there are many degrees of involvement that 'reflect a spectrum of engagement' from information giving to influence as shown in Figure 10. Blank forms were used and completed with the key workers as they described different ways in which they had involved the young people they worked with. In Figure 10, examples of initiatives from teenage pregnancy workers' interviews are linked to the dimensions. In Appendix 3 the completed proformas from the key worker interviews have been combined by area of vulnerability e.g. both key workers' examples of participatory practice for travellers are merged onto the same document, teenage pregnancy workers' documents have been merged and so on.

Teenage Pregnancy	INFORMATION	FEEDBACK	INFLUENCE
INDÍVIDUÁL	Face to face information given about a range of services	Sexual health clinic forms - complaints procedure and suggestion box	Help structure Sex and Relationships Education (SRE) lessons
	YP directory of services Leaflet - Sexual Health Services Contraceptive service advertising	Sex & Relationships Education – Q & As furry box- Write any Q or worry to guide the lesson	Young people designed evaluation form, and confidentiality statement
COLLECTIVE	Galaxy Radio / SH Media group / Website (feedback on services) Young person's confidentiality statement	Comment on HIV / AIDS leaflets – check level of understanding & aesthetics  "Sex in the Country" – Consultation in rural areas with teenagers - Barriers and fears to using services	Influencing, Interviewing procedure and recruitment  Mystery shopper initiative in General Practice  Action being taken in school. Meeting to implement - Young people feed back to professionals

Figure 10: Main dimensions of public and patient involvement – linking teenage pregnancy initiatives to the key dimensions

Finally, the 'signposts' framework is linked to performance management and in Figure 11 examples of possible outcomes are stated. In the Signposts guidance (Office of Public Management, 2001) examples of participation shared are generally patient orientated and outcomes shared are primarily service outcomes, which ultimately impact on patient or public satisfaction. However, the model can still be successfully used in mapping out participation across agencies irrespective of whether the relationship is a health one or a duty of care one as with young people in the Looked After System.

In this research whilst service outcomes have sometimes been shared and are important, the emphasis is on the impact of participation on the individual. The impacts of participation including the outcomes for the young person are shared in the stories told in Chapters 7 and 8, and are summarised in the Conclusion.

Teenage	INFORMATION	FEEDBACK	INFLUENCE
Pregnancy			
INDIVIDUAL	Face to face information given about a range of services  YP directory of services	Sexual health clinic forms - complaints procedure and suggestion box	Help structure Sex and Relationships Education (SRE) lessons
	leaflet Sexual Health Services	SRE – Q & As furry box- Write any Q or worry to guide the lesson	Young people designed evaluation form, and confidentiality statement
	Contraceptive service advertising		
COLLECTIVE	Galaxy Radio / SH Media group / Website (feedback on services)	Comment on HIV / AIDS leaflets – check level of understanding aesthetics	Influencing, Interviewing and recruitment
	Young person's confidentiality statement	"Sex in the Country" – Consultation in rural areas with teenagers - Barriers and fears to using services	Action being taken in school. Meeting to implement - Young people feed back to professionals
	Improved	Service improvement	Appropriate staff
OUTCOMES	understanding of service provision	and development Increased confidence in sharing views	appointments agreed by users of service
			New skills in interviewing

Figure 11: Outcomes linked to examples of participation with young people regarding sexual health

# 6.3 Findings from mapping exercise

Within Appendix 3 the completed dimensions of Public and Patient Involvement proformas are presented and as a whole demonstrate a wide range of participatory activity across all dimensions. However, when analysing each individual form representing each of the marginalised groups, it is clear that the level and nature of involvement varies considerably by group. Findings from the mapping exercise are presented in the next section by firstly observing differences between individual and collective participatory activity, and secondly

by examining the degrees of participation from information giving to decision making.

The codes (Quote referencing) linked with each quote are shown in Appendix 4.

#### 6.4 Individual or collective involvement

Whilst it is essential for young people in marginalised groups to have an individual voice in determining need and care, the collective voice of groups of young people has greater power to influence change in and across services. It was therefore important to scrutinise the degree of individual and collective work undertaken.

Work undertaken across the dimensions with young people 'excluded from school' is primarily at an individual level. The majority of work is undertaken one to one and involves assessing need and discussing options. A small percentage of the young people excluded from school go to programmes run by a local college or to a group set up in a community resource where they learn together but have very limited chance to participate in sharing their views as a group. The group work tends to be education focused albeit via flexible learning and is not related to their experiences of being excluded. This focus of participatory work at a one to one level further isolates children who have already been removed from their peers because of their behaviour, and may further impact on their self esteem and confidence as an important social network is removed. The key worker interviewed does her best to encourage learning in groups and where possible involves children in building their self esteem and confidence. One key worker describes a struggle to bring young people together in a group almost exclusively due to lack of suitable venues and funds to support this. She also further describes how this leads to little ability to share and celebrate good individual work and effort. In school, work would be displayed and praised offering discussion and incentive. For these young people work is in isolation to others and is often home based and as such is rarely shared with others.

The key worker actively works to develop methods to acknowledge the student's self worth and progress, and had developed a booklet as follows:

'Well, what, the aim of the booklet is really to get the youngsters to develop their own reflective processes about where they are going, what they have done. And it was to try and in-build some praise, because, em, a lot of them haven't had any praise for a long, long time. And so I am looking for ways really of getting someone to write something very positive'. KW EX2 lines 495-498

In observing the type of work undertaken with young carers it becomes clear that the nature of participation i.e. either individual or group is also strongly linked to social circumstance and personal desire to share. The young carers sharing their voices through the 'SORTED' service (a local multi agency outreach substance misuse service), and who care for parents who misuse substances, often remain in an individual situation with the worker. This situation appears to be due to fear, on the young person's part, of compromising his or her parent, fear of being removed from the home and a lack of awareness that they are carers.

'Em, getting these young people into groups has been quite difficult because they are very protective still of the life they live. And 'yes' they need to express themselves and talk about their concerns, and to be able to do that in a close environment, in a confidential environment where they know they are being supported. To get them into groups was quite difficult... Now I have developed groups of outdoor activities during the summer months that I got young people together with, and they thoroughly enjoyed it. But they were all very reluctant because these young people all came from very different backgrounds, from families where; you know their parents were working full-time; they had you know, all their needs were met within the family; but emotionally their needs weren't being met; to young people who were living in foster care because [of] their parents usage; some young people were living with grandparents, so very, very different right across the board. Now to bring these young people together and say you know, you are a group of young carers, it was, they really sort of resisted being titled that in the beginning.' KW YC2 Lines 201-218

Curtis et al (2004a, pp 168), highlights that young people can be excluded from taking part if they are uneasy or unfamiliar with the give and take of group or one-

to-one discussion, due to reticence about the problems that may arise out of the discussion. The above quote exposes the challenges faced by key workers in the positive promotion of group work, and in recognising possible barriers.

For other young carers where the work was a little more developed the participation had moved to a collective level with groups meeting regularly and their voices being shared through local and national conference presentations. Individual carers had also become involved in specific pieces of work such as leaflet design for the Trust, and journal pieces for National publications.

Young people's involvement in the travelling community tends to span both individual and group participation but strongly involves the parents in finding out about the work before allowing access to the young people. Therefore the participation is balanced between whole community and children and young people's participation. Both key workers interviewed implied that access to the young people is often a protracted process and that parents are very protective of their children, specifically in attending residential weekends. However, one mother initially present whilst her son was interviewed in the travelling community described this as a parent's natural concern to make sure their child is happy and safe. As a researcher previously unknown to the parents of the travelling children being interviewed, the mothers of both children chose to meet me first prior to interview. The children in this community were also however the youngest of those interviewed.

For young women who are teenage mothers and children in the looked after system the participatory work appears to be more advanced and diverse. This may be due to the statutory and strategic requirements placed on service providers working with these groups, which has resulted in greater investment in participation.

# 6.5 Information, feedback and influence

Mapping participatory activity across the dimensions from information to influence allowed for degrees and levels of decision making to be assessed, and in line with Hart's Ladder (1992), allowed for a general assessment of the degrees of power relinquished through the participation.

#### 6.5.1 Information dimension

Information is shared both verbally and through written materials being given to young people and sometimes their families and carers. In some services information is well developed and the production of information is through the direct involvement of the young people themselves.

'We have done the 'young people's directory of services' leaflet. We have done some leaflets for the psychosexual service and the GUM service information giving leaflets. We have been involved in doing a confidentiality rights statement leaflet where we involved; we did that with young people'. **KWTP1 Lines 119-122** 

Often this information is readily available and is displayed so the young people can pick and choose what they want to receive. However, where there are no common meeting places and limited group work, the role of information giver falls to the key worker. Exchange is often one to one and verbal. The key worker below, working with children excluded from school, talks of information giving and describes an advocacy role within her post and states:

'It's really getting all the information, making sure that the people know their rights, trying to get that person involved in some way. I mean for a lot of families and young people, schools are really scary places. You know, you go in and the, I mean people say 'ah yeah', even my role as a Reintegration Officer, and I find it really difficult working into a school myself. You have to be quite self confident and be able to really be quite skilled in dealing with people to function in school. And a lot of these young people have not got those skills. They find it really difficult and eh, and they either use, they become frustrated and try and act out in schools, em, because it's where they are coming from. I mean a lot of the time I find the young

people who are excluded, even though they don't say it physically, they do actually mourn not being in a school because it's the only structured place they know, but they have not got the skills to deal with that kind of structure. I think it is really getting families and young people more involved in the school and making them more friendly a place where it is quite comfortable to go in and comfortable to talk to people.'

# KW EX 1 Lines 73-86

Information giving for this key worker is primarily around ensuring the young person and family know their rights and can negotiate the system. She acknowledges the perceived barriers imposed by schools, and how challenging the school environment can be for parents and children alike, and sees the potential for development work here. Such perceived barriers impose real barriers on attempting to move participation from information giving into the influence domain.

Sometimes 'information giving' is about preparing individuals for the participation itself. This is seen by many of the key workers as essential to the engagement of some of the individuals they work with.

'Sometimes when we have wanted to involve young people in work, if they have been particularly marginalised young people like young mums, we have seen them on a one-to-one to explain what that process [is], to give information about what the process of participation would be like. So we have done that on an individual level, because to even bring them into a group at that point would have probably excluded them anyway'.

#### **KWTP1 Lines 97-106**

Often the young people are given information and support to prepare material for other young people and potential service users. Where a young person does not have the capacity or wish to be involved in a group efforts are made to help the young person to get involved as follows:

'[There] was one young person who again was very marginalised, who we gave some information to and he did a poster on service advertising

....That might actually be about influence. That was an advertised service'.

## **KWTP1 Lines 131-6**

Here the key worker is reflective and realises as she speaks that influence is also possible at an individual level. Other marginalised young people 'information give' via the sharing of experiences at conferences. Young carers and their workers describe how they share information about what it is like to be a carer in the hope that it might inform service providers of the challenges they face.

#### 6.5.2 Feedback dimension

Some feedback between the key worker and the pupil is seen on a one to one basis for children excluded from school but collectively there appears to be limitations. Again the key worker acts as advocate attempting to feedback and influence the relationship between schools and pupils. However, this is not about pupils or their parents having influence, this is about the key worker attempting to educate and influence schools to act differently.

'I find quite a lot, with working with exclusions that, it is so different across the county, the levels of tolerance through the schools. Em, and what I do is try ... to feedback... what other schools might have done in that situation and may be influence the decisions.' **KW EX1Lines 280 -84** 

Taylor (2005) highlights limited involvement of young people in the exclusion process and the key workers' accounts reflect this, but also a big variation across schools.

Work defined as 'consultation' tends to fall into the 'feedback' dimension and is usually focused on determining needs. The traveller community has been involved in a number of 'consultations'. Children trained in participatory research have sought community views through the 'Gypsy Joe from Mexico' Project (Wansbeck Council for Voluntary Service, 2002), and other initiatives. Although young people are involved in consultations, and key workers describe a feedback loop, young people's transcripts highlight a lack of knowledge about how the

findings are used. Whilst actions may be taken as a direct result of the consultation, vagueness by participants regarding outcomes may indicate a lack of feedback, as such young people are not always sure if they have had an 'influence'.

Service specific consultations appear to be more easily be translated into actions. For example, consultation with teenagers living in rural areas about sexual health services has resulted in the development of many outreach services. In working with teenage mothers and fathers the teenage pregnancy team also appears to evaluate consultation and service planning events seeking the views of those who have taken part in helping to shape services.

".... and just every time I have done it, it's about seeking feedback from them about how it felt being involved and just getting their views on what you are asking them, and what the process was like." **KWTP1 lines 50-53** 

Due to the unpredictability of the lives of marginalised young people, less is known about the impact of this involvement work on them. The very nature of their potentially complicated lives may well mean that the continuity of involvement in participatory work is interrupted. Young people may have moved on, be experiencing social change or difficult issues in their lives. This potentially can exclude them not just from the participatory event itself, but also from the follow up and evaluation when it does occur. Where marginalised young people have taken part it may lead to difficulties in assessing the impact on that individual, and difficulties in feeding back outcomes.

#### 6.5.3 Influence dimension

Children excluded from school appear to have little influence in changing systems and structures, and again are totally reliant on the key worker to advocate on their behalf.

'Well, what I do is, em, on an individual basis I will feedback to my line manager. What I used to do was, em, I used to compile a report about all the things that were happening and then look at what happened after, after they had left school and how that impacted. And then do statistics about who got back into school, what they are actually doing. And one year I found out that there was only about 16% had not gone into full time education from exclusion, or got a job, or gone onto a course. There was only 16% and they wanted me to compare that, it's all the time being able to do that and the time it takes. To be honest I became quite despondent with the whole thing and I am starting to collect information again this year, but there are lots of things within the system that I am not very happy about myself personally because of like, I feel that the young person's voice is being lost. And that because of what we are doing, is not meeting a lot of their needs, where we seem to be shoving them here, there and everywhere without that proper follow up and that's part of that, the collective information is not getting passed on, it isn't being utilised.'

#### KW EX1 Lines 444-457

This view is borne out when observing the participation map. Very limited information was offered by key workers working with excluded children to populate the collective dimension and there is limited information shared in the interviews to suggest that children, young people and their families have an arena for feedback and influence. Where information is shared it tends to be specific to work professionals are doing, rather than direct participation of young people excluded from school. If advocacy is legitimately a form of participation, this could be a strength in this area, but with key workers' passion compromised, sharing issues of concern to support change for these young people appears flawed.

Conversely, the teenage pregnancy team appears to involve young people in many decision making activities, and it is clear that some of the work crosses marginalised groups. Teenage mothers and looked after children are involved in policy scrutiny, design and change relating to sexual health. Teenage parents are regularly involved in action planning to guide the work of the teenage pregnancy team, although it is not always clear the weight afforded to their views against that of a professional group.

Involving young people in interviewing key workers has become a regular and important activity, and all groups with the exception of those excluded from

school appear to be involved in training and then interviewing. Young people and key workers express varying degrees of influence. The following conversation illustrates these concerns.

**KW:** ...most of the staff in the teenage pregnancy team has been recruited by young people.

**DS:** So they are involved in the selection process and the interviewing process?

**KW:** Yes. Depending on the nature of the post, depends on the nature of their involvement. You know like sex education we have had to facilitate group work activity with the young people who had a scoring criteria of how they did that, but then for the young mums post the young mums were actually on the panel and had agreed questions and

**DS:** Brilliant. And did you evaluate how they felt afterwards?

**KW:** Yes we got some feedback. There were two young mums and we got some feedback off them and the things that were helpful were the people who were using language that they understand. They found the process helpful cause they had to research their own questions to find out what were ideal answers. And so one of them focused on child protection which was well researched, whether it was right to smack, so lots of things came out of that.

KWTP1 lines 476 - 494

Whilst the dimensions described above are important in achieving a better understanding of the nature of involvement, other factors influencing fair access to participatory activity have emerged and are described in section 6.6.

## 6.6 Representative / inclusive participation

Beyond the variations in levels and types of participation by sample group are issues of representiveness and access. In a large county with six district councils and a range of geography from urban to rural, involving young people poses a challenge in terms of offering opportunities equitably given the practical and economical difficulties. Sometimes this results in key workers focusing in on those most signed up to taking part.

'I mean my biggest concern is that, because Northumberland is such a large county, we have 6 area offices. it's very difficult to include everybody from across the county..... I think a lot of people are aware of what we are doing but we tend to, because of the spread, tend to go to where we know we can find it, and that's not the best, that's not the best way forward, and I am aware of it and I am trying to do something about it. So trying to think about how we can develop things up in Berwick for instance, that would do Berwick and Alnwick together maybe, and something out in the West. So that we can feel that the young people in those are more included in what's going on'. (KW LA2 Lines 683-697)

This difficulty in terms of practicality is emphasised across all sample groups, but appears particularly problematic when working with LAC.

'So if we were considering a person from, I will keep saying Berwick because that this the furthest point north, because if you were considering someone from Berwick to be part of the peer education group then you really would have to have the commitment of the worker to ensure that it happened. You know their care worker to ensure that it happened. It is probably less of a problem for Berwick than it would be for, if you choose someone in Alston where ....Which is as far west as you can go. **(KW LA2 Lines 814-823)** 

Whilst access to participation through geographical barriers is highlighted here by a key worker, key workers' narratives in section 7.2.1 also expose access restrictions, where the key workers themselves select young people into group work.

## 6.7 Critique of the model and mapping tool

The Signposts (Office of Public Management, 2001, pp 8-11) model has a clearly explained standardised format for mapping public and patient involvement work. Mapping out the ways in which participation presently takes place visually highlights levels of high and low participatory activity and as such also helps to highlight areas of possible improvement and an appreciation of conceptual versus practical application. Use of the mapping tool in this research has helped demonstrate the repertoire of methods used along a continuum. It has helped the

researcher establish that democratic and proactive community development methods are primarily used when working with marginalised young people. These are crucial to sustainable involvement but more importantly for marginalised young people to ensure they have high degrees of control throughout the process.

Once interviews started and the mapping of the work described by key workers began, problems in knowing where to place the information shared onto the framework arose. The model only works if participants are perceived to start at the same point i.e. all people feel comfortable to take part and have the skills and knowledge to do so. In re-listening to the key workers' tapes and re-reading the narratives it is clear that the 'information' dimension creates uncertainty for key workers when attempting to map the work undertaken with marginalised young people. It appears that involvement via information giving is much more complex with marginalised children and their families, than simply giving out a leaflet about a service or what to expect from care. Involvement in consultations and surveys or access to procedures about complaints is not straight forward. For these groups of children and their families often the key workers describe a huge amount of community development and relationship building that must take place before they enter in to any participatory work. For example, handing out a leaflet about services in the travelling community may be met with distrust where no previous relationship has been established. As a result key workers undertake huge amounts of work prior to any traditional information giving takes place.

The information dimension ideally needs to be split in two when mapping out work with marginalised groups. A new dimension labelled 'Preparatory Stage' spanning the individual and collective work needs to be added to reflect a different type of information giving and the support needs of these communities of young people. This new dimension could hold participatory activity demonstrating preparation and readiness to engage. Much negotiation, trust building and mutual understanding is often required prior to participation taking place. Much of this effort is aimed at building capacity within communities.

As the key workers describe through their narratives, their roles and their relationships with young people, an intrinsic learning style emerges. Much of the participatory work focuses on the building of life skills to get the young people to a point at which they feel comfortable and confident enough to share their views. There is a sense of each of the key workers getting to know their communities and the young people in a broad sense (acknowledging the needs of that particular community) and a more personal sense, through both their participatory work and through the necessary advocacy role that naturally develops at an individual level. The preparatory stage and the role of the key worker are explored further in Chapter 7, as are the individual and collective methods, opportunities and barriers to participation.

# Chapter 7 - Key worker's narratives

'I always think of the young people I work with as onions really, they are not like apples, which a lot of non-looked after young people are. Ours are much more complicated with lots and lots of layers to them and you have got to peel the layers off to get to the centre.

#### KW LA1 lines117-119

#### 7.1 Introduction

Key workers have played an important role in helping to understand the complex lives of the young people and the ways in which they are able to share their voices.

In line with the research objectives, key workers' narratives have helped establish the following;

- An improved understanding of the cohort with which they work
- An understanding of how key workers conceptualise participation
- The attributes required to promote and undertake participatory practice
- How they use this information from participation to influence practice and service change.

Each interview encounter also presented an opportunity to explain the role the young people would play in the research. Key workers were also asked to identify individuals who they thought would be suitable to be invited to participate.

In the following chapter the emerging themes generated from the analysis of the key workers' stories will be shared. The four areas of focus are then examined separately. They are however, interlinked and interrelated by their very natures. The ensuing account will explore links.

The codes linked with each quote are shown in Appendix 4.

# 7.2 An understanding of the cohort

Each of the key workers selected to take part in the interviews actively worked with young people from one of the sample groups i.e. Teenage mothers, young people from the travelling community, young carers, 'Looked after Children', or children excluded from school. They were therefore in a unique position to help improve understanding of the nature of the lives of the young people within these cohorts. Goodley (1996, p 337), states that 'stories not only present the subjective definition of a situation, as accounted for by the tellers, but they also highlight the social constraints upon each individual'.

Exploring the complexity of some of the described lives, examining the role that key workers play and methods used to engage with the young people helped raise awareness and understanding of the cohort under scrutiny.

Whilst the researcher had no illusions about how difficult some of those lives would be, the degree of complexity of many of the young people's lives were clearly described by the key workers and at times appeared extremely complicated. Knowledge of the complex context is important to fully appreciate the shared experiences of the young people and the personal impact that sharing their voices had. Exposing some of the complexities is also important practically in the development of participation standards (See Appendix 5); a task which the researcher was also involved in during the course of this research. With participation standards aimed at providing quality participation for all children and young people in Northumberland, it was important to recognise the challenges of working with children and young people in more complex living circumstances.

Understanding the way these young people live or have lived their lives helps practitioners put in place standards of good practice that acknowledge difference and diversity within the population. As one key worker stated during the interviews 'How can we know if we have not been looked after what it's like to be looked after' (KW LA1Lines 426-7). Another speaks of losing her 'middle

classness' and ignoring the negative attitudes of others towards the young people, in order to work with her client group (KW EX2 Lines 226-232). It is important that analysis is based on reality and recommendations are made after consideration of the context of the lives of these young people. The key workers help to paint a picture of the lived experience and therefore expose participation in context. Many methods are limiting in understanding social life and lives, narratives expose them (Riessman, 1993).

# 7.2.1 Exposing the complexities

The complexity of the young people's lives became increasingly apparent with each of the stories told. Whilst the young people were selected due to their potential to be marginalised, the key workers exposed the numerous complexities resulting at times in high levels of vulnerability; a key factor in justifying the need for continued high levels of participatory engagement with this group of young people. The following are examples of the young people's lives described by key workers interviewed.

The professional working with young carers of parents who misuse substances describes the family circumstances of the children and young people she works with. She emphasises clearly the complexity of the life of a child referred for support whose parent is a known drug user.

'... It's very different for every young person I work for. I would say my role is quite different and it's very geared around their needs. I don't just do specific work on, I should have said earlier, on em, substance use. You know, having a parent who is using substances and the impact on that. On top of that sits hand in hand mental health. Because, that came out very quickly that mental health, with the adults, is sitting very closely to substance use...Em and domestic violence on top of that. So I had to very much develop three programmes of work. One is for mental health, one is for domestic violence, one is for simple, I say simple, but you know, substance use in the family. And so each individual may be doing on a one-to-one they could all be doing quite a different programme with me... Depending, its all you know, you bring in the self-esteem a lot, solution focused work, but you have to gear it towards what are their needs at the time. **KWYC2 Lines 463 – 482** 

The 'Education Other Than at School' (EOTAS) teacher working with some children who have been excluded from school describes her week and the nature of the children accessing each session. Firstly describes the range of reasons why they may have been referred.

'...For a whole range of things; often aggression, violence, [a] composite of masses of problems in their lives. And I have a lot of youngsters who are in the year 9, 10, and 11 bracket, who have eventually fallen out of the school system because they can't cope, their behaviours can't be managed in school. They have done something that's pushed them too far. Or there is a medical needs group which is either the physical medical need and we have a great deal of youngsters who have mental health problems, phobias, em, compulsive obsessive disorders, co-morbidities of all kinds, just generally are very, very wobbly about going to school.'

**KW EX2 Lines 24-31** 

The teacher continues by describing some of the additional social and health problems facing these young people. She clearly describes the diversity of problems faced by the young people with these often sitting alongside a lack of opportunity resulting in a lack of experience of everyday living that many of us take for granted.

'So, I have got a group on a Monday which runs from 10.00 – 3.00 which is for excluded youngsters, em, that works with 2 staff, so at any one time we can have 6 kids and 2 staff there. On a Tuesday I have got 2 lovely tutors and I also teach in that group as well, who are looking after the 'vulnerables', what we call the 'vulnerables group'. So these are youngsters who em, feel very socially isolated, may not have been to school for a very long-time before a referral has come to us, em, have suffered with anxiety, perhaps some self-harming. Em, I have got one young lad who em, was abused by his step-father and went in to care for a time and then needed a lot of support to come back to live in \*\*\*\* and he's absolutely flourishing, loves it. And then on a Wednesday I have got the Middle School Group, which at the moment has only got 2 youngsters in, we did have 3, but they have both got ADHD and are on the autistic continuum and I have done loads and loads of out and about work with them this term. I have taken them on the Metro, I took them on the ferry, they have been to the Life Centre, they were at Warkworth Castle and Warkworth beach. They have never skimmed stones, rolled down sand dunes, paddled in water, never been on the Metro, never been on a boat in their lives, never been on a school trip.

KWEXCL2 Lines 52 - 66

Through the narratives the social isolation, the immensely challenging mental health issues start to emerge, exposing the complexities of their lives. These complexities present a concoction of difficulties for the key workers in helping the young people to become engaged, which results in many of the professionals emphasising the need for one to one participatory work. Many state that often individuals in their cohort never move to the collective or group setting to share their voices. Due to these complexities key workers need to be careful about who they select to take part in group participatory work. This can lead to the key worker becoming the gatekeeper regarding who will take part and share their voice and who will not. Whilst the reasons are professionally sound, for example concern for, safety, readiness and ability to be part of a group, it does limit opportunities for some young people.

KWLAC1 explains why she must be selective about who attends events, and in particular who attends residential weekends.

'So you have got to have, em, all the back-up in place, so it's about being fairly meticulous in what you are doing to make sure everybody is safe, emotionally and physically safe.'

**KWLAC1 Lines 806-808** 

'Yes, because they, em, have been involved in lots of risk taking behaviours etcetera. And we had to make sure that they did not run off or, not that we kept them incarcerated in anyway, but you know you have to really be quite selective.'

**KWLAC1 Lines 827-829** 

For the young carers the selection is less about risk taking behaviour and more about the young person's capacity to take part.

**KW:** ... from the one-to-one I have to very much look at who would work within a group, and who would not, because some, some of the young people, I have to say, would not be able to work within a group, would find it quite difficult and the one-to-one work for them was the ideal work for them.

**DS:** So do they all get the offer?

**KW**: They all get the offer. Em, I have to say there was one young boy that I could not give the offer to and that was very much looking at his own needs ... because he was very much referred because Mam's a heroin user.... Very quickly when I was working with him, I realised this boy had some quite severe learning needs that haven't been addressed because he had not been going to school because of Mam's inability to get him to school, and em, some quite strong needs in as much as his mental health issues as well. So, from that, he has now got a diagnosis of ADHD. He is on medication, so from that, from working with this young boy I realised very quickly he was good on a one-to-one, but there was no way he was going to work in a group.

**DS:** So you are in essence being professionally selective about who goes into the group work situation?

**KW**: Yeah, I would say in most cases yes they are offered. But you have to be very careful, you know if it's going to work and you have to think of every individual within that group, you know, if it is going to work we have got to make sure it is right for everybody there.

**DS:** Absolutely,

**KW2**: ... And I would not place him in a position whereby, to put him in a group and then to have to withdraw him would be quite awful for that young boy, rather than just not putting him in that group at all.

**KWYC2 Lines 279-312** 

## 7.2.2 Individual participation (1:1 work)

The complexities explained above have led to a variety of methods of engagement with young people depending upon their personal circumstances. The second theme that emerged was the need to work 1:1 with the young people. As discussed briefly in Chapter 6, participatory activity with more vulnerable young people requires good preparation and planning. An extended

preparation time working with individuals emerges as essential in the building of trusting relationships, and in enhancing young people skills and confidence to be able to effectively share their views and feelings.

For some young people participatory work takes place as a one to one encounter as above, and remains that way where personal vulnerability is high. Additionally, the encounter can be a protracted one. Many of the key workers refer to the amount of time required to build up trust with either the community or the individual young person before they can ever consider a group situation. Work with Looked after Children often presents its own difficulties because many have lived very public lives, yet because of their fragile social circumstances they often do not trust adults.

'There is one young lady that I have worked with for 5 years now, and she actually now does not fall directly in my remit, but the contact has been maintained and it started off with a direct sort of one-to-one situation of her needing information actually around sexual health. Which in itself is a very sensitive area and given the background of these young people it becomes even more skewed and sensitive if you like because of their past experiences. And she ah, was typical in that she was very defensive initially and I built that relationship up gradually over a period of time and what, I think what strikes me of how the most bazaar things can be a trigger, may be that's not the right word, but unusual things and with her it was baking cakes. Which sounds odd but she was so good at baking cakes, that became a talking point for us and that's where the relationship started to develop, because I am pretty useless at baking cakes. So she was teaching me that, and that helped the relationship. That was the seed planted really and helped the relationship to develop which meant that the more, I suppose it was a two-way thing then, she felt she was informing me, and if you can understand this, because it was safe platform to work from. I mean, baking cakes is fairly innocuous, but she had those real skills and I was able to develop the relationship with her, albeit it was centred around how many eggs you put in, whatever, and that was the platform that we worked from. And the more that I saw her the less we talked about cakes and the more we were able to talk about her feelings and then her actions and then I was able to start giving her information. So it's about peeling layers off. I always think of the young people I work with as onions really, they are not like apples, which a lot of non-looked after young people are, ours are much more complicated with lots and lots of layers to them and you have got to peel the layers off to get to the centre.

The quote above demonstrates the length of time it can take and the methods adopted in building up trusting relationships. This narrative starts to reveal some of the essential skills needed when working with more vulnerable young people. Varied methods of engagement in the early 1:1 contacts stage are exposed in the key workers' stories. Using cakes and cooking as a way to engage young people may seem innovative and unusual but many of the key workers used the young people's interests in this way. The EOTAS teacher describes in her account a whole term's curriculum based on chocolate in order maintain interests and the relationship.

'But find something this youngster loves, like, I have done projects on horses, I did a term's work on chocolate once, I did. Poor old Craig [tutor] was doing one on game systems which completely did his head in, but this kid would only talk about games and x-boxes, and he [Craig] would take them around Blockbusters and you get their maths through "Well how much is this and how much is that".

...And design a new game, but you are going to do the advertising campaign, so it brings out their art work and their literacy and ...I did a whole term on chocolate, so reinvent chocolate, your art work was done on the design of the packages, you did data collection on what people bought and you generated your graphs on excel from that.'

(KW EX2 Lines 891-910)

Professionals working with travellers describe cultural issues which impose potential barriers to collective participation, particularly where integration with others communities is part of the process.

'But they are very reluctant to let their older people go into houses, the same, as they are very reluctant to let them go into hospital. Traveller's will wait until the very last minute before they let their children or their older people go into hospital and they won't let their children, you know how we might say we are going to do a team-build weekend away, or do something, they are very, very reluctant to let their children sleep out overnight anywhere...So if you went down on to the site and said, "We are going to put a fun weekend on and we are going to take the children to Light Water Valley, or Disney", you know, they would be "oh no", they would dreadfully hate that.

We tried last year, X and I were on a site at XXX with one of the 'Our Part Researchers'<sup>2</sup>, and we were talking to Y who is the Warden's wife who lives in the house, and she was saying the best way to do anything here is on the site, have a fun day on the site, bring the things to the site and do the questionnaires and interviews on the site. **KWTR1 Lines 468-**

Professional constructs do not always concur with the travellers' own views and can feed into the notion that such communities are 'hard to reach'. In the interview with TR2, the boy's mother disputes the key worker's perception that the travelling communities are highly protective parents due to culture, which impacts on the children's access to participate. When asked if she was comfortable with her son going away for the weekend she states:

'He had his mobile phone, we could phone each other all the time and then if he did want to come home, we said 'if you ever wanted to come home', we would come and collect him. So we knew like there wasn't like rules and regulations that we couldn't...' **Mother of YPTR2 (421-424)** 

When asked if any travellers would be 'anti' their child going away, the mother stated 'yes' but explains the anxiety as being a natural parenting concern, not a cultural one.

No, probably just because everybody feels the same way about their children don't they? **Mother of YPTR2 (432-433)** 

KW TR2 states additional barriers to collective participation taking place outside of the travelling community.

'I think, to keep that particular community on side, you have to go at their pace I think. After 9-11 they would not go into Newcastle, because they were scared of bombs, and we were arranging a night in Newcastle to meet with young people from different ethnic backgrounds ...our young people in Wansbeck had a chance to meet other young people from Newcastle and we had a great night there, but the traveller families would not let their children come, because it was in Newcastle and it was a City and there was a risk, and they were scared. They would not even go shopping in Newcastle for a few months after 9-11.' **KW TR2 (Lines 1079-1085)** 

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<sup>&</sup>lt;sup>2</sup> Our Part Researchers are young people in Northumberland trained in Participatory Research

Whether travellers were any more cautious than the general population at this time is difficult to determine. However, the professional misconceptions and stereotypes need to be continually challenged to ensure that they themselves do not create or reinforce stereotypes or stigmatise groups.

# 7.2.3 Collective participation

Collective participation through group work can also be challenging where lives are complex, with participants bringing with them their own vulnerabilities and diverse backgrounds to a group setting. An emerging theme throughout the key worker's accounts was their need to have a heightened awareness of new problems and the rapidly changing circumstances in some of the young people's lives. The key workers need to have a heightened knowledge and responsiveness to meet the young people's needs in order to run effective and safe group participation activities. A key worker describes the types of issues teenage mothers face.

"...Because as young parents they typically have got massive issues in their lives. They may have poor self-esteem, lack of confidence, be very judged by their community, their society, their parents, their friends, em, and I think for and woman particularly, having a baby can have a massive effect on your personality. And em, but to do that when you are perhaps, when you have just come through puberty or you are still in mid-teens, and you know you are neither an adult nor a child and then to be thrust into being responsible for another body and, and then having, I think there is issues around how they feel and what they want. But, in [their] ability to verbalise it or articulate it or even get it." **KWTP3 Lines 20-28** 

She continues to describe a situation where the whole group and the key workers were affected by the rare exposure to crime and social problems within this teenage mother's family.

'During the last event, the feedback event, we had, quite an unpredictable event take place, and that was that this should have been a really glorious event where the girls celebrated what they had done, and em, there had been an incident in a community in the West locality, where a guy had

tried to attack and kill his ex-wife and that, that man was one of the girls' father... So when she came along to this event, it was 5 days after the killing of her father [father not mother subsequently lost their life], and she had witnessed that and so had her 2-year old child. So, she hadn't cried and she wanted to come on the day, because she wanted to try and keep things normal for her child and then somebody had said to her "Are you ok", and the floodgates opened and she just broke down completely. And that was really difficult for us to manage because we had to help her with her grief, which was enormous, life changing grief; no words could ever in the moment support her through that. It was just allowing her a bit space to cry and then asking her what she wanted to do and arranging that. So we then had to arrange for her to be taken home, but then we were left with a group with difficult feelings around, 'ah God how huge is this', and to then think about, woe, hang on we have got a task to do here.'

**KWTP3 Lines 1317 – 1332** 

Here the key worker had to manage the personal safety and emotions of the one person immediately affected and the emotions of those indirectly affected. Such a situation highlights some of the important key worker attributes shared later in this chapter.

Children in the looked after system appear to share openly once they have built up trusting relationships as illustrated below.

'... it was really again about establishing trust, with the group, and we found this with looked after young people, it's a bit like network building, they kind of know of each other or know each other. So the group did not take too long to gel, because they had already, there were a few already established relationships in there, but they, we worked with them in establishing trust and boundaries etc, etc...also by building self-esteem, because if we want them to talk sex, we need them to feel comfortable in doing that.' **KWLA1 Lines 308 – 314** 

This can result in difficulties within group participation. The key worker describes a difficult group situation that emerged whilst they worked with young people to develop a sexual health policy for young people in care.

"...on one occasion it became very graphic, we had a young man in the group who had recently come out, and we were very concerned about a situation he was in. We knew he was in a relationship where there was quite a bit of power imbalance, should we say. And we were aware of his dilemma. And during this group work he on one morning was extremely graphic about a sexual activity that had gone on the night before. Which prompted another two of them within the group to share their experiences and we really had to, we had to do two things there. We had to call them back to the group contract and the respect part of that, and the other thing we had to do was we had to take some of the issues this young man had talked about back through the Child Protection Sector Young Children's channels. **KWLA1 Lines 573 - 582** 

In summary, the multiple complexities described ranged from dealing with limited life experience of what most of us would perceive as everyday experiences e.g. going on the metro; to social exclusion due to family circumstance, breakdown in relationships, e.g. family, school, with carers and friends and cultural difference.

## 7.3 Key Worker's perceptions of participation and advocacy

Within the one to one interviews key workers were asked a number of direct questions, which preceded their broader accounts of participatory work. This included a request to define 'participation and involvement work', to separately define 'advocacy' and to compare and contrast the two. The way in which the key workers defined the terms is shared in Appendix 7 where the table depicts the definitions and the aim of each if shared.

Key workers found defining the two terms difficult, and often it was hard to decipher the difference between the terms. One key worker however, was very clear about how to define and contrast the terms. She describes involvement as follows;

'For me involvement it's not just about inviting people to come along and do something that, you know, we talk about. It's about getting the young people involved in, you know, Arnstein's Participation Ladder. On the bottom level you kind of invite them along, it's your event you have organised. At the other end you have got young people actually organising something, getting everything into play and organising the adults – if they want to involve adults. Almost on an advisory capacity if you like ... to me

that's what involvement's about. It's about involving young people at every possible stage that they can.'

**KWLAC3 Lines 166-173** 

This key worker is specifically employed to provide information and get 'Looked after' Young People involved and acts as a participation worker, which may be why she defines with more clarity and confidence than some of the other key workers. Advocacy is described in similar specific terms;

'For me, advocacy is supporting someone. You may not personally collude to a person's view, but you are there to speak on behalf of that young person to enable that young person to be heard... it's about wishes and feelings, wants and needs, and it's about supporting that person to get their voice heard and to actually get their views across. It's also about perhaps, you know, helping that person to understand that whilst they might want and wish, that is not always possible. But at least it helps get them through it.

**KWLAC3 Lines 191-95** 

This key worker's statement demonstrates how hard it is to separate the two from one another, and as such all key workers appear to act as both advocate and participation worker, irrespective of their role. This appears to be essential in working with marginalised young people, who when first in contact with key workers may not feel able to speak out for themselves. Perhaps advocacy is an implicit part of the process of participation. Certainly, a 'preparatory stage' preformal voice sharing is evident and has a strong advocacy function as well as a skills development, and mutual relationship building function.

The following teenage pregnancy key worker explains the skills she feels are essential to help young people to participate. Advocacy, she believes requires the practitioner to have a good knowledge of the rights agenda and issues surrounding that particular group. This in turn helps them to participate ethically and to share their voice albeit indirectly.

'Advocacy I think is when people express views or opinions on behalf of somebody else. So they would get peoples' needs met by being their voice I guess, doing it through the third person. So I could advocate on behalf of young mothers, if young mothers were not able to be there. I could seek their views....

I think in terms of advocacy, I have got a good knowledge; I think I have a good knowledge base about some of the gaps and some of the issues, so I have that theoretical knowledge which I think you need to be an advocate. It is not just about what they are telling you it's about what you know in terms of facts and things. I think I have got interpersonal skills in terms of being able to listen and value other people's opinions. I have got a sound understanding of the rights agenda as well which I think has been useful in terms of young people's participation where there has been an ethical thing around consent and stuff.'

#### **KWTP1 Lines 22-37**

This statement also emphasises the educating and information giving function implicit in advocacy and participation. Most of the key workers intertwine their definitions of advocacy and participation. Key Worker (TR2) discusses the movement from one to another, and her expectations of a new advocacy worker.

'I think the advocate will build up relationships with the young people he is working with, to the extent that they probably will find their voice'.

#### KWTR2 Lines 103-6

This short statement implies that advocacy may lead to young people's voices being heard. Key workers tend to mention key components that might allow advocacy and participation to occur such as 'support' and 'encouragement' in their definitions. Another teenage pregnancy worker describes what she sees as the difference between the two.

'I think for me advocacy is about somebody wanting or needing something and needing support or help how to get that.

...and I think about the participation, is that there is not necessarily, there does not necessarily have to be an end product, but part of it is about being involved in it somehow, that it may influence something for, for themselves, hopefully, if that's what they want, or for others like them'.

**KWTP3 Lines 62-70** 

The key worker appears to be indicating that advocacy is specifically for 'self gain' and helps an individual, whereas participation is aimed at making a difference for oneself and others. Key Worker (YC3) defines participation as something that allows young people to become visible in the system.

'....participation, it's for young people to be able to be recognised, in who they are and they have recognition for the way they experience life at the moment.'

#### KW YC3 Lines 375-77

The education based key workers conceptualise 'participation' slightly differently than the health and social care staff. The education workers appear to have a very strong liaison and facilitative role; with participation work explicitly described as an assessment of need. Throughout the accounts participation feels more service rather than child focused. This is not to say that the workers are not passionate about the children they work with. That is very evident and will be described a little later. However, the participation described does appear to be a much more arduous task. The key worker talks of the need to 'draw' information out of the children, and the need to 'stick with it'. One key worker describes how she involves herself from 'individual' to 'organisational' level to develop policies to help the young people, rather than how the children are involved in policy development themselves. She describes participation as follows:

'Well I think involvement or participation means to me, that you have the will for the other person to actually want to do something with you. A participatory thing isn't it? You inflicting on someone, it isn't about you imposing a set of rules, its about a kind of a contractual em, mutually em, negotiated, a mutual respect thing that this other person has, has views, has rights, has something that they love that hasn't been nurtured in them that maybe you could draw out of them. Em, it can be very, very tricky with some of our youngsters because they can be very angry sometimes, er, but if you stick with it and if you approach them, like they are a human being and they do have a lot to interest you, then the participation comes.'

**KWEX2 Lines 197-205** 

Although clear about what advocacy is, the key worker appears to find the function equally difficult. This is not exclusive to one education key worker, KWEX1 finds herself pulled between her alliances with the family and her alliances with the school as part of the local authority. As such she has had to remove herself from the appeals procedures, which is an arena where evidence demonstrates low participation by families at risk of exclusion from school (Taylor, 2005)

**KW:** It's really getting all the information, making sure that the people know their rights, trying to get that person involved in some way. I mean for a lot of families and young people, schools are really scary places.... and I find it really difficult working into a school myself, you have to be quite self-confident and be able to really be quite skilled in dealing with people to function in school. And a lot of these young people have not got those skills, they find it really difficult and eh, and they either use, they become frustrated and try and act out in schools, em, because it's where they are coming from. I mean a lot of the time I find the young people who are excluded, even though they don't say it physically, they do actually mourn not being in a school because it's the only structured place they know, but they have not got the skills to deal with that kind of structure. I think it is really getting families and young people more involved in the school and making them more friendly a place where it is quite comfortable to go in and comfortable to talk to people.

**DS:** So in that way do you not act as an advocate or a go-between, between the school and the forum

**KW:** I do. I do in that respect, I act as an advocate in that respect. I would like, when I am going into school and trying to get the young person back into a school, I would first of all meet with the teachers, meet with other professional people and try and like map out a plan to help support that young person in the school and be an advocate on that. Maybe I've gotten confused with like advocacy and like the appeal process and things, because I can't get involved in anything like that'.

#### **KWEX1 Lines 73-96**

The struggle between one's own personal values and those of the young person makes this an emotive role. Remaining a support and advocate for the young

person when your views are not aligned to theirs is part of the emotional tensions placed on the worker.

'Em, I need to have good communication skills. I need to be able to build rapport, I need to be able to empathise with them, I need to understand their needs and be able to meet their needs in terms of their participation and engagement....

## **KWTP3 Lines 102-104**

'I need to be supportive, welcoming, approachable and certainly non-judgmental, because their views may well be very different from my personal beliefs and values and I think above all I need to be respectful.'

#### **KWTP3 Lines 113-115**

The above statements expose the skills and importance of impartiality and a respect for diversity in advocacy and participation work, and start to expose the key attributes required to be a good participatory worker.

# 7.4 Attributes key workers require to undertake participation work with marginalised young people

In line with the key objectives a number of key themes emerged when focusing analysis on the attributes of the key workers. Firstly, the role of the key worker appears to be fluid and ever changing in relation to the sample group. The vulnerabilities of many of the young people result in at times, rapidly changing needs. The key workers demonstrate the ability, at times due to practical necessity, to move with the given needs of the group they work with at any time. Maslow's theories of motivation (1954, 1971) provide an interesting backdrop to observe the practices and role of the key workers against the behaviour of the young person.

In acting as a participation worker or advocate to the marginalised young people, the key worker constantly functions in a responsive role, with the potential and reality of a young person moving up and down Maslow's 'Hierarchy of Needs'. The ultimate goal of the key worker might be to assist the young person in

reaching their full human potential, but in living such complex lives, some of these young people may only hope to touch the periphery of 'self fulfillment' and 'self actualization' (internal cognitive growth); and as Maslow states (1971, p45) 'It means experiencing without the self-consciousness of adolescence'. Maslow suggests that very few people experience self-actualization, but that some may achieve real growth and realisation of their inner potential. He describes these as 'peak experiences'. These young people describe 'peak experiences' within their accounts and key workers may well recognise moments and glimpses of personal growth, but often the basic needs of survival, belonging and security are all too real to these young people. As such, any small movement up into the peak of the pyramid of needs is a potential success. The young people's complex circumstances are reflected in the responsive role of the key worker that swings seamlessly between participatory activity and advocacy. In observing the epiphanies (See chapter 8 and Appendix 6) in these young people's accounts one can see the potential for personal growth. Sometimes this is clearly recognised as a 'peak experience' and a moment of recognition of personal growth is shared.

Maslow's work in the psychology of teaching and the role teacher's play in developing students can also be considered in observing the role of the key worker. Curzon, (1992 p98) describes Maslow's 'extrinsic' and 'intrinsic' learning, with extrinsic learning being 'learning of the outside, learning of the impersonal, of arbitrary associations, of arbitrary conditioning, this is, of arbitrary (or at best, culturally determined) meaning and responses'.

Alternatively in intrinsic learning the development of life skills is necessary and;

"...The teacher who wishes to assist in the process of intrinsic learning must see himself as a helper, counsellor and guide. He must be receptive rather than intrusive; he must accept the student as he is and assist him to learn what kind of person he is. He must acquaint himself with the student's style, aptitudes and potentialities. He will concern himself above all with the student's growth and self-actualization."

(Curzon, 1992, p 98)

As the key workers describe through their narratives, their role and their relationships with their community of interest, an intrinsic learning style emerges. Much of the participatory work focuses on the building of life skills to get the young people to a point at which they feel comfortable and confident enough to share their views. There is a sense of each of the key workers getting to know their communities and the young people in a broad sense (acknowledging the needs of that particular community) and in a more personal sense, through both their participatory work and through the necessary advocacy role that naturally develops. Here they demonstrate 'receptive' rather than 'intrusive' qualities. They often, in their accounts emerge as 'helper, counsellor and guide'. They consider and value the point at which the community or young person is at, before attempting to undertake the participatory work in hand. They all describe a strong 'preparatory stage' of working either with the broad community and / or individuals before moving into the 'involvement work'. What emerge are strongly reflexive and flexible practitioners, with a clear goal, but acknowledgement that a long pathway of mutual development is often trodden before the goal is reached. Along that path is a gradual build up of trust, confidence, knowledge and skills.

## 7.5 Key workers descriptions of 'self'.

All key workers answered the direct question asking them to describe the skills and attributes a participatory worker would need (See Appendix 6 for a summary of the attributes by each worker), and as such a list of attributes can be generated. The stories, however most powerfully expose some of the key attributes frontline key workers need to practice effectively and deal with the complexity of the young people's lives. This demonstrates the importance of the narrative in naturally, through story telling, exposing the ways of working, and the key attributes embedded in the accounts.

### 7.5.1 'Self' as experiential learner

The internal cognitive development is as much with the key worker as it is with the communities and young people they are working with. Many acknowledge learning on route and being prepared to 'have a go'. All acknowledge making mistakes and learning by them. During their explanations of the skills and knowledge required to be a good participation worker many described a development of good practice over time, each of them learning through personal success and failure. Most describe a learning cycle with strong reflective skills and these comments are backed up by practical examples.

**KW:** 'I have probably learnt a lot of it on route. I think it's probably been experiential kind of learning and development and I think that every time I have done it I have learnt something new that I have applied the next time. So sometimes it's around the venues, making the assumptions that you take them somewhere nice, so that's a treat, when actually it's a barrier. Things like that really, and just every time I have done it, it's about seeking feedback from them about how it felt and just getting their views on what you are asking them, but what the process was like.' **(KW TP1 Lines 46-52)** 

**DS:** And tell me why you said [venue name] was the wrong place to take them?

**KW:** Because, partly because people were looking down their noses at them, which was not, not the people that were with us, but other people were [the people who worked at Longhirst]. They were automatically seen as young 'charver' lads with caps on, scruffy trainers, who were swearing and going outside for cigarette breaks. So there was partly that, they were looked down on, which is what they were used to happening in other places. And secondly they could not understand how to, it was quite a formal restaurant and like the menu and they did not understand some of that stuff. And they felt like they did not deserve to be there and we felt that we wanted them to think that they did, but it was like a step too far. And some of the young mums had told us that as well that they felt uncomfortable, that they felt embarrassed and they felt inferior, when we were trying to do the opposite.' **KW TP1 Lines 835-847** 

This worker's reflections bring a new appreciation of what young people might judge as a special treat or reward. Often decisions can be made based on

personal and professional perception of what a treat for example might look like rather than asking the young people where they would like to go. Here a clash a potential clash of social cultures are exposed with the organiser's middle class perception of a treat not in line with that of the young people. Additionally, given this was to be a participatory event, asking the young people where they would like it to be held may have been a sensible starting point. However, the quote also exposes public mind sets and some of the social barriers and misconceptions the public hold about certain groups of young people.

Key workers openly share their own limitations an important element of experiential learning, and value the community voice in helping develop and share important knowledge. The key worker linked to the travelling community describes the importance of having an embedded community voice alongside her as part of her own learning.

I have spoken to [traveller] I have said that "if I went to a meeting about travellers it would be really useful to have you with me and in that meeting all the things I don't know you could tell me, and yes you might not feel confident enough to speak up, but that would be so useful to me, you just sit and say well 'that's not right, or this is what happens'. And then if we went on to a travelling site somewhere else your experiences would be really, really useful to me because you would be in your own there and I would be the person that is learning from you so". **KWTR1 lines 242-249** 

Such partnership equally helps develop the capacity and skills of the person accompanying the professional, opens up more meaningful dialogue and the possibility of future access. Importantly, the professional learns how to act, as described further in the next section. The ability for key workers to learn through experience reflects the dynamic process of on-going interpretation, exposed through narrative methods.

# 7.5.2. Physical and emotional 'self'

Many of the key workers share in their accounts an awareness of how they should act and look. Key workers are aware that personal image potentially prevents barriers and allows or maintains access. Most also clearly understand that their involvement work must be genuine, non judgemental and requires sustained effort. In essence, they describe a community development way of working.

'Well in my own experience it's about being non-judgemental, it's about being approachable, it's about getting trust and respect from the group of people you are working with. It's about going in at a level that they are comfortable at because if you don't do that you won't get anywhere and it takes time. It's not about going in for one visit and trying to get all the information in one, you know teasing this information out. It's about spending some time with the group and finding, you find some of what they are really unhappy about and you have to sometimes talk through other issues that you did not particularly go there to do...

Well you need good listening skills, you need to be very approachable, friendly, fit into their... if I went down on to a traveller's site I would go dressed like this, I would not go dressed in a suit, you know with a brief case and, its about making them comfortable with you and yes you are a professional person, but its about not frightening them when you actually go along. **KWTR1 Lines 41-57** 

'I am going to be really, really cheeky now and say lose your middle-classness, number one; you know, I have heard other people say "ah well you know they come from N or L, or, you know what do you expect its blah blah", its easy to write kids off and there are a whole raft of reasons and I can understand why it's happened when people have gone in, put in a lot of resources and stuff, but I think the attributes that you need, you need, masses of patience, you need not to be quoted by the negative attitudes of other people.' **KWEX2 226-232** 

The awareness the key workers have regarding personal image, their ability to continually reflect, start to demonstrate their on-going commitment to the groups of people their work with.

#### 7.5.3. Self as committed worker

The interviews expose a strong commitment, passion and desire to give the young people and their communities the best opportunity to share their voices and have their rights met. The passion is demonstrated as personal passion, commitment and self motivation and does not feel organisationally driven. If such passion was lost i.e. a worker leaves, a break in the quality connectivity between services and the young people may occur. The relationships are reliant on the nature and attributes of the key workers. A reliance of organisations on a passionate few might be all that is between good participation and none at all.

They are very direct with us. That is one thing that I have learnt with looked after young people, they are very direct. There are no holes barred. They are such an incredible group, really, em, I am absolutely humbled by them, which sounds a bit patronising, but they are an incredible group and they are immensely resilient and they have a lot, a lot to tell us. **KW LA1 Lines 192-6** 

'How some of them survive is beyond belief to me and that's where my admiration and affection for them comes from. Em, because of that I will always want to be doing this work. When I stop feeling like this, it's the time to move on from this job.' **KW LA1 Lines 662-665** 

The key workers commitment to skills development and good quality participation is evident in the following dialogue. The key worker shares her experience of preparing young people to interview new staff and how this preparation is rewarded when things don't go to plan.

**KW:** Well we knew we were going to have these workers... but I just felt that I did not know what the best worker would look like because the work they were doing was for young people and not for me. It was about delivering my agenda I guess but, I thought 'how can we get that right?' And they were already doing some work in schools with sex education, so we just asked some young people if they would like to be involved and we managed to get, I think, 8 young people out of school to do that. And I did it with the Boys and Young Men's Development Worker, and we took two Saturday's before the interviews because the kids were saying that they cannot get out of school to do it because it was going to be too much of a commitment. But they were prepared to do it on a Saturday, which meant

that we had to change a lot of things, we had to interview staff on a Saturday which is quite unique. We had to be, get staff to be part of the panel who had to work on a Saturday. For two Saturday's we took them off to Ashington Sports Centre, myself and the development worker for boys and young men, and it was just a great process, because these were kids who would never have thought about having an interview themselves. They were quite marginalised young kids you know, not really doing very well at school academically. We had to start way back, we had to start by saying what would you do if someone was fat, what would you do if someone was black, what would you do if someone acted a bit like a poof? So it was kind of that [was] where we were coming from and we were looking at each opportunity.

**DS**: A challenge?

**KW:** and we really had to get them to think about that and what would you do if they were a bit smelly, what would you do if they were old? So we really had to iron out all of the equal opportunities stuff and that was great, that day was absolutely cracking. And we got to a point where they actually understood what equal opportunities were and where they started to think about well, what do we need to have as fair criteria and we talked a lot to them about an interview process and how the candidate might be feeling and so that was great. Then the second day we got them to actually develop a scoring criteria for the candidate based on what equal opportunities were. So they could not give them a job because they did not like their shoes, or they thought they looked a bit like a 'charver' or whatever. They came up with this sheet and it was fabulous and it was things like smiling, making eye contact, we got them thinking about people that they liked and what was it about them that they liked, not using big words, so it was excellent. And we made them understand what their level of participation was and that they couldn't see their interview applications forms. We were very clear, what their boundaries were around their involvement and talked about what they would do if the person they liked didn't get the job and they would potentially be an office worker so there was some power there. So we got through that whole process and then the next Saturday we all went off to Fulbeck Grange and it was great. What was great about that was something that went wrong, because the taxi didn't, we had booked taxis and we thought we had done everything but the taxi didn't turn up for two young girls. And they could have chosen not to come. I mean they had to get up out of bed to be there for 10.00am. But they had got someone's friend dad to drive them to Fulbeck Grange because they were so committed and they had rung up Fulbeck Grange. They had got the number and asked them to tell them that they were going to be late. So it was just like [pause] that for me was their commitment to the process to be involved and wanting to be involved really.

**DS:** And do you think they would have done that if you had not done the preparatory work before?

**KW:** No. No. Because I think they [pause] when we got them in the room [initially], we were saying what do you think you are going to do? And they really did not know, they really did not know, for them it was just it sounds like a bit of a laugh and we are going to get our dinner and you know. But by the end of it they were so in to it and they were so, they were really checking themselves around well is it because she's got weird clothes that I don't like her, or is it because she is not talking to me. It felt like an excellent process. **KW TP1 Lines 583-643** 

The quote emphasises changes in normal practice in order to ensure engagement, a high level of support to ensure the young people were prepared and the huge amount of new learning by key workers and the young people to ensure that they could be part of the decision making end of participatory practice.

This level of commitment, although exemplary, is not unique amongst those interviewed. Many work flexibly and all appear young people centred in their working practice. The time commitment emphasised here is essential to building trusting relationships and there is a strong sense of enduring relationships with their communities of interest.

'I think it's about, acknowledging that they need the skills, acknowledging that and also accepting their limitations. I think that's essential. The main [skill] that I see is em being a good listener and I think you need tolerance and patience in that if you are wanting somebody to share their feelings and thoughts. You have got to spend time building a relationship with them.' **KW LA1 Lines 42-48** 

Whilst work with vulnerable young people has to be well planned, the complexity of the young people's lives requires the professional to be flexible and spontaneous.

### 7.5.4. Self as reflexive practitioner

The key workers accounts expose responsive and reflexive practitioners, constantly operating in an ever changing environment. The following two accounts are an example of the way in which the practitioners have described the uncertainty of their work. The main reason for engaging with the community may be superseded by other events deemed more important by the community or individual. Awareness of personal or community crisis or tensions, being able to measure the level of support required and having the resilience to deal with this potential uncertainty are skills regularly called upon when advocating and involving communities, as seen in Section 7.2.3. The following key worker describes how negative media about the travelling community impacted on her purpose for going to the site.

**KW**: The piece of work I was going to describe to you or the project was the day I went down to the site to talk about the Children's Centre, and all over the newspapers was the fact that they were going to cut the travelling gypsies sites. They were not going to; the Government did not want to have anymore sites. I went down with Children's Centre in mind and I just got absolutely bombarded.

**DS**: So what was your aim in going down that day?

**KW:** To talk about the Children's Centre. To try and get them involved in Children's Centre and what I actually ended up doing.

**DS:** Involvement in Children's Centre. How were you going to go about that? Just talk through it.

**KW:** We were going to talk about the possibility of having a fun day and maybe looking at doing some artwork and thinking about, would they like to influence any of the plans or the interior of the Children's Centre. Would they like to be part of a parents' group that was going to be part of the community involvement group that I led on? You know saying is there anything you would like in the décor, is there anything? And of course the day I got to the site [pause]

**DS:** Negative media.

**KW:** The newspapers were all over and the whole site was up in arms and it kind of put me in a vulnerable position because a couple of the comments were "ah you are just one of them, you are just using us to hit some of your targets!" And I was just like 'Hang on a minute, you know some of the work we have done and talked about, you have seen what I have done'. And then when they had cooled off a bit they were "right, ok we are sorry, we did not mean those comments, it just like when this kind of the thing happens, we re-group and we kind of pull ourselves back in and we have only got ourselves to rely on and does anybody really care about us out there?" and I went "yes I care about you and let us talk about it". Some of it they could not read, so when I went to see \*\*\*\*\*\*\*\*, she was like, 'read that to me'.

**DS:** Right, so you ended up moving completely away from the participatory work and doing some participation and seeking views and debating issues around the newspapers those days?

**KW:** Yes. So I spent a couple of hours saying to \*\*\*\*\*\*\*, "well we do care about you in health and we you know we are trying really hard to involve you in some of [the] things that we want young people and you and your children [to be involved in] and you know Northumberland Care Trust does care". "But you work for them", but I was like "yes I do work for them, but I am me, and you are important to me and your views are important and that's why I am here, and yes let us talk about this and try and sort it out". So when I came away, none of what I had gone down to do had got done. But what did get done was, I was probably there at the right time to reassure them that health was important and that, you know if we could help, or if I could help, and I said I would take this back to my Boss and say "this is how they are feeling today and this is what is happening". And I told them, I went to see \*\*\*\*\*\* [a senior manager], because you know there was a paper written about homelessness and vulnerability, and he was interested to have a chat and I told him some of what they had told me, was going in that paper, so yes your views were being passed on and I was not just popping them down. I was really keen that day to keep them on board. KW TR1 Lines 286-342

The worker's personal motivation and strong sense of passion and commitment for this community is demonstrated. She also displays good negotiation skills, managing the potential conflict well. This is essential to maintaining good relations. Equally important in this narrative was the previous relationship she had developed. She was able to draw on her own track record of reliability to defend her position under difficult circumstances. Often the key workers share

emotionally charged or challenging situations where reflexive practice is essential to managing the situation or maintaining the equilibrium.

The multiple complexities and vulnerabilities of the young people with whom the key workers wish to engage in participation result in the following attributes thematically represented below. Key workers are:

- · Contextually, temporarily and culturally aware
- Dynamic and flexible
- Good role models
- · Reflective and self aware, and
- Risk conscious

This results in participation offer being a safe, learning experience, varied and relative to present time and place.

### 7.6 How key workers influence practice and service change.

Key workers appear to influence practice and service change in two ways. Firstly by facilitating young people to directly share their views, ideas and voices through specific participatory methods, for example:

- Decision making about new staff appointments through the interview process
- Conference presentation to raise awareness regarding the needs of young people
- Service Planning events where young people share their needs and preferences regarding how funds are spent and services developed

Secondly, the young people's views are indirectly shared as part of the advocacy function of the key worker described previously. This manifests itself through a number of shared methods as follows;

 Direct feedback to peers and managerial staff to highlight or negotiate change

- Feedback at formal meetings and conferences on behalf of the young people to include the sharing of good practice
- Through personal changes to the service where they have the power to directly change things without further negotiation.

Whilst strong motivation to help change things for these young people is evident in the passion of the key workers themselves, managers' understanding of participatory practice and robust systems are not always evident and potentially create constraints on true and good participatory practice at all levels. Many of the key workers shared organisational constraints after the taped interview had finished; an issue in this research that cannot be ignored but that is also difficult to evidence. This issue was raised at a subsequent action learning group set up as part of the validation of the analysed data. Feedback from the group revealed a number of practice based issues making feedback to managers difficult.

- Many area managers individually interpreting information in different ways and this lead to differences in service change in different areas which lead to inequity
- Not all key workers are part of a team and access to a manager is limited
- A lack of managerial understanding of the complexities of the participatory work and the nature of that work with marginalised young people.

'Because I don't know, saying to the Care Trust, well I've actually been down on the traveller's site, I've read the newspaper, I've had a cup of coffee, I've had, you know, (laughs). [They would think] What sort of holiday are you on? But they wouldn't always necessarily recognise that you needed to do those bits to actually get the things you wanted.' (From workplace action learning set)

This raises issues regarding organisational and managerial interpretation of the purpose of participation, and points to a need for collective and shared understandings. One key worker described the conversation she had before visiting the Travellers site.

She [my manager] actually said to me, well I hope you're going on with the police (laughs). I said 'the police', she said, "Well surely you'll be taking a policeman with you". Well I couldn't even explain to her how inappropriate that would be and that was, you know, she just had no idea, no understanding, her background was statistics, you know, she's not particularly a people person, but I mean, could you imagine if I went onto the site with a policeman. (Laughs) (From workplace action learning set)

- A lack of investment by managers in good quality participation
- A lack of understanding that those involved in participation need much more emotional support than presently on offer, and sometimes support requirements are immediate.

The key worker interviews preceded the young people's with each key worker interview ending in a discussion related to selection of young people for interview, a reiteration of the criteria for selection and the procedures. An analysis of the young people interviews follows in Chapter 8. However, whilst the findings from key worker and young people interviews are separated by chapters, both are valued equally as participants, being able to contribute to providing new insights into participatory practice and its impacts.

## Chapter 8 - Young people's narratives

#### 8.1 Introduction

In the following chapter findings from the young people's narratives will be presented. The young people's narratives are analysed under three main sections in line with the research objectives, and sub headings represent the emerging themes relating to the specific objective:

- Exposure of the lives the young people are living or have lived. Understanding these helps establish the constraining and enabling factors leading to the young person's willingness and readiness to engage in participation or not.
  - Multiple vulnerabilities e.g. family history and social experience
  - ➤ The right to be a young person, not a 'label'
- The impact of participation and involvement work on young people and services from their perspective
  - On the young person
    - Increased self worth, self value and confidence
    - Enhanced skills
    - Expression of self and therapeutic effects
    - Development of new relationships
    - Increased aspiration

#### On services

- Service improvements
- Practice improvements
- Ability to help others
- Feedback loop
- Attributes of the key worker and their value in participatory work
  - Access to and learning from a role model
  - Advocacy
  - Personality

Throughout the study direct quotes are used to illuminate the author's findings and debate. Local dialects are retained within the shared quotes to ensure

authenticity and openly demonstrate the value of this difference. However to ensure that the reader can understand the quote at times the words are followed by bracketed alternatives.

Where possible direct narrative text is used to illuminate the themes across the stories told. The codes linked with each quote are shown in Appendix 4.

## 8.2 The young people's lives

During the early stages and throughout the key worker interviews the complexity of the young people's lives is described both directly and indirectly. The key workers offered their own views of the complexity of the young people's lives through their own experiences of working with particular marginalised or more vulnerable groups over time as described in Chapter 7.

The young people also shared the complexity of their lives, although they rarely described them directly as complex. In the initial stage of the interviews each young person was given an opportunity to share a little about their growing up and their views on things today. This was partly to help the young person ease into the interview before sharing their own experiences about the participatory work, but was important to the researcher in remaining true to the philosophy underpinning the work. Understanding the context of the lives has helped to better understand the impact that the participatory work has had upon the young person and the services with which they are connected. For example, where a young carer reflects on her own needs in a context of normally only considering family needs, the impact is significant.

By asking an individual to share his or her experiences of childhood and of growing up the story telling method is facilitated. To assist the reader in better understanding the personal accounts, a short vignette of each of these shared lives is summarised in Appendix 6. Where possible quotes are contextualised. At times it is necessary to share long quotes and conversations in order not to decontextualise the data and to represent the individually fairly.

In line with the research objective to 'Explore the constraining and enabling factors that marginalised young people experience in taking part', the following themes emerged from within the texts.

### 8.2.1 Multiple vulnerabilities

Each young person was selected if they met the criteria and fell into one of the five categories of potential vulnerability. Once at interview, it became apparent that many of the young people by chance fell into more than one of the categories and some fell into many. This in itself highlighted the complexity of their lives. The following young person was selected as she is a teenage mother, but it became apparent as she reflected on her childhood and her present circumstances how complex life had been. YPTP1 describes growing up as 'hard' due to 'family circumstances', and quickly it became evident that she fell into many of the categories for selection. The young person describes anger with her mother for walking out on her and her siblings. She has been in looked after care with the same foster carer for seven years and describes a complex family structure of many half brothers and sisters via her father's relationships. She is aware of and in contact with some siblings.

She describes her exclusion and dislike of school, and later talks of her family circumstances making her different from others at this particular school. A move to another part of the county and into foster care, to a new school and new friendship groups are what she finally feels helped her to gain control of her life.

[I hated] school, the people, the teachers, the children that were there. You know, they got me into a lot of trouble, and I mean a lot. I was at the point where I was breaking the windows and things like that, dragging the kids along the grass by their hair....I thought it was really funny, and people were laughing at me, because they thought it was funny. But now, I am embarrassed by myself....Although I know deep down it was me. It's just an embarrassment, to where I have gotten now'. YP TP1 Lines 701-712

This honest self reflection is indicative of many of the accounts. The above quote reflects how the young person measures her own progress. The history shared

enables the person to view how she is now against her own perception of what she was like. Such characteristics and personal experience make her well placed to help to develop services with and for other young people in similar circumstances. This teenage mother is not unusual in her multiple vulnerabilities. Both the young people selected in the Looked after Care category are also teenage mothers. YP LA1 describes the circumstances that lead to many foster placements and a lot of lost schooling.

'I was in there [in care] for, I was in there for, when I was 11 for a few months, then I went back home to my Mam [mum], cause there was just loads of stuff with my Mam and my dad looking after them [us]. He was a trucker, and he couldn't, he was taken away and we lost a lot of schooling. And unfortunately I was the one who got put in to care, and my brother got put with my mam's [mums] friend and then she [mother] come back into our lives and says 'I am fine, I have got a house now'. So we moved back into there'. **YP LA1 lines 16-21** 

This is followed by a final blunt and public rejection.

'My mam had a partner who's very violent and I couldn't cope with the fact that my Mam kept getting beaten up everyday, so I used to do a runner. And, just one day the Police picked me up and my Mam just basically said "I don't want her", and the Police said "what do you want?" and I said "same here", and I was in care for 3 years'. **YP LA1 Lines 36 – 40** 

After four foster placements in three years YP LA1 moved back with her mother. She experienced problems at college due to bullying and moved on to undertake Maths and English at another college. She states that she did not learn the outcome of her examinations as she left due to being pregnant with her first child. This yo-yo relationship with her mother, and the regular interruptions to her education, create the potential for broader and additional vulnerabilities. They also help demonstrate the potential difficulties young people and key workers have in maintaining regular contact through participatory work.

The second young person in the looked after system sharing her story also describes fraught relationships in and out of school and home life, and again mixed levels of school attendance.

The level of vulnerability for each young person became very real through the course of the research. For example, a young man excluded from school interviewed early in the data collection phase had ended up in prison less than one year on from interview. Perversely his story was one of the least complex narratives and at that time he fitted into the category of excluded from school only and appeared to have a fairly stable family background.

Often the complexities are hidden until shared within an account. The participation environment may also expose hidden stories and needs for the first time. For effective and safe practice key workers must have the resources to deal with such uncertainty. The first young carer interviewed demonstrated her carer's role through the following emotive narrative, and demonstrates a developing resilience and the complex issues that many carers must negotiate in life.

'Cause, I used to be like embarrassed to walk around with my Dad, when he used to have, or he still has 'Tourette's Syndrome', because everybody turns and stares at you, but now I don't care I just walk around.

I think when they stand and stare, and when they actually move their children out of the way of them [him], that he is some outward paedophile or something. It's horrible. He does not talk about it, but I know that he must realise and I know it must upset him. He does not talk about any of his emotions really but, it's just, it kind of hurts me to know that he is getting hurt by these people and it makes me angry. Like the amount of times that I have let my Dad go-ahead like and actually said something to the people. Like when he is not there so that he does not see, but actually [I've] said something to the people about how stupid they have just been and how rude, and they are all apologetic but they just don't understand'.

YP YC1 Lines 552-570

Such accounts move the stereotypes of young people caring within a family from a private role to a more public one. In addition, the story highlights how many of the young people interviewed have developed an array of coping strategies to ease or deal with their circumstances. Such experience and new learning could be usefully shared with their peers, as a method of participatory practice.

The following story is shared by a 15 year old girl who presently lives with her grandmother and describes the complexity of living in multiple homes. She describes the emotions and reality of living in unstable environments. When she was asked what it was like growing up she states:

'I don't know it's kind of been mixed emotions like. I was quite happy when I was younger. Then I got to a certain age and I just started being cheeky and back answering everyone, and then it got to my mam and my step dad, and I didn't like him and I didn't want him there. So we used to fight a lot and he used to hit me and it got to the stage where I hit him back and then me and my mam used to fight over it.... I must have been about 10 when he started hitting me and I was about 14 when I hit him back for the first time.' YP EX 2 lines 10-15

#### She continues:

'I gave her [mother] an ultimate between me and him and she didn't want to pick. So it got to me being moved from different places. I got put with my dad and I stayed there for a bit, but I didn't like it, eh, 'cause my dad's gay. I can accept the fact that he's gay, but it's a totally different matter when you are living with him and he's got his partner there... I was scared to have my friends round.' **YP EX 2 lines 26-34** 

Indifference or straight rejection by a parent is demonstrated in a number of the stories. Whilst this young woman demonstrates an acceptance about her father's sexuality, her openness consequently leads to bullying at school, and also demonstrates the instability of many of her relationships.

'I told one of my close friends when I was in middle school and we fell out and she told everybody and I got bullied for a bit. But then I just told them to think what they want cause he's still my dad at the end of the day and he is who he is and then ... I don't know.' **YP EX 2 lines 47-50** 

As she continues to describe her relationship living with her mother and her mother's partner, the reality of her early teenage experience starts to emerge. The lack of positive role models in her immediate environment and the importance of her sustained relationship with her grandmother start to emerge.

**YP:** I liked him to start with, but then I took an instant dislike to him after that.

**DS:** What happened to make you ...?

**YP:** He was just being horrible to my mam and shouted at her and calling her names and drinking a lot, and he's a regular cannabis user. Stuff like that.

**DS:** How did that make you feel then?

**YP:** It didn't bother me to start with because he wasn't drinking as much, but then he started drinking a lot and like he would just flip over the slightest things. Like, I'd come home in the old house down [specifies area] and Man U lost a match, and he flipped then. And we had to get my Nana, and granddad and my Uncle down and we had to come and stop up here [Nana's house] and had to get him arrested and he hurt my dog.

YP EX 2 lines 67 -82

This young woman describes decisions being made about where she would live without her knowledge and involvement. Additional movement within the family follows as her behaviour becomes too difficult for her father to handle and the inevitable school moves at each stage. Even though this young woman has experienced both a violent home life with her mum's partner and a less traditional home life with her dad she appears throughout her story to be grounded, accepting and relatively optimistic about her future. However, it appears that the instability does impact on her behaviour and possibly also leads to her exclusion from school.

'I was at [specifies school], but I was living at North Shields. So I stayed at XX until the summer holidays and then I moved to XX. And [I] thought it would have been alright at first, like a new school, a new start. But then me and my dad started arguing and I wouldn't do anything he told me to do. Just being a typical teenager and he couldn't deal with it. So I started getting in to trouble at school.' **YP EX2 Lines 110 - 115** 

"...It was hard because I didn't know anybody, but I make friends quite easily, I'm the sort of person who can make friends quite easily....At first I got into a really bad group. I was getting into trouble but then I finally backed off a bit and tried to concentrate on my work. But then I started having loads of difficulty at home and I was getting moved up to here,

back down to North Shields, then back here with my dad's mam.' **YP EX2** Lines 141 - 146

The impact of the uncertainty not only resulted in negative behaviour at school and home but also resulted in a cry for help. Perhaps a more stable and supportive family may have prevented the following;

'I got sick of it in the end. And I come [came] up home at the Christmas, and I had a boyfriend at the time and then I went back down, and I thought he had been cheating on me and I overdosed........... But it wasn't just that, it was just stuff getting on top of me. I just didn't like what I was doing to my dad and my family and I just thought they'd be better off with out me.' **YP EX2 Lines 150 -158** 

The complexity of this young woman's life unfolds as she shares more of her experiences. She eventually moves into care. Initially, chosen through her key worker due to her exclusion from school, like many other young people selected for this research, she now meets more than one criterion for selection.

These complexities can constrain or enable a person to share their views. In most cases it appears that the young people have been enabled through their links with significant others, such as, but not only, the key workers interviewed. The preparatory work described in Chapters 6 and 7, appears to be essential when working with marginalised young people, to ensure that their needs have been met and to increase the chances of engagement in participatory work. For some young people the key worker is the only reliable adult in their lives. For the young person, having a role in participatory work may help to keep them in contact with a reliable and trustworthy adult, and may give them a sense of belonging in an otherwise chaotic life.

Given the detailed and complex stories told it is important to acknowledge the role of the researcher in the sharing of these accounts. Some of the stories told were extremely emotive for both the teller and the listener. Borbasi et al (2003, pg. 499) suggests that nurse researchers may be better placed to deal with contingencies that other social researchers, and nurses often draw on their skills in building rapport. Such skills will have contributed to the extent to which the young people felt comfortable to share.

### 8.2.2 The right to be a young person not a 'label'

There are often tensions in public health practice when resources are targeted at more vulnerable groups to address inequalities. Targeting resources can potentially label and further marginalise the group. Firstly, professionals and the public are often quick to apportion blame emphasising the unhealthy choices and actions of specific groups, rather than considering underlying social determinants of health e.g. issues of dominance, power, poverty, and racism (Carr, Matheson & Tipene-Leach, 2001). A good example of this blame culture and of public ignorance is the notion of deliberate teenage pregnancy linked to an increased access to limited social housing. Secondly, the focus on a group can result in further inappropriate labeling e.g. the label of 'unwanted' rather than 'unplanned' pregnancy used as a negative slant. In the Ottawa Charter (WHO, 1986) community development approaches to health improvement were advocated to help replace the deficit model that implies poor health outcomes are a problem of an individual's own making. Here the empowerment of communities, their participation in setting priorities and making decisions and taking action challenges professional dominance and helps acknowledge inequalities in power, ownership and control.

Goodley (1996, p 334), in critically examining life history research with people with learning difficulties, states that 'these writings [self stories] remind us of the lives that exist behind the label'. The following young people shared their views within the narratives about the need to be a person not a label.

A young person in the 'looked after system' is asked what skills and competences a key worker might need. She focuses on their skills and knowledge development which should, she stresses, come primarily from the young people themselves. However, she quickly moves to her frustrations with teachers.

'I think we should train them, and part of their training should be to listen to us and say what we think. I have always said that, I always have, always will. [I] Did the foster care training, did the teachers thing, which the teachers were just ridiculous .They did not listen to you...Every teacher, like [in] all the schools, if you are in care, they know that you are in care but they wanted to have one teacher who you could talk to and had to have meetings with and we just thought no this is ridiculous. And I was saying you go to school to try and forget about it all. We don't want a teacher coming up saying "Are you alright today, would you like to talk?" And that's just singling us out to people, because some people, I know some people in care did not want their friends to know that they were in care and they lived this lie, because one or two were ashamed. I never did like but. It's ridiculous a teacher coming up to you "How are you doing, would you like to talk about anything, how's your life in care doing". I hated it, but they just didn't listen. I was at boiling point. I hated it.'

#### YP LA1 Lines 1094 -1107

This young woman clearly wanted school to be a neutral place, a place where she could be part of the norm or mainstream. She continues and clearly describes the very public lives some young people have to live. This emphasises why school needs to be a neutral and separate place for some.

'You have got like your Mam who is, like your parents who are involved with Social Services because you are, and you go home to your foster carer or your carers and then you have to go to meetings and the only time, like if you play outside you are still in a children's home, that with that foster carer; at school it's you. It's time to be you and forget about all of your being in care or, you know what I mean.' **YP LA1 Lines 1114-1119** 

The last paragraph succinctly describes the many ways in which a label can subsume one's life, and how many young people appear to struggle for some independence and normality. School appears to be the one haven where this is possible. Practitioners need to be mindful of this, and with moves towards more participation in schools, appropriateness of school as an appropriate venue needs to be considered. Borland et al (2001) reports that young people unanimously said school is the best environment for consultation (provided it is private and facilitated by an 'outsider'), as it reaches large audiences. Some marginalised young people's views in this research did not concur with this.

Similar comments are made in many of the accounts, and the following quote from a young carer also clearly demonstrates the need for the school environment to be a neutral place for a child deemed as vulnerable. However, within the following narrative the young carer also describes a request for help from her father's CPN and the lack of appropriate support offered. She then describes why alternative support through school would not be appropriate for her.

**YP:** I asked [Dad's Community Psychiatric Nurse] once about a year ago; if I could see somebody because me and my Dad don't really get along unfortunately... Em, I think its rather emotional dis-attachment really, like we don't understand each other. Because I get frustrated and even though I keep on telling myself, it's a mental illness, there is something inside of you which makes you think no its not, its actually him and you cant get rid of that, no matter who you are, I think. Em, they would not help. They just said it was not their responsibility and they said what they could do is 'we can get a phone number for somebody else for you', but I did not want to ring somebody up. I wanted somebody to be there who could just do it at that moment, when I felt like I was able to.

**DS:** Is there anybody at school?

**YP:** I don't know anybody at school. There probably was you know, but I don't actually know.

**DS:** Did you not get offered any support as a young carer at school?

YP: No

**DS:** Did they know about the fact that you had a Dad with mental health problems at school?

**YP:** Well actually, I can tell you a story right, when I was very little. There was this Head Mistress. I don't think this would happen any more, ok, but like, it was when I was very little. And em, my Mam actually told her [about her dad's illness] and then she started picking on me, because she did not like people with mental health problems, and like she used to say that I was dyslexic. She used to say that I needed to go to a school for people who were apparently "backwards". That was the exact phrase. Em, she said I was a disruption to the class that I should not be taught around others. Em

**DS:** Why was she saying those things, just because your Mum had shared that your Dad had problems?

**YP:** I did not know at that point why she was, I was just, I did not have a clue and my Mam knew, but I did not tell my Mam at first what was happening, and then em, because she was like alienating me. The pupils picked up on it and they started to like bully me, because

**DS:** About you or about your Dad?

**YP:** About me at first. And then, em, what happened one day is my parents came in, to like, because they were wondering why I was upset and why I did not want to go to school and em, the pupils saw my Dad, and his appearance is like, he does not look after it, and he has got Tourette's syndrome as well, so it is noticeable....and the pupils seen that and they started copying him around me and stuff. And when em, this teacher, she used to let me go last in the queue, saying I was fat enough, so I started to not eat and stuff and then em, she just turned around on the day that I left saying "you know, if you are not careful you are going to end up like your Dad".

**DS:** And when you went to senior school, I mean you have been in senior school for sometime now and obviously you are doing exceptionally well - so far from 'backward'. What sort of support has there been on offer for you there?

YP: I haven't had any.

**DS**: Do you just choose not to?

**YP**: After that, because it stuck with me all the time, because I was always afraid that somebody would judge me differently and they probably wouldn't of you know, now I totally belief that, but you just, after people have said stuff about it you start and think "well I don't really want to tell them because I don't want things to change". Like they viewed me as what I was in the school. They viewed me as me. They didn't see like my family life

**DS:** And was that good actually?

**YP:** Yeah. Because then nobody, cause the worse thing ever I think for carers would be, young carers would be in the school if the teachers started to say "well you don't have to hand your homework in" because the pupils will realise. They would be "oh well how come she does not have to hand her homework in and we are getting into trouble". And they will isolate you, as soon as they know. It needs an exceptionally good teacher for them not to do that.

(YP YC1 Lines 325 -426)

Different support systems are required for different people but the above emotive narrative demonstrates how personal experiences, even those in early childhood, can massively impact on one's future requests for support. This young carer required support within the home environment but received little guidance in finding the support she required. She also describes the need to be treated like any other pupil at school, so as not to be alienated or 'isolated' from others. It appears to be both a protective method preventing her from being viewed as different as in first school, and about personal identity, and the need to be a young person not a young carer. Eventually, this young carer gained support through her mother's adult carers group. Whilst an adult carer's group may not be the best support for a young person, who may have different needs from the adults, attendance to this group and contact with the key worker through it led to the development of young carers support in Northumberland.

Labels have emerged as strongly defined stereotypes within the stories. The young people described many instances of public and professionals judging them to be 'of a type' or pre determining their needs based on preconceived ideas about what a teenage mum for example would be capable of. The following young person describes her frustrations with professionals in maternity and post natal care.

**YP:** So I sort of knew what I was doing, but people just seem to talk down to me, like I didn't know what I was doing, because I was so young.

**DS:** Who were the people that were talking down to you?

**YP:** Like professionals. Like when I was in hospital they asked me if I knew how to do a bottle and explain how to make a bottle. So I explained how to do it. And they were going "well we'll still have to see your mam [mum], we'll have to show your mam how to do it before you leave the hospital". And I thought I've just explained how you do it and it's not wrong. If it was wrong they would have said, 'no that's not how you do it', but they didn't. "Well we'll still have to show your mam". I thought 'me [my] mother's had 2 kids; she knows how to make a bottle'.

**DS:** And it's your baby.

**YP:** Yeah, just cos [because] I'm so young. They weren't even willing, going to show me, they had to show my mam and it's not right. It's my baby not hers. I'm the one who is going to look after him....And just different bits, like when the Health Visitors came and that. There was one really nice one and then one who would dig deeper and deeper into things.

**DS:** But it didn't matter.

**YP:** No, I didn't know, I just started going off professionals. I just thought if they all think [pause] then, what's the point of even .... You know what I mean; I just thought what an opinion they've got of me. They don't even know me and they've just got this big opinion of me. **YPTP2 Lines 197-224** 

These quotes emphasise why the dominant discourse representing young people as lacking knowledge and competence needs challenging. The midwives were in a prime position to support and praise this young woman but appear to have missed a clear opportunity to do so. Recourse to John's work (2003) on power in Chapter 2 in relation to children's rights is relevant to consider. In the preceding quote, the midwives involved have struggled to relinquish their adult power, i.e. by ignoring the young person's ability and knowledge, which in turn undermines the young person's chances of independence and potentially limits the development of the young person. Here the professional in a position of care and authority 'divides' the power and responsibility up (as explained in Chapter 2), where a 'shared' approach would have been more empowering for this young mum.

The following participant interviewed because she had been in the looked after system, was also a young mother. She explains how people's preconceived ideas have impacted on her parenting. This appears to be a protective mechanism to prevent 'labeling' and finger pointing occurring.

**DS:** What's it like being a young mum?

**YP:** Fine. I got told it would be dead hard. I am very funny though, like I will always have my kids clean. I will go out and I will always say to him [partner]. He says "ah what are you doing, he's only going to his

Grandma's". [She says] "Yes, but I am teenage mum and people look at my kids more than they would like at a 30 year old's child". I like them to be presentable.

**DS:** So do you think you are just more aware of how people judge you then because of your own circumstances?

**YP:** Yeah. People look at you and then look at your kids and look at you like that [ pulls a disapproving face], so I am a bit like that, I like, I don't want people looking down at my kids because I do quite a good job, I think I do a good job.

**YP LA1 Lines 947-969** 

Whilst it is essential that young people can openly share negative accounts, there are also many positive examples of how young people see their key workers. YPTP2 has positive role models that treat her with respect, and here again the value of not labeling young people is seen. This young woman described the loss and abusive behaviour of many of her friends during her story, and could so easily have role modelled their poor behaviour.

'I value that they [key workers] listen, that's the big positive, because they listen, they don't judge you. None of the people I work with judge you. And most of them treat me normally. You know, when I used to speak to J and that, she never ever treat [treated] me like I was a kid. She always treat[ed] me like I was a person. I used to love talking to J because that was the way she treat[ed] me. G and K were the same..... Yes, because I used to hate being pointed out as that's a young mother. I know I am, but I'm also a person. I'm also me. I know I'm a young person, I don't know, that's just the way I used to think. Because it's true I wasn't just a young mother. I was a person and well as a mother.'

**YPTP2 Lines 954-972** 

The issues of labeling and stereotyping raised in the stories highlight an important developmental need for all professionals working with young people. A simple change in the construction of a sentence before referring to the young person may make the difference between feeling respected or not.

# 8.3 The impact of participation and involvement work on young people from their perspective

The impact of sharing one's voice, views and feelings is expressed in the narratives in many ways. Analysis of texts reveals both impacts on the young people themselves and on the services with which they are aligned. However, not all young people experience equal impacts as one would expect, with each individual on a different journey with a different starting point and varying needs.

The direct impacts shared by young people on themselves were:

- · Greater recognition of self worth and self value
- Increased confidence in own knowledge and ability
- Enhanced skills (Interviewing, facilitating, listening skills)
- Opportunity to express self, feelings and reflect on own situation therapeutic effects
- · Development of new relationships
- Increased aspirations

Whilst the above are a combination of the information shared across all the stories, in the interviews with children who had been excluded from school, no service impacts were stated and there were few examples of collective work. There were no mechanisms to directly get young people's voices heard apart from via the key worker acting in an advocacy role. The individual impacts listed above are often strongly interlinked and related to each other. For example having access to a role model is strongly linked with increased self confidence. As the young people learn through their key workers, model their behaviour based on experience, they subsequently develop confidence.

The following is a description of the impacts that the young people shared either directly to questions or naturally within their accounts.

8.3.1 Increased self worth, self value and confidence

The young travellers in this research were the youngest of those interviewed. The

following 11 year old girl had been involved in participatory action research since

she was about 8 years old. She describes her actions when at a conference an

adult makes offensive remarks about travellers.

**YP:** Well, on one occasion, they did not know that I was a traveller, I was with X [Key worker], and they got them [the conference participants] to

write down what they thought about Gypsies, and one of them wrote down "dogs".... But they did not know, anyway and then, they did not ask them to like put their name on it or nothing so we did not know who it was from.

Then I stood up and said "well actually, I am a Traveller, and we are not dogs, we are quite educated. Em and when it had all finished they said

'great one'.

DS: Absolutely fabulous, how did you feel about standing up and saying

that?

YP: Well the look on the peoples faces, it was just like "ah" [shows

shocked face]

**DS:** Well they probably thought you were really brave

YP: Yeah

**DS:** Did you feel proud?

YP: Yes

YP TR1 Lines 825 - 859

This is a worryingly confrontational example of how young people can be

exposed in a public conference situation, and raises training needs for staff. It

also emphasises why some of the preparatory work is important in building

resilience prior to such exposure. However, as a result of some of her work this

young girl feels that she can challenge and change people's attitudes. When

asked what she felt the best bit of the conference was she states:

'What we have got out of it? Like em, now I think people are trying to, sort

of like change their views about it [about travellers].'

**YP TR1 Lines 877-878** 

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This ability to influence is evidently empowering and helps to build confidence. During the interview an inner strength and quiet confidence is seen which is exposed in her ability to stand up in front of an adult audience and voice her opinions, and stand up for her community. This exposure to prejudice in the real world and experience of positive action to challenge such views further reinforces her confidence and knowledge.

The following teenage mum in dialogue about her experience of presenting at a 'Connexions' Conference talks of a growing confidence and what inspires her to share her voice.

**DS:** What's the difference in how you felt between moving from that first stage where you got involved, through to actually standing up in front of a group of professionals, where you know best?

**YP:** Erm, I don't know, I did think it was a bit different. I thought, "Well you are going to sit and listen to us". It wasn't until it got a lot later on, yous [you] are going to [decide] whether you want to or not. Cause we are the ones that they should be listening to not the bloody professionals. Professionals don't know what we know.

**DS:** No, that's absolutely right.

**YP:** And they want to work with people like us, therefore they have to listen to what our views are. There's no point in just saying to somebody from the Teenage Pregnancy Team, ah we want this, this and this. They're best off talking to the people - aren't you?

**DS:** Absolutely

**YP:** If I wanted to know something about a job I would go and see somebody about that job. I wouldn't just talk about it to other people, there's no point in it. Am I making sense?

**DS:** Yeah, absolutely.

**YP:** I wasn't bothered. I wasn't bothered what it was going to be like. I just thought I'm going to get my point across.

**DS:** It sounds like by that stage, how long ago was this, about a year ago?

YP: Yes

**DS:** It sounds like what you've described is quite an increase in your confidence.

**YP:** Oh, yes, my confidence is growing and growing and growing. **YP TP2 Lines 684-719** 

The following young person describes the fun she experienced in sharing the work she undertook at a conference back home in residential care, and her movement from shyness to pride and the strong emotions that run alongside.

'It was just absolutely brilliant. But two months later, when we come [came] back...I had to do it all again in front of all the residential care officers....

Why we had done it and how we represented it. Eee I was so embarrassed. There was staff from XX, there was staff from XXXX. Eee my god but there was three members of staff from XXX I knew, they were sitting there making faces and everything and I was standing there trying not to laugh. And I says 'Right I need a break' right in the middle of the whole lot cos they were making is [us] laugh so much and it was just great.' YP LAC2 lines 478-495

When asked what the experience was like from the beginning to the end, she continues:

Well I was doing it in front of all the staff, like the residential care officers. I was like shy and everything but by the time it was all finished I felt great in myself and then I started crying because I was so proud of myself. **YPLAC2 lines 506-509** 

The participatory experience has clearly developed and challenged this young woman and has resulted in positive personal outcomes. Such epiphanal moments are not always overtly obvious in participatory work, but these experiences should not be under estimated in a young person's development.

Often the increased self worth, self value and confidence leads to an increased self awareness. It is hard to distinguish whether the impact on the young person

is as a direct result of the participatory work or whether it is due to contact with the key workers through normal service activity and the advocacy role; or whether it is simply as a direct result of the challenging circumstances they find themselves in. When asked directly what the experience of being in care has been like this young person reflects on her situation and states:

'Like being in care has made me open-minded, like drugs and sex and stuff like that, its hard. Like if I see a homeless person, I am not like "urgh", [shows repulsion] I always go up to them and I talk to them and I give them some money or I will, if I don't give them any money I will go out and buy them a cup of tea. And say "there you are, I cannot give you money but I will give you this". So I am very open-minded. I am not racist, I am not nothing [anything], I just get on with it, because I know how hard it is.'

YP LAC1 Line 936 – 941

It is possible that some of the exploration of feelings, some of the skills development and personal support through discussions with key workers may have helped the young person develop into this sensitive and aware young woman. However, the impact may simply come from the broader and more complex life lived by this young person, and the things she has been exposed to.

## 8.3.2 Enhanced skills

In order to involve young people in sharing their voices many of the key workers have instigated specific training to ensure that the young people can play an active role. Much of the training is aimed at participation to improve services. However the key workers are aware of the impact on the young person in developing life skills which may increase their future opportunities by building their capacity.

During the interviews many young people shared skills that had naturally developed though the course of sharing their voices. However, they were all directly asked what they thought they had personally gained from the involvement work.

This young traveller, a boy aged 14, spoke of the importance of the NVQ he had gained through undertaking participatory research. He also spoke of the rewards he had received, from helicopter rides to residential weekends. He stated that the qualifications were more important than the other rewards. When asked what the experience meant to him personally he states;

**YP:** I have learnt how to talk to people and not like, I have learnt how to communicate better.

**DS:** You're very confident. Do you think you confidence has increased?

**YP:** Yeah I am not that shy of people anymore.

**YP TR2 Lines 1161-1166** 

In the closing conversation with a young teenage mother who has been involved in sharing her voice through group work, peer education and conference work, she clearly demonstrates improved communication skills, emphasising her controlled response in a tense situation. Again this sits hand in hand with an increased confidence, and demonstrates the therapeutic effects of participatory work (See section 8.33). Importantly the young woman has learnt to value her own contribution.

**YP:** I sort of get a buzz out of it. It's sort of addictive, once you do one, you've got to do another one, but every time you've got to push yourself that bit further. I think it's just to say I've done it, but every time I do it I get a bit more confidence out of it. So I do like doing it, and think I could anyway, especially that one at the Holiday Inn. That was a really good one, because we were put into separate groups and stuff. And there was [were] a lot of women, well there was one woman, who was just like, going on and going on at me about something. I don't know it was about being a teenage mother. And I thought, honestly, I could not sit there any longer and that was it I had to bite back. I wasn't nasty or anything, I was very good, but I told her exactly what I thought in a very nice way.

**DS:** [Laughs] more controlled.

**YP:** Yes, X [key worker] said she was very proud of me.

**DS:** And how did that make you feel when X said that?

**YP:** I could have cried. It was a long time since somebody had said that to me. So yes it was very nice. But, yes, this woman just kept on going and I thought she can't just sit there and assume what young mothers think. So I thought right, there were other young mothers in the group and I thought they are not going to say anything so I will. So I did. And then she shut up.

#### YP TP2 Lines 1017-1039

Whilst an obvious confidence has developed as a result of her own commitment, the role of the key worker in acknowledging her positive contribution was as important in maintaining her confidence. In many cases the key worker is the only person who offers a positive response to the young people's actions. In the above quote that simple acknowledgement by the key worker that she was proud of the young person not only made the young person feel good, but also positively reinforced her actions. The following final paragraph sums up her confidence and knowledge that what is shared will be of use.

'The only thing that I've really learnt is not to sit quiet[ly] and if I've got something to say, say it; because it normally comes in useful for people. That's really it probably.' **YP TP2 Lines 113-1140** 

# 8.3.3 Opportunity to express self and the therapeutic effects of participation

Whilst some of the young people verbally state how they felt emotions such as 'pride', others describe physical manifestations such as 'tears of joy' or achievement.

In the final paragraph of the young carer's account previously shared the therapeutic effects of sharing her voice are clear to see. Participation in the carers' support project and sharing her story in a conference situation has enabled this young woman to reflect on her life for the first time and better understand her personal circumstances and achievements. Within the following paragraph she shares her grounded almost stoic view and creates a positive emphasis from a potentially damaging experience.

'No. I was fine, and because I became involved in this volunteer thing, like just to speak about like my experiences, em, that helped me. Because like I was telling somebody it and I was thinking through in my own head while

it was happening. Because I had never actually thought about what had happened all the way through until I did my first talk, and it was just like, it makes you feel good about yourself. Because you think well this happened, and this happened, but like I don't regret it. Even though I got picked on at first school about it, I don't feel as if that wrecked my life or anything. I think it actually helped me, because you become stronger. I know it's a cliché, but you genuinely do'.

**YP YC1 lines 430 - 438** 

Within this epiphany, a first focused reflection on her own life, and the experience of participation, she describes a personal growth of strength of character, as many of the other young people do in their accounts.

A young person from the Looked After system describes her first experience of being able to express her feeling about being in care at a workshop and conference. The opportunity introduces her to new ways of learning and self expression.

**YP:** I had the opportunity to go to the Conference in Scotland for 3 days, so there was me, me ... 3 lads and two members of staff, N and C and we went along for like the weekend and it was great....I mean we had our say in what we wanted to do, we got to name what we wanted to call the conference, 'A Life for Us' and it was just the most amazing thing I had ever done in my life. I mean there was like a big massive group of people at the end because I had decided to do the art image, how I feel care is but in the painting.... they just wanted to know how we felt in care but I decided to do painting on it. So what I fancied doing is I done [did] like a em, it was like the streets of New York sort of thing; and this little person sitting next to the like house and then there's a river in front of them to see the reflection. And it's like when you're in care you can be lonely or you can, but on top of one of the buildings we put like these little disco light things on all different spot of paints and that, or you could be happy up a height like the lower you are the lower your self esteem is. The higher you are the happier you are, and I just found that amazing and ...

...There was [were] loads of people; there was people from Africa, not Africa, em Iraq and things like that in Scotland. And well the two Iraq lassies we were stopping with, we didn't understand a word they were saying but they were pointing at us and trying to tell us stuff and we just had to get their foster carer to translate ...

Some put their ideas out into drama, there was 4 of us that done the painting, 3 of them that done the street dance and 6 of them that done the big massive poster. And like the members of staff were there to help us and give us ideas, but they weren't allowed to do it for us.

...And when we done it in front of all the big... well I call them bigwigs cos they're big people and their higher up in their jobs and things like that.... we had to read it out but then 3, like ...Well I was just reading, cos we had done the painting we decided we would do a story to go with the painting and I had to read out a bit where it goes "life isn't always sad when your in care cos you've got a lot of fun and opportunities like this one, coming to Scotland and showing how I feel with other people from all over the world". There was [were] people from America and everything. It was a great opportunity to meet all those people who had the same feelings and who are in the same situation.

**DS:** But from different lives?

**YP:** Ahuh, totally different lives. I mean the lassies from Iraq weren't that rich, but the people from America were loaded with stuff. It was amazing, well yet I'm just stuck in the middle just a normal person really....

YP LAC2 Lines 389-459

The narrative demonstrates a number of opportunities for learning and expressions of self. Learning about the culture and experience of others helps the young person personally reflect on her own circumstance, reaffirming a sense of self. This young woman was able to place herself in a position of 'normality' when comparing herself with her peers. She judges the others in relation to wealth or poverty but in doing so considers herself to be a 'normal person'. She clearly expresses herself and her feelings through the reflection in the river, and describes the highs and lows of being in care, and demonstrates an awareness of how this has impacted on her self esteem. Listening to the tape a second time, the young person is heard to describe her experience and 'opportunity' with great passion. What is not clear is whether the participation would have been any different for any young person experiencing an international setting for the first time. However, what is important is that this young person has been given a unique opportunity, and her positive experience and passion is clearly evident through words such as 'amazing', 'a great opportunity', 'it was just the most

amazing thing I had ever done in my life'. What is also important is that this memory is recalled directly after the young person had just shared and described her fraught family and social life.

### 8.3.4 Development of new relationships

The young woman in the Looked After system above clearly describes how the participatory event has led to new relationships albeit passing friendships. Such exposure offers the young people a chance to build friendships beyond what at times is a limited social circle and discover different cultures and the bigger world out there. Whilst this is part of growing up for most young people, for some of these young people huge financial constraints can lead to a lack of opportunity that perhaps others will be exposed to.

Morrow (2003, p166), by exploring the social networks of 12-15 year olds, their sense of belonging and identity, and the extent to which they engage in civic and local community activity, highlights the importance of friendships. In their written and oral accounts, social relationships rather than geographical place impacted on how they felt about where they lived. A young person's proximity to their friends helped determine how they viewed the neighbourhoods and also gave them a strong sense of belonging.

Throughout the narratives it is evident that the participatory event extends the young people's friendship groups, which for many of these young people living transient lives may also help increase their sense of belonging. Putnam (1995) refers to the development of these more distant ties as 'bridging' networks and relationships, which he believes bring together socially and economically different people, leading to increased social harmony and prosperity. Unlike financial capital, social capital is not expended when drawn upon, but acts to build the capacity of individuals and communities.

The following account from a teenage mum demonstrates how the participation improved and extended her friendship circle in an environment where she had previously felt ostracised.

'I never really had many friends around me because they all disowned me, after I got pregnant with X. Just sort of dropped away from me, spoke to me when they seen [saw] me. Apart from one, who was a lad and has been friends with me for years and years. He was the only one who still bothers with me. So that's quite hard. So I got my friends back when I went to that Young Mother's Group and I'm still in touch with one of them ... So things just got better from then for me' **YP TP2 Lines 300-306** 

For others where participatory opportunity has been limited it is social circumstances that have led to new friendships, and although many young people acknowledge a role model as important, often finding a person that prevents them from being 'different' helps normalise life. This young woman excluded from school also found herself in care.

'And the other person who has influenced me has got to be X [a friend in care], because what she's been through, I've been through, we've been through more or less the same things, like, she got hit off her step dad, I got hit by my step dad. Her mam [mum] didn't want her there, my mam [mum] didn't want me with her and we were just like, we were just the same.' **YP EX2 Lines 1169-1173** 

The looked after system offers her an opportunity to form extended networks, which have been lost through school exclusion, particularly important where as above the 'bonded' family ties are broken i.e. close family, friends and neighbours, (Putnam, 1995).

Through the involvement work and care systems, many young people describe the development of new friendships, and these also act as enablers to take part. Many of the new friends have experienced similar difficulties and these mutual experiences help bind them together and strengthen their voices. Opportunities to meet others build new friendships and share their new found skills in group sessions should not be under estimated as a positive impact of participatory work for marginalised young people. This finding adds to the evidence base that participation increases friendship groups and strengthens peer relationships (Kirkby and Bryson, 2002).

## 8.3.5 Increased aspiration

Throughout the stories all the young people have some aims and thoughts about where they would like to be in the future. Many of the aspirations directly link to their own difficult circumstances. For example YPEX 2, a young woman who has spent a great deal of time in and out of care, is motivated to get her GCSEs so she can follow in her role models' footsteps.

'I just wanted to get my GCSEs; they're the main thing to me. I mean I am I feel stupid for getting excluded from school'. **YPEX2 Lines 641-2** 

'I want to be a Residential Child Care Officer, but you've got, there has to be 4 years gap between you and the youngest young person and the youngest young person you can take is 18.... So I'll have to be like 22.... as long as you've got GCSEs and you've been to college and you've got an A' Level in childcare. You don't even have to go to university if you don't want to.' **YPEX2 Lines 737-755** 

The young man excluded from school also shares employment aspirations. He is buoyant when he walks in the room as he has just secured a training place after an interview through the support of his key worker.

**DS:** So what do you think has changed for you in that time, you know from the time you said you were a 'bit bad' and you were acting out a bit

**EX:** I think that everything is alright now.

**DS:** What changed though? What made you a different person do you think?

**EX:** Like getting on to this course, realising that I don't want to be bad no [any] more. I want to stick in with it and get a job.'

**YP EX1 Lines 60-68** 

When asked how he has shared his views at one to one interview with his key worker he states:

'Well, I just said that I wanted to err do something more practical.'

YPEX1 Line 86

'That's all I have always wanted to do, just doing something with my hands.' YP EX1 Lines 298-299

Sadly, this young man was not offered employment after he completed his work experience and things started to go wrong again. This culminated in a conviction and time in a young offenders' unit. This demonstrates how fragile the complex lives are and the continued vulnerability of these young people when support diminishes. Key workers attempt to raise aspirations but must confidence build to ensure young people are able to deal with disappointment.

For others aspirations appear straight forward but given the complex lives many are living, a great deal of support is essential to help the young people realise their aspirations. YP LA2 simply wants an opportunity to work with children, and is presently studying childcare at college.

'I really want to work like, I don't care who I work with as long it's between babies and 16 year olds...' **YP LA2 Lines 721-2** 

However, she shares numerous hurdles to maintaining attendance at college and the support in place necessary to keep her there. She shares stories about broken friendships, the father of her child verbally abusing her or ignoring her at college, and the emotional difficulty of being in foster care away from her biological family.

Some young people such as the young man above (YPEX1) have grounded and practical aspirations, others through their circumstances and inner confidence aim higher. The breadth of aspirations is wide ranging. For the young carer interviewed she demonstrated immense person resilience and drive and in her opening paragraph she states:

'I have just finished 6<sup>th</sup> form now, where I was Head Girl, waiting for my results on the 18<sup>th</sup>, its going to be a nightmare that day. [Laughing] And then apply for University after that. I have been predicted three A's, so if I get them then I will be applying at Cambridge to do Social Sciences and

Politics... because I would love to be Prime Minister.' [Laughing] **YPYC1** Lines 13-20

## 8.4 Impact on services

The direct impacts shared by young people on the services with which they are engaged were:

- Services improvements
- Practice improvements e.g. Increasing knowledge & skills of professionals
- The ability to help others like themselves

Some of the accounts help demonstrate where the young people's voices have literally changed service provision. Other demonstrate more subtle changes, such as challenging professional views and stereotypes that in time will impact on how the young people are viewed and treated within services.

# 8.4.1 Service improvement

A young person from the looked after system who has been involved in an 'after care group' describes the impact of her involvement primarily in service development. As she shares her perception of the impact on services, she expresses pride in her ability to influence change.

**YP:** I don't know, just that we were finally getting Social Workers setting everything up. You were allowed to be part of that, making decisions. And then where it would come up was like 'I helped do that', makes you really proud.

**DS:** Excellent. Yeah. So you did see changes happen then did you?

**YP:** Pathway plans changed. We started to get listened to off Social Workers and we weren't just clients and just another kid in care, we really got listened to. Really being able to like, if there was something we didn't like about the after care workers, we were able to say "well we don't like that attitude. We don't like this". So it has been good. **YP LAC1 Lines 448** - **466** 

This quote again demonstrates the importance the young person places on being viewed as responsible and important rather than a client with an ascribed label.

#### 8.4.2 Practice improvement

The same young person also described developing a training video by interviewing and filming professionals including senior managers involved in providing the after care system. The aim of the video was to train and raise awareness amongst professionals working with young people in the looked after system.

'But we did everything. We thought of who we wanted. Like she said we have got like three groups. How you want to look at – was it care workers, young people and like big bosses. Who do you want [to interview] and we all sat down and said "well this is good". We could not really think of much [many] foster carers and X said well there is a great foster carer in Washington. She is fantastic. She said we will go and see her.'

**YP LAC1 lines 570 - 574** 

This work was followed by development of an adult focused and then young person focused sexual health policy for young people in the looked after system.

... I did last year's one, that was the sexual health with XX. She wanted to make a young person's sexual health policy which I was consultant on that ... And like we had to ask other questions, go out and ask questions again. And it was just, she was just asking us questions and what we would put in it. Like "what do you think about contraception", what do you think, and we had to put it in. But I think that was for the adults section of the health policy. X decided there should be a young person's one... Cause, like we could look at the adult's one but it was like that thick and we could make it shorter and use our words... Instead of like the big complicate words, we could like use silly things instead of penis we would use Willy or something. Just make it for us, and that's what we did.

**YPLAC1 Lines 628 -693** 

The young people's involvement in changing and developing practice has knock on effects for the next generation of young people coming through the system. A young mum encouraged to share her views with the teenage pregnancy team, helps influence the service provision in setting up a new group for young mums.

She is able to change the professionals' views regarding what is needed from the onset.

**YP**: [They said] we were going to open a new mother's group thing, and then they wanted our views on that, so I told them my views, their ideas were just crap.

...They just wanted to open a group to young mothers and what things they should be doing and stuff and they were putting courses on and things like that. And I said 'well at the beginning of a new group you can't put courses on because that is going to put people off'. You've got to get people into, get them used to each other, before you start courses. Your better off putting like a 'mother's drop in' to start with, just so people know they can go.

**DS**: More of a social thing?

**YP**: Yes, just so they can get used to each, because I wouldn't want to go to a course, like to just start off with at a real young age, I would want to know the people that was there first.

YPTP2 Lines 636-654

The social connections are clearly a priority over the intellectual ones. Meeting other young people and forming friendships is essential to sustainability of the groups. Many of the young people clearly state that their involvement is aimed at helping others like themselves, again reiterating the importance of the social component meeting.

## 8.4.3 The ability to help others like themselves

Service and practice improvement is driven at times by the young people's desire to improve the services for others like themselves. Helping others can be about creating a positive physical image of other young people in similar circumstances i.e. challenging and changing professional's views. The young carer shares how some people expect young carers to be physically different. After one presentation to adult mental workers she recalls a comment:

YP: But somebody says "you know what you look exceptionally beautiful" and you got the impression that they thought that carers are ugly and that, that they don't look the same as anybody else. They don't look as if they

care for their appearance or anything, and I just, I think it's, think it's nice that they actually say it because you think this is a normal person.

DS: That's strange isn't it?

YP: Somebody else said, "You know just looking at you I would not have thought you were a carer", and I was thinking well I can't understand what one really looks like. (Laughing)

YPYC1 Lines 583-593

This young woman wants to help other young people in caring roles and links helping others to feeling good.

'It's like self-satisfaction, because you are doing it and you think, "Well hopefully this will help somebody else" **YPYC1 Lines 504-5** 

YPYC1 talks of sharing her voice to improve things for young carers and what motivates her to do so. Her connection with other young carers creates emotive experiences which inspire her to continue to share her voice to ensure service change.

**DS:** And so did you learn through that experience?

**YP:** Yeah. I think you learn that no matter what you are doing, there is always somebody worse. Like there was this one girl that, she had like, she had to live with her Grandma, because her Mother was trying to commit suicide the whole time, so I thought that would be the worse thing ever....She was only about 8. That's what really hit you. Em,

**DS:** So do you go away from that feeling ok?

**YP:** You feel a little bit, you feel sad for them, but like, it drives you to want to change things even more if you can... So when you are asked to do something else, you are like, yeah definitely.

YPYC1 Lines 1025-1047

Personal motivation and drive results directly from the voice sharing opportunities provided by the key workers, and helps ensure a continued engagement of

young people in helping services improve. A necessary challenge to practitioners and services emerges.

When directly asked what it has been like being involved in so many things YPLAC1, a young mother and person from the looked after system states:

'I enjoyed doing it. I don't know why because people look at me as if I am stupid. My partner he says "why do you do it, you are not 10 no [any] more, you have got two kids to look after, why do you keep on doing it?" I don't know myself. I just love doing it, anything which needs doing. Like, we are trying to constitutionalise our group [after care steering group]. Yeah, but we are going to make our own group and like X and X [workers] are going to like take a step back and we can do events and, to make other kids better, like, do you know what I mean?'

So we are trying to get funding off the "big boost" which I have been doing for the past month trying to write out, because a lot of us didn't really understand that like all the forms and that. I said to X, give me it here and I will go through them and I will write it for us. YP LAC1 Lines 1018-1039

Even against significant peer pressure she has continued to be involved and demonstrates a movement and desire to lead and take more responsibility. The primary impact of 'enjoyment' motivates her to be an active member of the group to make a difference for 'other kids'. This personal enjoyment and desire to improve things for others indicate that there is a reciprocal driver. The desire to share their voices because they want to make a difference not directly to service provision but to help others emerges in many of the accounts. The young person is often inspired to help others in similar circumstances to themselves. There are numerous conversations within the stories where young people appear to be inspired in this way. For example, a teenage mother about to embark on delivering peer education in school is asked how she feels about this.

"...Scary to know that I will be doing it, but relieved that I am doing it for a good cause. ....For the young mums really, and children".

YPTP1 Lines 1288-1293

When asked what could be improved for young mums, the same young woman talks of speaking on their behalf. The following text demonstrates her ability to advocate and therefore help others. This could be because she has personally

received positive support from her key worker and she has built the confidence to do so.

**YP:** To speak up for them if they can't speak. Half of them [those] girls in Sure Start, when I go on a Thursday they are just, they are quiet and unless someone speaks. Like last week, no-one spoke and we had this massage we were all getting, which is like [we] get paid really for like speaking and things like that, em, but no-one spoke, and I thought well, am I going to be the one who speaks or is J going to speak? And I just thought V [refers to self] just open your mouth and speak, so I did.

**DS:** And that encourages the others to start does it?

**TP:** Yes, for someone to speak and like to start conversations. **YPTP1 lines 1270-1279** 

Whilst many young people clearly felt positive about their involvement, young people's awareness of the impact that sharing their voices has had on services was at times poor. Feeding back outcomes and impacts of participation is seen as essential and good practice (Wade & Badham, 2005).

## 8.4.4 The feedback loop

A number of young people were unaware to what extent sharing their views had in changing practice or indeed about how the information shared was used, others guessed and some, who were involved in explicit work, saw a clear outcome i.e. in policy development.

A young girl from the traveling community was involved in a piece of participatory research, was trained to undertake interviews with her elders with other young people and took part in collecting a huge amount of important data about the cultures of the traveling community. When asked what resulted from the information she thought very hard and stated:

'I think it went out in the book, like the shops and that' **YPTR1 Line 292** 

But it was clear that although this was shared as a positive experience she was very unsure of the outcome.

Sometimes young people were frustrated at not being listened to, and although rare this young woman shares an interesting tension that emerged from some participatory work undertaken to improve communications with young carers. She talks of falling out with one of the participation workers, and when asked why she states:

**YP:** Ah, because I am designing these leaflets for them, and like, I am not getting paid for it or anything because I did it out of ... I think I was kind of forced [laughing]. But em, I am not going to lie, but they look really, really good, but she does not like [them], because she thought to an extend one of the lines was an insult to the Care Trust

DS: Why?

**YP:** Because, it was a quote by a Carer who said em, lets try and remember "to take on the role of Carer is a journey into the unknown, little information is given and little signposting", and that was it.

**DS:** That's fine that is true.

**YP:** No it's not apparently. So me and her had... well she called it an argument, but I prefer the term discussion. And she [laughing] I know, I think you work in the Care Trust, but she was, it was as if she was censoring it. I did not like that, so I stood up

**YP:** I don't think it went down too well for her

**DS:** So is it staying in the leaflet or not?

**YP:** It's been altered, because what happened was, I don't really know her, I am just being paranoid, but there was a second meeting last week, and em, there was three other people there who had all had a meeting with X that week without X telling anybody else, and em, they all started having a go about it, just to me as well, and I felt I could not stand up for myself against three.

**DS:** Ah that's a shame

**YP:** Three professionals, I could [stand up] against one no problem, but not against three.

**DS:** So that's interesting, isn't it, in itself that you felt empowered to do the leaflet and to share that stuff but when it came to the crunch and people

did not agree with some of it, then you did feel less empowered. Well disempowered.

**YP:** You know what I think, the only way that things will possibly change, if each of the groups who are trying to help carers, I think if they started to work together and stopped having their own agenda. **YPYC1 Lines 263-309** 

The conversation raises concerns about professional versus lay power, which appears imbalanced. Feedback regarding this young woman's work raises questions regarding the degree of clarity given prior to starting the work, as to who would have the last say. Fielding (2004) suggests that children's views and voices may be subverted if not in keeping with the adult's agenda. This has the potential to silence voices in a process which sets out to encourage them. The young woman concerned was a confident and intelligent individual and was able to defend her view to a certain extent. Other less confident individuals may have felt less inclined to continue to take part. These tensions raise training issues regarding participatory practice and devolvement of power as an important implicit part of good participatory work. It also raises issues, not unlike ethical research, regarding where the resources and funding comes from to support for example the production of leaflets generated by young people's views and needs. The young carer above felt obliged to conform as the following quote illustrates:

'Like, we had to change that because we are getting a certain amount of money from the Care Trust and I think they were worried in case they would not get that money anymore because the leaflets would not be able to be produced without.' **YPYC1 Lines 312-14** 

Feedback is strongly linked to clarity of purpose about participation, roles and responsibilities. Understanding the outcome of a piece of work or knowing how structures allow for the continued sharing of young people's views are an important part of the process and may influence the personal impacts on a young person. The researcher found little evidence of feedback to the young people. This may be due to the primarily adult instigated, project focused participation

exposed and will be discussed in Chapter 9. The lack of feedback may result in young people believing that no change resulted from the participation, which can result in young people feeling that the participation has not been taken seriously (Kirby et al, 2003)

## 8.5 Attributes of the key worker from a young person's perspective

The young people's narratives were analysed to determine the attributes of the key worker in line with the key objectives. In doing so three key themes emerged as follows;

- Access to and learning from a role model
- Advocacy
- Personality

## 8.5.1 Access to and learning from a role model

Key workers have the ability to positively improve the lives of these young people and although they are aware of the importance of their behaviours they may be unaware of how the young people view them. The following clearly demonstrates the effects they have on the young people. This young person describes the impact the key workers have had on the group.

Everything, they've done everything for us. I mean the whole group. I mean we have our moments with J and V sometimes but I know the group love her....I mean J and V have done a lot for us really. They brought out my confidence that's for sure. Cos ever since I was pregnant I was getting called fat and everything, and I felt that when I was with J and V I just lightened up. I bloomed apparently. When you're like at school the whole situation is different, people calling you and throwing things at you like. But J and V have changed my whole world as well as the staff at K [Residential Unit]. I mean I used to be bad tempered, but when I met J she was so calm. And I had this argument with N and she sat there like that [sits back calmly in seat in relaxed manner, with slightly crossed arms]. And I turned around and says 'I'm sorry I forgot we were doing a meeting here', I just get carried away when I argue with people. She was just like "it's alright it's a little blip". But now when people argue I just think of J sitting there like that, then like I'm not even getting involved.'

YPLA2 Lines 920-943

The young person can clearly visualise the situation and her key worker's posture

and words. This directly demonstrates how the young person manages her anger

differently by replicating the passive behaviour of the key worker.

Role models are not always traditionally nurturing. Some young people respect

their key worker because they push them into action. TP1 describes her initial

uncertainty about taking part. When asked what influenced her to do so, she

states:

YP: Probably the persuasion of the midwife...she has had a very big

impact on me. [Laughing]

**DS**: Is that good or bad?

**YP**: Quite good actually.

**DS**: So is there a certain amount of persuasion that is needed, because I

think there is a fine line between wanting to do it and being persuaded

against your will isn't there?

**YP**: Because like, what I do on Monday with [key worker], she persuaded me to go to that one and she actually ripped like my slip out for me and

sent it away. And I thought to myself "she can't be doing things like this",

and I turned around and I went, 'I am glad', I went, 'I am glad she did that

because she like pushed me to do it'.

**DS**: Is there an element of that needed do you think?

YP: Yes

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**YPTP1 Lines 1207-1220** 

Participatory practice is bound up in empowerment, and a young person's ability

and opportunity to share their voice and help make decisions. Moving from

rhetoric to reality, where a vulnerable young person may find this a challenge

requires a number of strategies. Copying a role model is a key component of

skills development for vulnerable young people as it is learnt through good

practice and observation. Aligning role modeling with advocacy, particularly 'self

advocacy', where individuals or groups are supported to help themselves (Webb,

193

2002), helps to strengthen the learning. It also positively reinforces good social skills.

## 8.5.2. Advocacy

During the initial interviews some key workers struggled to define and contrast participation from advocacy. The key worker interviews exposed many instances of the worker acting as an advocate, with this being particularly important in the process of participatory work. The young people also describe the advocacy function within their accounts.

Advocacy was particularly strong in the stories shared by adults working with young people excluded from school. Young people excluded from school primarily talk of advocacy rather than participatory work. YPEX1 describes this function:

'[Key Worker] fought my case basically cause I was, you know when I was in school, I was at college doing construction, I got chucked out of the construction bit, and err, [Key Worker] fought my case and she says that 'he has turned a corner' and she has got me on to this course, called Block Paving'.

YPEX1 Lines 44-47

The following participant talks of advocacy qualities when describing the positive attributes of her key worker:

"...Someone who kind of values your opinions as well, who won't try and enforce theirs on you the whole time. Who won't say 'No, you should do it this way', when you have got a possibility of doing it another way.' **YP YC1** lines 816-819

The personality of the individual is important in advocacy work, and the young carer quoted above stresses the importance of the key worker offering hope, demonstrating real interest, and supporting when necessary. Personality was seen by all the young people as crucial to the sustainability of the relationship.

# 8.5.3. Personality

The key workers interviewed in this research all demonstrated a huge amount of knowledge and experience in working with young people from more challenging circumstances. The young people were all asked what they thought an ideal key worker should be like. The personality of the individual as an enabler is a very important part of engagement. Whether the key workers have to work hard to emphasis these elements of their personality or whether this type of work draws people with these attributes is not known. However, what the young people describe is important in training terms especially as most statements are followed with young people's reasons why they feel such personal attributes are important. For example, acknowledgement that the client group can be challenging but also that they are streetwise and will recognise disingenuous behaviour.

They've got to be very bubbly and they have to be very outgoing and got to have patience. I know if you work with me you need patience. **YPTP** Lines 984-5

......don't know they have just got to be friendly and be their self, because trying to be somebody else around you just doesn't work.

YPTP Lines 1003- 4

A genuine caring person, who can be relied on and with whom a young person can build a relationship with over time appears important.

**YP:** Somebody who understood what I was going on about as well. Like, em, sometimes you worry about like professionals, about how they are only there for their job and that, but I think with X you felt as if she was like, being, taking it on trust. Like me and her developed quite a good relationship. Like, I was attacked just before Christmas. em Just outside my house, when I was walking up the road, and he got away. We still don't know where he lives, but like I am going to receive counselling about that.

**DS**: Ah goodness

**YP:** She sent a card and everything so that was really nice. I think, outside is only good if you build up a relationship with them, not if like you

get a different person in every week or whatever. It has to be somebody that you like.

**DS:** Yeah, and em, what sort of skills do they need to have?

**YP:** I think it helps if they have got children. Cause then they understand like what it's like to have children, they understand to an extent young children just want what they can get and stuff like that. Em, but just being able to talk and having the time to talk, and getting back to your emails, rather than taking years to do it.

**YPYC1 Lines 769-791** 

This young woman who holds her own mother in high esteem also values the motherly instincts of her key worker, and the caring attitude she so clearly has towards the young person.

The longevity of the relationship, even with breaks in contact over time, is important where lives are so unpredictable. Where issues start to emerge again and support is required it is vital to have comfortable links. When YPEX2 is asked what she likes about the key worker she states;

'I like her, she's straight, she's very straight, she's understanding, I feel like I can talk to her, because she understands and I trust her 100% and I know I can trust her. I don't know I've known her since I was in Year 7, so that's .... 4 years, 4 to 5 years'.

**YPEX2 Lines 616-25** 

YPTP2 has positive role models that treat her with respect, and here again the value of not labeling young people is seen. This is the same young woman who has shared the loss and abusive behaviour of many of her friends, and who so easily could have role modelled their poor behaviour.

'I value that they listen, that's the big positive, because they listen, they don't judge you. None of the people I work with judge you. And most of them treat me normally. You know, when I used to speak to J and that, she never ever treat [treated] me like I was a kid. She always treat[ed] me like I was a person. I used to love talking to J because that was the way she treat[ed] me. G and K were the same..... Yes, because I used to hate being pointed out as that's a young mother. I know I am, but I'm also a person. I'm also me. I know I'm a young person, I don't know, that's just

the way I used to think. Because it's true I wasn't just a young mother. I was a person and well as a mother.'

YPTP2 Lines 954-972

The young man excluded from school holds extremely negative views about school and his victimisation by certain teachers still reflects on the attributes of one teacher.

'Cause like he was the only one teacher that like, that knew the crack, he used to crack on with the kids and that. Like all the other teachers were like proper like strict, like don't like talk to, like, err, the PE teacher used to say what have you done at the weekend and all that, but other teachers did not do that.'

**YPEX1 Lines 939-41** 

A genuine interest in the young people and an ability to not prejudge are important key worker attributes in maintaining good relationships.

The young people's narratives have enhanced understanding of the context of their lives and importantly how participation can assist young people in their development of broader life skills whilst giving them opportunities to share their views and feelings. Considering these stories alongside those of their key workers is important in developing practice and highlighting any differences essential for organisations to consider when working with marginalised young people.

In Chapter 9, a discussion of the findings in relation to the theoretical models and literature review at the beginning of this study is presented. Additionally key findings are presented with discussion of how the study builds on the knowledge base.

#### Chapter 9 – Discussion

#### 9.1 Introduction

This study set out to answer the question

'How can marginalised young people be assured meaningful, fulfilling and positive experiences when sharing their voices through participation?'

The question emerged from the paucity of literature examining the experiences marginalised young people themselves had when involved in sharing their voices. Outcomes, it would appear from participation, focused on service change, although little is known about how children's and young people's participation brings about the change (Cavet and Sloper, 2004). Where the literature evidences personal impacts from participation, the studies tend to focus on less marginalised young people or lack clarity regarding exactly which young people have been engaged in sharing their views. There is also little evidence of evaluation of the impact on the young people involved in participation (Kirkby and Bryson, 2002).

In this research the participation and its impact on the young people asked to share their views, have been contextualised. Young people's views of the key workers and the participatory experience sit within the complex and sometimes challenging lives they lead. The key workers' experiences of working with the young people sit within the context of their own personal experience of participation, of the groups of young people they work with and finally are contextualised within professional cultures and the culture of the organisation.

To a certain extent the research design and the whole research process, has allowed for the 'degree' of impact to be exposed. Previous researchers have highlighted many of the outcomes for young people stated within this research. However, in this study the young people share their views whilst also sharing detailed information about their lives. In this way the extent of personal growth and learning is given clarity, which many other studies fail to do.

## 9.2 The contribution to new learning

This research makes a unique contribution to the young people's participation debate. By examining in detail the key workers' accounts, a new way of working with marginalised young people is exposed, which in turn assists in ensuring that marginalised young people can have meaningful, fulfilling and positive experiences of voice sharing. By examining the young people's stories essential professional issues that will contribute to an increase in positive outcomes for these young people when shared in practice are highlighted. Primarily, the importance of the advocacy function embedded in participatory activity for these young people. This builds on Webb's commentary (2002, p175) suggesting the importance of advocacy, particularly for vulnerable young people, in making decision for themselves to meet their needs or where there is conflict with a carer. It has also increased understanding of the nature of some of these young people's lives that must be considered in determining the best way to ensure they have a voice. The attributes of the key workers have also emerged as important factors to consider alongside the key workers approach. This is presented as a new 'Model of the process of participation for marginalised young people' and is detailed within this chapter (section 9.4). It should be noted that for many adult facilitators working in this way comes naturally and is embedded in everyday practice. However, by exposing the processes and methods openly, novice workers, those that are less self aware, managers and organisations can be helped to understand the importance of working in this way for positive outcomes. As such some of the research is translated into practice through training and debate.

In addition to the learning regarding ways of working with marginalised young people, the stories shared have highlighted specific outcomes of participation for marginalised young people and their key workers. This has helped the researcher re-conceptualise the way in which outcomes are considered. As such a new 'Outcomes model of participation for marginalised young people' is presented in section 9.5.

Finally, the research design and process itself, has enabled new learning to emerge, and as such, by listening to and analysing the stories, the researcher has been able to contribute new evidence to add to the debate about how best to conduct research with marginalised young people and research embedded in practice, (Section 9.6).

Whilst the new models and ways of thinking are specifically important to working with more vulnerable young people, the principles are potentially transferable into practice for all young people. However, that said, this way of working is resource intensive given the vulnerability of the young people researched, and such intense work would be hard to resource for all young people. Understanding the impact of participation on both practice and the young person assists in promoting the whole purpose and importance of being a participatory organisation, one that moves participation from a legal imperative to a valued act. Participation should be seen as a catalyst for change at an organisational and service level and at the level of the young person invited to take part.

Learning and new insights from the research are discussed in more detail in relation to the:

- Theoretical issues, leading to:
  - A new model of 'Processes of Participation for Marginalised Young People'
  - A new model of 'Outcomes of Participation for Marginalised Young People', and
- Methodological approach
- Professional Issues

#### 9.3 Theory generation

This research is embedded, through its underpinning philosophy and the narrative research methods, in socio-cultural theory (Vygotsky, 1978). In phenomenology researcher observation must precede theory generation (Bowling, 1997, p128). Some believe that the goal of phenomenology is not to generate models and theories (Field & Morse, 1996). However, in research

embedded in practice (as is the case in this research), the generation of a model derived from the data is useful in taking evidence and learning back into practice, thus helping to ensure knowledge translation occurs. The idiographic method attempts to understand people and their social circumstances in relation to their uniqueness without attempting to make generalisations. Data are derived from the stories told with meaning assigned to the perceptions and experiences of the key workers and the young people. Interpretive researchers believe meaning occurs through interaction, and that perceptions and experience can change over time. The interaction between the researcher and the researched is important in producing further understanding (Bruner, 1984). This is a process of human interpretation.

During the re-listening to interviews and the reading of transcripts the many levels of interpretation were exposed. The natural sharing of an issue, followed by a justification and personal shared interpretation, was constantly evident. Most often the key worker or young person was openly interpreting their own words in order to make sense of it themselves. Further clarification often follows to ensure that the listener has understood, and this was sometimes followed by further researcher questioning, to develop deeper understanding or clarify meaning. It is this level of interpretation that helps justify and verify the findings. The natural investigative conversation results in a huge amount of learning through reflection, and potentially acts in the same way as collective participatory activity. It provides an arena for deliberation and as in Kashefi and Mort's (2004) 'deliberative democracy' as described in Chapter 2, can be transformational in testing and developing beliefs. It is anticipated that by taking this learning back into practice via dissemination of findings and discussions regarding the processes and pitfalls that the researcher can help translate this research into meaning for frontline practitioners. Knowledge translation through training, debate, and policy change has a huge potential to create a more responsive and reflective workforce.

The research process has resulted in a new way of thinking about participation – leading to theory generation. The research has allowed both the development of a new model of participation relevant to marginalised young people to emerge,

whilst also allowing the researcher to view with new eyes the existing models of participation discussed at the beginning of this study. The new emerging model is shared in section 9.4.

When the researcher set out on this journey a focus on exemplary practice was derived from the 'ladder of participation' concept (Arnstein, 1969 & Hart, 1993). The notion of power linked to participation is a concept especially important when working with more vulnerable young people who may have felt deprived of power at times in their lives. The notion of aiming high on the ladder to ensure joint decision making remains important, but somehow less important as the researcher reflects on the continually changing lives of these young people. Timely opportunities to participate at a level that satisfies present need for the young person should not be viewed as an easy option for the worker or organisation. Rather they present a view of participation that is young person centred rather that organisationally egocentric. For these young people an array of offers needs to be available. Participation methods and opportunities need to allow the young person to make the best contribution they feel they can at that time. Continued assessment of need 'with' the young person, drawing on the valued and trusting relationships built with key workers is essential.

Whilst some excellent work is described in these accounts resulting in positive impacts, most of the participatory activity appears to be adult initiated. Qualitative research draws on both critical and creative thinking (Patton, 1990, p434) and theory generation helps to increase understanding (Strauss & Corbin, 1990), and also generates new questions. Whether marginalised young people want to initiate participation and feel empowered to do so needs examining. There is some limited evidence in this study that through their work with adults, the young people now feel able to lead and sustain the work.

Tisdall (2008) in her re-examination of children's and young people's participation in public decision making suggests looking more strategically and less at the immediacy of the participatory work. She challenges child-focused approaches, and suggests that to move the agenda forward perhaps the focus should be on

the transformation of organisations (acceptance of children and young people as key stakeholders, examining governance arrangements etc). In this research, the stories help expose the organisation behind the key workers. This is discussed further in sections 9.7 & 9.8.

In Chapter 2 a number of models of participation are shared and discussed. Reflection at this stage is important given the learning en route. The ladder of participation acts as an important cornerstone from which other models can develop. The relationship between power and participation is apparent. However, power is clearly not only linked to the type of participation, but also the setting in which the voice sharing takes place, the support systems aiding active engagement, and the starting point of the individual taking part, for example, the degree of confidence felt and the level of information and knowledge available are mediated through those experiences. As stated in the literature review there has been insufficient theorising about how processes and contexts inter-relate to produce outcomes (Kirkby & Bryson, 2002). This study begins to describe the structures that help support participation with marginalised young people, thus enabling them to be democratically represented.

Figure 12 in 9.4, depicts a theoretical model that has emerged as a direct result of the accounts shared by marginalised young people and their key workers. The model recognises a different approach for those less resourced and more vulnerable entering participation. It represents an understanding of how vulnerable young people are presently engaged according to their individual needs; and highlights the need for flexibility within the system of engagement. The theory generated from this research will help practitioners and other researchers understand how marginalised young people can be safely and fairly engaged in participatory activity, without compromising their autonomy and rights to democratic thinking.

## 9.4 Processes of participation

In the reflections of the dialogue from the participants in the final seminar challenging 'Social Inclusion' in Scotland in 2002-2003, (Davis M & Edwards R, 2004, p. 98) professionals are asked to consider 'how understandings of diversity and inclusiveness lead to more or less participation'. The model in Figure 12, attempts to demonstrate not so much the amount but more importantly the nature of that participation, and how it starts to ensure inclusiveness of marginalised young people in the participatory process. The model in essence depicts the reality of attempting to offer some possibility of participation and voice sharing for young people leading more challenging and complex lives; and offers a continuum of movement towards a perhaps more traditional view of collective and public participation that allows for debate and decision making. It is anticipated that the model could be used in awareness raising interactive training to help emphasise and debate the differences of participatory activity with marginalised young people. The researcher believes that this is only possible with full and open debate if knowledge translation is to occur, because although this is a model developed with and for marginalised young people, they are not a homogenous group, and variations in practice still need to be discussed and understood.

Key workers clearly exhibit passion and determination in their attempts to ensure that marginalised young people's voices are heard. The emphasis of effort afforded to each stage of the process depicted as two conjoined circles in Figure 12, appears to be different than it would be when engaging mainstream young people. Whilst mainstream young people might engage in a participation process with moderate to high levels of confidence and self esteem, many of the young people interviewed within this research are personally less well resourced. The narratives have revealed sensitive and challenging home and social circumstances, and often interrupted education. The accounts also expose an embedded lack of trust in some adults through perceived lack of support or interrupted and insufficient care. These circumstances often result in a lack of

previous experience or opportunity to voice their opinions in traditional environments. Many of the young people are entering into the possibilities of participation through care and support circumstances, rather than as part of more mainstream activities, e.g. via school councils or as part of traditional family life. In order to safely engage marginalised young people in taking part, key workers will or have already spent a great deal of time on a one to one basis, working with and very often advocating for the young person (See (1) Figure 12). Even where confidence is apparent in the interviewee as in the young carer's interview, there is still a clear indication of previous reliance and continued contact. The presence of continued respect for the key worker who has helped the individual through the process can also be detected.

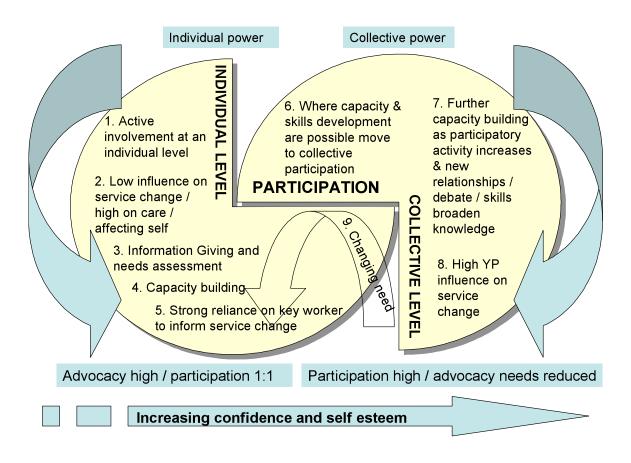


Figure 12: Model of the process of participation for marginalised young people

Most marginalised young people therefore enter the process at points 1 & 2, (Figure 12) where involvement and participation tends to be focused on the individual needs of the young person towards better care or support. Participation as a process towards service change for all is far removed from this scenario.

Here individual power to influence self care is high (although it may not initially feel so) but collective power to influence change for others is low. However, the process is a journey towards perhaps participation as depicted in many of the models discussed in Chapter 2 (Arnstein, 1969; Hart, 1992) with power to influence increasing as opportunities to share views and decision making develop.

It is essential to note that at certain times collective participatory work is not always suitable, and the key workers make professional judgements based on their working knowledge and assessment of a young person during each encounter. Here the emphasis on mutual decision making is essential, but often work is adult initiated (Badham, 2004, p146).

This has implications for practice, and therefore by using the model as a training tool individual practitioners can consider how they might increase their child initiated participation and help them make decisions regarding their own level of involvement. It is possible that the emphasis on adult initiated participation is aligned to the abundance of top down targets imposed on professionals. Pressure to meet those targets may result in adults initiating action through the time constraints imposed rather than thinking through the level and type of involvement with the young people. It is vital that these issues are debated to ensure knowledge is translated from this research into practice. As discussed in chapter one, a process that sets out to give voice to young people has the potential to silence them if young people are not fully engaged and given opportunities to both opt in and opt out (Lewis, 2008).

The role of the key worker is to give information and assess needs, and when able, start to build the individual's capacity to move into a collective participation arena (points 3 and 4, Figure 12). Key workers bring young people together when they judge them to be ready. These are professional judgements bound up in

safeguarding issues. Whilst intentions are honorable, the power remains strongly with the key worker who is decision maker and also advocate. KW YC2 selects individuals into a group situation based on her opinion of suitability (see chapter 7.2.1). This is a key point where practitioners need to be trained to scrutinise their decisions and avoid making them in isolation of others and avoid judging young people as incapable of taking part (Tisdall, 2008). Voices and opinions shared at this level of one to one work can be weak in relation to service and practice change, unless the key worker is resourced, and has systems and structures in place to make individual voices collective ones. The key worker is reliant on an organisation receptive to the young people's voices and willing to instigate change accordingly (point 5, Figure 12). Within this research there are examples of limited sharing of individual voices into potentially more powerful collective ones. There are also examples of the key workers' function not being fully understood and informal undeveloped systems in place to share individual voices, which limits their own ability to act, and as such highlights an area of practice development (See section 6.5.3 & Chapter 7).

Many young people in the process of building a trusting relationship with their key workers do move to collective participation and involvement work. The stories point towards initial capacity building at a one to one level, especially work directed at building self esteem, and skills development at a collective level e.g. interviewing skills (Point 6, Figure 12). New experiences appear to derive from the collective work where real debate and the challenging of each other's views and behaviours are possible. These encounters help build capacity, develop negotiation skills, help individuals to understand and value diversity, but equally appears to help individuals develop new relationships (Point 7, Figure 12). These social networks and the social support derived from collective work can increase access to on going support (Whiting & Harper, 2003, p 9). The young person's voice is no longer an isolated one, and the possibilities of direct influence increase (Point 8, Figure 12). There is strength in numbers as more people engage in voice sharing together (increasing the potential for peer support), and as the young people's confidence heightens, the need for advocacy reduces.

One of the biggest challenges front line workers and organisational leaders have is strengthening 'private voices' into 'collective public ones ' as it is these collective voices that help build social capital. The norms of reciprocity and trustworthiness grow as individuals connect (Putnam, 2000), qualities that are particularly important to marginalised young people. Collective and cooperative action is then possible, as trust, mutual understandings, shared values and behaviours develop (Cohen & Prusak, 2001). There are methodological limitations here as the meaningful measurement of 'trust', 'reciprocity' and an increased 'sense of belonging' are problematic (Morrow, 2003). However, the skills development and the experience of collective, structured and organised voice sharing described within the accounts helps increase the potential of these young people actively engaging with existing and new communities. The sample in this research was chosen due to their social, health and educational needs, and knowledge that the relationship between each has impacts on the young people's life chances. Participation emerges strongly as a learning opportunity, not in the traditional educational attainment sense, but as a way of building social skills. Morrow (2003, p164) revisits Bourdieu's understanding and ideas about social capital. She highlights how he distinguishes between social and cultural capital, a distinction worth consideration. Cultural capital exists in the following forms:

'Institutional cultural capital (that is, academic qualifications); embodied cultural capital (...use of language, forms of social etiquette and competence, as well as a degree of confidence and self assurance); and objectified cultural capital (material goods...)'.

Social capital consists of two elements, namely 'social networks and connections' – places which create obligations, exchanges and shared identities, and 'sociability' explained as the necessary skills and disposition for sustainability of these networks.

It is specifically the embodied cultural capital and the sociability that resonates through the experience of participatory work and the subsequent skills development in this research. Young people through participation are offered opportunities to meet with and relate to new groups and communities, and in essence learn how to act, how to share their views in ways acceptable to society.

Whilst the model appears to be a linear progression from individual to collective participation and from high advocacy to low, the ever changing social and emotional circumstances of these young people, so evident in the research stories, mean that the young people's needs are also ever changing. The need for additional support and advocacy weakens and strengthens depending upon present circumstances; as such the young person may move between the conjoined circles (Point 9, Figure 12).

Figure 13 helps explain and depicts the movement between advocacy and participation. As more is experienced by a young person and good practice is demonstrated by the key workers, the individuals appear to build their capacity to cope and continue to take part. The young people appear to look on their key workers as role models. This results in some cases in movement between the conjoined circles, creating a movement towards autonomy and independence and an extended spiral of movement emerging (Figure 13).

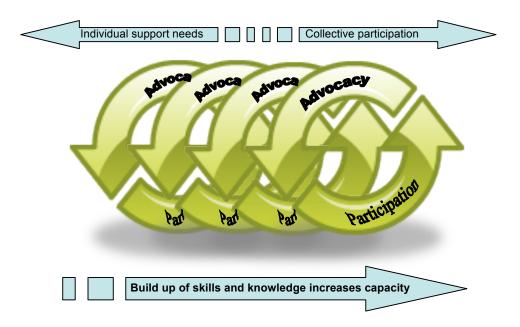


Figure 13: Movement between advocacy and participation

Individuals may well move backwards into the high advocacy, individual level of work with a key worker. However, when circumstances are challenging, it would be rare if not impossible for an individual to return to the initial state of well being, knowledge and skills when first in contact with a key worker. Although circumstances may be difficult the individual will have different knowledge and skills through the previous capacity building than they previously had resulting in some but not full movement backwards. So although the need for advocacy and support may limit the collective participatory voice temporarily, when able the young person's readiness to do so is more advanced than in the first encounter.

Equally important is the potential through a positive experience or epiphany to move forwards rapidly, as some of the accounts demonstrate. It is here where the emancipatory and therapeutic effects of participation can be demonstrated. The combination of impacts from participation (Kirkby & Bryson, 2002; Davis et al, 2008) as described in Chapter 2 and evidenced within the stories appears to result in a sense of well being. The 'addictive' nature of participatory work (as described in 8.3.3) assists in young people wanting to stay involved. Participation is crucial to the growth of social capital. Putnam (2000) talks of the psychological and biological benefits of building social capital, and the ability of communities to fight illness and cope with traumas more effectively where social capital is developed.

The accounts and definitions of participation and advocacy within the key workers' stories (Section 6.3) are important in establishing a shared language for understanding. The researcher believes that theory emerging from practice is both meaningful and important in helping practitioners consider how they presently act and how they wish to develop further. This practice development helps integrate theoretical evidence with practice values, context and environments (Clarke & Proctor, 1999). The shared understandings of participation and advocacy have helped shape the model described. The questions and debate generated from the research have instigated some self

reflection in frontline practitioners. The difficulty that ensued in key workers attempting to define the two concepts and the diversity of responses suggests that the methodology was successful in generating respondent led data. The relationship between researcher and practitioner through the research being embedded in practice helps practitioners connect with the evidence base. Sharing the stories or parts of them to demonstrate young people's views and experiences helps make the evidence more tangible and potentially makes change more desirable, thus highlighting narratives and narrative analysis as good training tools in practice.

# 9.5 Outcomes model of participation for marginalised young people

Emerging outcomes and impacts of participation embedded and overtly shared within the stories told have resulted in a conceptual outcomes model of participation for marginalised young people. Whilst the outcomes stated are primarily related to the young people and services for young people, it is clear that there are also positive outcomes for key workers as professionals working in a participatory capacity. As key workers' outcomes are intrinsically linked to the young person's outcomes they too will be shared under each of the following headings. The model provides a new way of thinking about participation and specifies four main areas which although described separately should be considered together as all are interdependent on each other for full impact.

In the outcomes model participation is conceptualised in the following ways;

- Participation as power
- Participation as therapy
- Participation as capacity builder
- Participation as practice changer

#### 9.5.1 Participation as power

In chapter 2 a number of models of participation are critiqued. Arnstein's (1969) and latterly Hart's (1992) modified ladder of participation offer an accessible way

of considering power relinquishment and control in relation to different levels of participation. However, both models are heavily directional implying better and fairer participation with movement up the ladder. They potentially place pressure on both workers and participants to aim for the top of the ladder where all decisions or a high percentage of the decision making lies with the participant or young person. In some ways this places pressure on individuals to only take part in participatory activity towards the top of the ladder, and in doing so removes the degree of choice each player has (or potentially places pressure on the young person to operate at that level). It also undermines 'good quality' consultation, or individuals who wish to take part but who do not wish to make decisions on behalf of others. Potentially it undermines the impact of a voice shared lower down the ladder which may be the chosen point or more suitable level of participatory work for a young person who feels vulnerable. Simply sharing that voice or receiving information may give an individual a huge sense of well being and this may feel very power giving. Whilst the researcher does not advocate 'tokenism' as described by Arnstein (1969) and Hart (1992) acknowledgement of the need for simple voice sharing as a starting point is important for some. In the research presented many of those who do get involved, often do progress up the ladder, but this remains a matter of professional and personal choice and capacity, and is often based on temporal personal circumstance. It is also heavily reliant on the role and capacity of the key worker, and the capacity of the young person to do so. Marginalised young people's lives are dynamic and constantly changing as many of the narratives within this research highlight, making long term commitment to participation difficult (IPPF, 2004). There is still limited evidence examining to what extent individuals want to get involved in decision making (Kirkby & Bryson, 2002). Involvement in broader participation can be hindered by 'cynicism' about how well adults listen (Percy-Smith & Malone, 2001, p21). A small move of sharing personal views one to one, from a position previously of silence, is hugely important for some of the more vulnerable young people. However, such voice sharing in isolation is reliant on the advocate's voice being strong, honest and clear if the encounter is to be a power giving one.

Key workers need to remain true to the young person in the way they interpret and share that voice, a position not dissimilar to the role of an interpretative researcher (Bowling 1997, p.112). It should be noted that power felt and exerted in a young person also impacts on the degree to which a key worker can instigate change. The stronger the young person's voice, the harder it becomes for an organisation to ignore, especially where the voice is a collective one.

The role of the key worker as a significant role model is important to acknowledge in an environment where experiences of parenting have often been negative. Where a young person has been previously discouraged from sharing his or her views, as is often the case with a parent with low perceived power (Bugental and Happaney 2000), the role of the key worker in initiating participation and voice sharing activities is made all the more difficult. Gadamer's (1976) work questioning how the world at a particular time and place is understood offers a philosophical framework for appreciating how the history of these young people has the potential to impact on their present understanding of their experiences. Young people's perceptions of adults' behaviour can be hard to change where young people have been discouraged from debate and discussion in the home or have been chastised or abused for being 'challenging' and 'verbal' (Bugental and Happaney 2000). Where previous experience of powerlessness is strong, the role of the key worker is vital in helping the young person to have a voice and to demonstrate that that voice is valued. This lack of 'say' and power is particularly evident in working with children excluded from school (chapters 6 & 7) as are the young people's skill and development needs, with many young people struggling to negotiate the system to get themselves heard (Taylor, 2005). There are tensions for schools. Politicians see schools as drivers of social and economic change, but tend to drive this 'escape from poverty' through educational attainment targets. As Munn states (2000, p 168), that for the more vulnerable young person the present systems and structures that drive this notion of 'meritocracy tend to individualize explanations for success and failure in examinations and to distract attention from structural explanations of disadvantage'. She emphasises the important role schools have in instilling

values and giving pupils a sense of their own worth, and the need for greater understanding of the norms and values that create particular networks essential to personal and social development. The young persons voice helps create an understanding of cultural and social capital, and with Government pushing for pupil voices to be strengthened, it is important that disadvantaged young people's norms and values are considered alongside more mainstream young people.

In the initial models of participation examined in Chapter 2, no notion of joint or individual participation work is debated. The emphasis in the participation models is on the degrees of power relinquished to individuals aligned to each type of participation. For marginalised young people, power felt and exerted at an individual and collective level is important. Even though decision making at an individual level may only influence self (although with the right organisational systems it can influence beyond self), it places the individual on a pathway towards collective participation which is more likely to impact on other social relationships for example the development and formation of new friendships (Kirkby & Bryson, 2002) and an increase in sustainable social networks (Putnam, 2000).

On exposing the low level of group work with children excluded from school or amongst those young carers whose parents misuse substances, concerns arise regarding the limitations this creates. A lack of group participation could potentially lead to fewer opportunities to listen to and debate other young people's views, learning from peers and the potential to normalise or understand their own situation, all impacts that emerge strongly from this research. These factors further impact on the limited social encounters and interactions that many of these young people may have. Young people are more powerful if they can make informed choices. In this research, group work creates a greater opportunity for informed choice created by the varied views and arguments shared.

Participation which allows for the young people's voices to be heard potentially also empowers the key worker. Often the key workers are aware of the service change needs from individually and collectively listening to the young people and sometimes their families over time. The voice of the young people can potentially strengthen the key workers' chances of actioning change especially when the young people themselves face service managers at workshops and conferences. As NHS organisations strive to become world class commissioners and proactively seek to build continuous and meaningful engagement with patients and the public (DH, 2007c) employees' voices should become more powerful. A number of the workers felt powerless to make changes in organisations where resources were and are limited or where senior managers do not fully understand the nature of their work. This potentially disempowers the key worker, may leave them disillusioned and can result in slow movement to service change. Here the importance of organisational commitment to participation to help support frontline workers in their efforts to engage marginalised young people is emphasised as essential as advocated in the 'Hear by Rights' Standards Framework (Wade & Badham, 2005).

# 9.5.2 Participation as therapy

Early in the research process participatory practice emerged as a therapeutic intervention. Initially it was exposed through the story telling method itself, with key workers invited to share their experiences through the telling of stories of participatory practice. During and post interview with key workers they stated how good it felt to be able to share their experiences, which exposed the notion of story telling or voice sharing as a therapeutic intervention. Some key workers suggested this was the only opportunity they had been given to formally reflect on their practice, which appeared to enhance the experience. It was only when the young people spoke in their accounts of both the therapeutic and addictive nature of sharing their voices and views that the notion of participation as therapy strengthened. Frank (2000) in researching illness narratives describes them as not just experiences, but also highlights the therapeutic and emancipatory

effects, impacts that the researcher had not anticipated being so strong in participatory activity in this broader field. As the specific method of participatory practice chosen can have farther reaching consequences, it further emphasises why method consideration is so important. Story telling type methods may be particularly effective for those in more challenging circumstances.

The young people participating have been given new opportunities, new ways of learning and self expression. For some simply being able to share their circumstances with like minded people in a safe environment for the first time can have therapeutic effects. For others overcoming difficulties and sharing and meeting those challenges more openly can hugely impact on their self esteem and confidence resulting in a strong 'feel good factor'. The therapeutic effects are enhanced by the opportunity afforded to the young people in being able to debate issues within a group setting or one to one with the key worker. The strong evidence of an increase in confidence and self esteem in this research concurs with previous study findings (Kirkby and Bryson, 2002), re-affirming participation as therapy.

Many of the young people are driven to continue to take part as a result of recognition of the work commitment they have already made. Simply being told by the key workers that they are proud of them has a huge impact on many young people. This small response by the key workers positively affirms the young person's contribution. This and the involvement work itself results in young people stating that they are proud of what they have done and achieved. This may be particularly strong in marginalised young people as previously many have had little to be proud about, or perceive this to be the case.

Story telling is used in psychotherapeutic treatment, where the client identifies with and uses the actions and outcomes of invented scenarios and stories to make personal change. Blenkiron (2005) describes the use of stories, analogies and metaphors in Cognitive Behaviour Therapy in assessing suitability for treatment. However, in participation the slant is different. Often young people will share a specific experience to emphasise a need for change. The sharing takes

place in less structured non therapeutic environments with a resulting therapeutic effect emerging from the shared experience.

In recent years therapeutic education has emerged. This therapeutic ethos is defined by Ecclestone and Hayes (2009, preface) as 'an exponential extension of counselling, psychoanalysis and psychology into more areas of personal and social life, policy and professional practice'. They add that it also offers 'a new sensibility, a form of cultural script, a set of explanations and underlying assumptions about appropriate feelings and responses to events, and a set of appropriate practices and rituals through which people make sense of themselves and others'. Ecclestone and Hayes (2009) states that therapeutic learning can raise a negative portrayal of learners and suggests populist orthodoxies reflect and reinforce the 'diminished self' i.e. emotional fragility resulting in individuals suffering from an emotional deficit. They believe that therapeutic education is underpinned by claims that past life experiences have long term negative emotional effects on everyone, and to a lesser or greater extent we are all vulnerable and therefore need support. They suggest that therapeutic learning denies intellectual potential and privileges the emotional, creating emotional labels relating to attitude, behaviours and achievement.

For many of the young people in this research, they already have ascribed labels and stereotypically embedded in these existing labels are some of the emotional labels described e.g. 'Hard to reach' and 'disaffected and disengaged'. The researcher argues that the therapeutic potential of voice sharing can also expose the positive attributes of individuals against this negative backdrop. There is acceptance that the voice sharing may expose an emotional or developmental need en route but therapeutic interventions can provide a process towards a positive outcome. The question that is most relevant is where should such therapeutic interventions take place? Circle time and developing emotional literacy, lobbying and pressure groups may not always be well placed in a school environment. Young people in this research did not see school as a positive environment to share their views, and many did not wish to disclose emotional needs to others in the school environment. Many of the therapeutic education

methods do advocate voice sharing through the curriculum but others specifically advocate voice sharing between mainstream and more vulnerable pupils. Such methods need to be considered carefully, and have the potential to further silence the voices of vulnerable children in school.

Participation as therapy may not have emerged if the qualitative story telling method had not been utilised. Such methods require personal contact with the participants, a subjective position that many positivist researchers reject. Structured and semi structured interviews can lead to restricted answers based around what the researcher sees as important, thus lessening the teller's opportunity to share primarily what matters to him or her. The subjectivity of the story telling method strengthens this research in the same way as objectivity strengthens the scientific method. Patton, (1990, p. 54) suggests that empathy develops from the personal contact the qualitative researcher has with the participant, and that this empathy develops greater understanding. This is important in the phenomenological doctrine of Verstehen, which asserts that human beings are different from other forms of life and the Verstehen tradition 'places emphasis on the human capacity to know and understand others through empathetic introspection and reflection based on direct observation of and interaction with people' (Patton, 1990, p. 57). It could be argued therefore that the methods employed within this research and the participatory activity, which permit individuals to share their experiences and reflect on them have led to participation emerging as a therapy. Patton (1990) also suggests that the qualitative approach also legitimises the researcher sharing her own feelings, perspective, and insights as part of data collection. The interaction during the research interview whether visual or verbal, may also have contributed to the therapeutic effects shared by the key workers, as many have stayed in close contact with the researcher in and through practice after the data collection was completed.

Participatory activity, by its very nature, leads to high levels of personal reflection. The primary aim of participatory work is often service improvement. However, by asking young people to help plan future provision and reflect on the existing services through the many methods shared, the young people naturally reflect on their own circumstances. As such they often relive and rethink how services have impacted on them dealing with their own individual life events. The complex lives exposed and the intimate and difficult circumstances shared in this research highlight the magnitude of the emotional movement forward that many can make by simply sharing and reflecting on their own lives. This personal reflection strengthens participation as a nurturing and empowering process.

Empowerment is strongly linked with increased well being. Changes in work practice without employee involvement have been associated with low trust and feelings of disempowerment by occupational psychologists, with the opposite associated with employee participation in decision making (Wall, Wood & Leach, 2004). Other researchers of management theory have highlighted an increase in self belief and resilience when faced with set backs (Thomas & Velthouse, 1990).

# 9.5.3 Participation as capacity builder

Building the capacity of young people is strongly linked with 'Participation as Power'. According to Wade and Badham, (2005, p. 7) skills development links strongly to an increase in confidence and self esteem. They also suggest that the most successful approaches to the active involvement of children and young people in decision making include capacity building initiatives. As the young people increase their self esteem and confidence, life skills and specific knowledge, they increase their potential to influence. Increased knowledge and ability to reflect on their own experience (participation as therapy), gives them a greater chance to debate effectively. The accounts in this study indicate that many of these skills are learnt through their role models (who are often their key workers), specifically how to act or behave in certain circumstances. The increased life skills e.g. ability to negotiate, listening skills, coupled with their increased knowledge helps build their confidence, and with that comes a stronger position of influence. For some of the young people a lack of life skills can lead to negative circumstances, e.g. the professionals working with excluded children

link the young person's lack of skills directly to the exclusion (Chapter 7). Potentially an increase in human capital (skills, knowledge and qualifications) will positively increase social capital and young people's active involvement in society (National Statistics Social Analysis and Reporting Division 2001).

However, as Morrow (2003, p.177) highlights 'community for children appears to be located in a sense of belonging that resides in relationships', and not in geographically bounded areas as portrayed by Putnam (1993). Participatory activity and the clear process of preparation to take part shared within this study, appears to help the young people negotiate social interactions. For these marginalised young people many are transient and have experienced numerous geographically bounded communities. As Morrow (2003, p177) states 'community is more often a virtual community of friends' based around different locations, many of which may not be geographically close. She also highlights practical, environmental and economic constraints for children in building social capital. Factors which she suggests are usually ignored in studies relating to health behaviours. Whilst, this study highlights capacity building through skills development, key workers have also highlighted some of the economic constraints for these young people. Free movement due to the physical geography of the rural and built environment has been exposed alongside the financial constraints associated with access specifically for more marginalised young people.

The process of participation shared at the beginning of this chapter, reveals a strong individual needs based approach to participation leading to joint consultation and decision making. Kashefi and Mort (2004) suggest consultation without deliberation is not legitimate and highlight the 'transformation of values and preferences' through deliberation. Whilst one to one participation helps key workers meet the immediate needs of young people it is the group work and collective participatory activity that offers the best arena for deliberation and thus the greatest potential for transformation of values and preferences. Learning to negotiate different relationships and viewpoints, debate effectively, change and

modify opinions and behaviours, is crucial to improving the social capital in our communities, and as such participation with these young people should be seen as an essential investment for the future.

It is important to offer all marginalised young people an opportunity to collectively meet when appropriate to support more 'deliberative democracy' (Kashefi and Mort 2004). In this way young people can advance their knowledge and skills by:

- Hearing and acknowledging differing views and opinions from their own, or listening to others who feel the same;
- Consider their opinions against organisational drivers and limited resources, and help make informed decisions.

The participatory activity also appears to provide at times disengaged young people with an opportunity to develop skills that in alternative or more mainstream environments may well have been rejected by the young person. For example, being offered a chance to learn interviewing skills in an academic environment may not sound appealing, but when shared as a means to make decisions about the right type of worker to be employed to work with looked after children, the skills development takes on a whole new practical and relevant meaning. Many young people in this research have been engaged in skills development because of their social circumstances and their vulnerabilities. Skills development ranges from specific and directed work on, for example, anger management through to the development of broader skills to provide 'peer support'. Building the capacity of our young people, particularly those in greatest need, may have much more long lasting effects for the individual and society than can be demonstrated in this research, but has clearly helped build confidence within many of the young people interviewed. Skills development can lead to young people being more involved in social and civic participation (Whiting & Harper, 2003 p 8-9) which ultimately benefit others in the community.

### 9.5.4 Participation as practice changer

Whilst participation of marginalised young people has the capacity to change practice, when power for decision making is not devolved to the young people

themselves they become heavily reliant on key professionals to share their views and act on their behalf. Where views do not concur with those of the professionals, especially where young people challenge present practice, views may not be fully shared (8.4.4 YPYC1). Changes in practice may be structural or skills based. It is often the structural changes that are easier to demonstrate and less contentious to share such as a change in opening hours to meet the needs of young people or a change in venue. Those which link to the attitude of professionals or organisations can be difficult to share especially if service providers are also the participatory workers.

However, there are clear examples in this research of how young people have been able and supported to change attitudes e.g. through the mystery shopper scenario in participation with teenage parents (Appendix 2) and where the young gypsy traveller stood up and challenged a conference attendee.

The newly updated 'You're Welcome Quality Criteria' (DH, 2007a) support implementation of standard 4 of the National Service Framework for Children, Young People and Maternity Services. This specifies that 'All young people have access to age appropriate services which are responsive to their specific needs as they grow into adulthood.' (p. 119). The new criteria aim to make all health services young people friendly through improved accessibility, good publicity, clear policy on confidentiality and consent, safe and suitable environments and importantly, staff training 'on communicating easily with young people, promoting attitudes and values that are young people friendly..' (p. 5). This places an important emphasis on services rather than the young people and doing so it is acknowledged that it is rarely the young person who is 'hard to reach' but the services themselves.

The impact of participation on practice and service change is far easier to demonstrate than the impact of participation on the young person themselves. In some ways the two go hand in hand, for if practice change can be demonstrated as coming directly from the shared voices of the young people, the potential for increased confidence and self esteem results. Young people need to know that they have made a difference and workers should ensure that the young people

know the fruits of their labours. In this research feedback to young people regarding service change appears weak and therefore concurs with previous research findings (Arnstein, 2004; Davis et al, 2008 & Coad et al, 2008). Kashefi and Mort (2004) refer to the importance of 'integration' in participation with any community, with involvement from inception to realisation through existing networks. Where feedback is weak realisation does not occur. This may partially be due to marginalised young people living more disruptive lives, moving on and being less available at times. The feedback loop needs to be strengthened and formalised via further organisational commitment and structural change. Key workers should be assured manager's time to share learning and should be resourced to feedback to their client group. Feedback to other workers should be via continuing professional development opportunities such as in service training. Children who fall under mainstream services have links to stable settings where feedback is less complex. Further research is needed to determine the best format for feedback for marginalised young people, but at the very least those actively involved in consultation should receive a summary of the outcomes via newsletters, website or text messaging.

### 9.6 Methodological approach

Examination of participatory practice calls for an exemplary methodology from philosophy to method, sample to data, findings to validity. Underpinning the research is a philosophy that values lay language and the important conversations that emerge from and expose, the experiences and personal interpretations young people and professionals have. It is the researcher's role to discover meaning through interpretation of participants' words (Maggs-Rapport, 2000). The researcher acknowledges the power and limitations of temporal exploration, and although further reflection and experience can change the way life is viewed over time, the researcher values the shared accounts as genuine views and experiences of the participants at that time. The free expression facilitated in this research has moved the data from restrained limited accounts to

rich emotive stories that have taken the research down, at times, unexpected paths.

These discoveries have emerged as direct result of the chosen method, one of story telling. Story telling is a natural human activity that places the power firmly with the individual who is sharing their story. Each narrative, whilst guided to ensure the research question could be answered, is unique. The approach has allowed for a naturally occurring self interpretation and reflection by participants to be exposed, less forced and directed than in semi-structured interviewing, which has made each account all the more rich and valuable. The telling of 'Self Stories' gave the young people and also the professionals, an opportunity to think through, tell and reflect, retell through explanations and justifications, actions and beliefs, their stories. As such it has provided an ideal research method to explore the experiences of the participants.

Equally by asking the young people to contextualise their experiences of participation i.e. share information about their childhood, critical points in their lives have been exposed. These epiphanies have advanced the researcher's understanding regarding the importance of contextualising data in order to fully appreciate the development and impact the participatory experience has had on each individual. Social interaction is context-bound (Silverman, 1993), and although the data are generated and experienced by the participant, the interview and the story allow both the participant (insider) and the researcher (outsider) to validate the account together. Knowledge of the contextual data help emphasise the difficulties in adopting 'a one size fits all' model for marginalised children and the need for flexible and diverse ranges of opportunities to be on offer (both in research with young people and practice based participation). The researcher's learning has developed through the method of story telling and narrative analysis. It is through a greater understanding of the complexity of the young people's lives that the impact of participation can be truly understood. The 'way' in which the key workers engage with their audience, in response to their specific needs at a given point in time, expose the different methods of engagement necessary that ensure the young people have positive experiences.

Asking the young people to speak of their experiences of growing up, resulted in at times very long and convoluted stories being told. The strength in allowing this to happen meant the content of the stories often exposed epiphanies that would be meaningful in understanding the story teller's present self, and more importantly why and how the participatory experience had impacted on them. The lengthy stories may sometimes have been at the expense of a more in depth investigation of the participatory work. Whilst a huge amount of involvement and participatory work is evident very few young people appear to know what has happened as a result of their involvement. A breakdown in the feedback loop from voice sharing to outcomes in some but not all cases is clear. This does not mean their voices were not acknowledged or that change did not happen, but the degree to which it did occur is unclear. On reflection, the researcher should have taken more time to investigate this with both key workers and the young people, as organisations have a responsibility, if only an ethical one, to ensure feedback is occurring.

The researcher did not anticipate the research interview being a therapeutic one for both key workers and the young people (Sections 8.3.3), even though the method was participatory and participation can result in an increased sense of well being amongst young people (Kirkby & Bryson, 2002; Davis et al, 2008). Qualitative and specifically phenomenological research in exploring certain experiences requires questions to be constantly asked (Field & Morse, 1996) of participants and thus creates a reflective environment. Whilst on the whole key workers were able to be honest and happy for their views to be taped and transcribed, the need for support and an advocate for their work became apparent post interview. Some workers wanted to share information and requested a listening ear directly after the tape was switched off, others phoned at a later date. This adds to the limited evidence suggesting that there are few

opportunities for adults to reflect and gain peer support in their participatory roles (Kirby & Bryson, 2002, p 45).

During the interviews it was evident that those young people selected were independent and confident enough to share their own views - another possible outcome of the participatory experience they had already been exposed to. This helps challenge the Government's deficit view of the child debated by Davies (2008) as to whether marginalised children are capable of contributing to decision making. Most of the young people and all the key workers told full and detailed stories about their experiences. The exceptions were the only males interviewed and the youngest female. For these three individuals the researcher resulted in more questioning to elicit their views and experiences and this resulted in less of a story being told and more of a semi structured interview process emerging. It is possible that gender, age and maturity played a part in the accessibility of the method with younger participants requiring more direction through the process. Booth & Booth (1997) suggest young people have less to say, and that this reticence is due to a lack of confidence in the validity of their own experience, characterised by youth. For the older female participants full and detailed stories emerged which required minimal prompting. At times the researcher needed to bring the story back to the research focus as the contact felt at times felt like an arena for the young person to 'off load', which again highlights the therapeutic nature of this method. The relationship between the young people and the researcher is important to acknowledge. The researcher must be genuine and non judgemental and develop a sense of equality and a caring situation where everyone feels comfortable (Moen, 2006). This can be challenging in research and participatory practice especially where young people share risk taking behaviours. Young people in this study comfortably shared negative experiences of life and the involvement work. Such openness confirmed the researcher's beliefs that those interviewed would be honest in their stories.

#### 9.7 Professional Issues

The methodology has created an organic approach to understanding the data from and with the participants accentuated by the researcher's closeness to practice. Although this is important in developing an in depth understanding of the issues for marginalised young people, the time consuming nature of attempting to support practitioners to make changes inspired and recognised as a direct result of the research interview resulted in a huge amount of unpredicted pressure on the researcher. Researching in practice brings with it constant demands on knowledge and time. Once connections are made the researcher can become a focus of attention from practitioners requiring further support created as a direct result of the research interview and the joint discussion and interpretation fundamental to the philosophy and the method.

The research itself therefore created a learning opportunity and a place for practitioner reflection. For example, defining 'participation' and 'advocacy' emerged as a challenging task for key workers. This surprised the researcher at the time but having listened to and analysed the stories the difficulty is clear. In requesting a definition, summarised, rigid and precise accounts were being requested. The stories evidence no firm definitions and nor should they. What they do demonstrate is diversity of purpose, process and outcome, and a flexible definition dependent and aligned to engagement with a particular young person or group of young people. In essence, the phenomenological approach has made the obscure plain, making the hidden meaning more obvious.

These ever changing definitions helped the researcher re-consider the initial models shared in Chapter 2 (Arnstein, 1969; Hart, 1992). The varied levels of relinquished power at rungs 4-8 need to be on offer to all young people but especially those marginalised by society. 'Mutual empowerment' as described in Chapter 2 (Children's & Society, 2004, p. 98) should be a goal for all young people, but more realistically 'redistribution of power' is often the safer option for these young people. This has changed the researcher's view of participation. The researcher is supportive of the Teenage Pregnancy Unit (DH, 2001) definition shared in Chapter 2 suggesting that participation can simply mean 'being

present". This is a very realistic option in the early stages of involvement for many of the young people interviewed. Importantly, the models help adults consider how young people can and should be involved and as such challenge practice and act as good training tools. The Hear by Right model (2005) discussed in Chapter 2, combined with the key workers' stories, have resulted in reflection on the role of the organisation.

In experiencing interpretation through conversations with the young people at research interview i.e. debate through explanation and justification, questioning and clarifying, and listening to the same in the stories told in the young person / key worker interaction, the research process has exposed the critical use of interpretative methods in both research and practice. Such interaction is viewed as normal conversation, but is critical in helping marginalised young people make informed decisions, and in helping key workers fully appreciate their needs. This emphasises the need for one to one support. However, the young people's positive learning experiences of shared decision-making through debate and open interpretation are not dissimilar to the learning that took place in the practice based action learning sets. This demonstrates the importance of group support in building capacity.

This movement from individual to collective participation has highlighted important professional issues relating to safeguarding. Although the social benefits of collectively sharing one's voice with others increases the potential to develop new skills and build self confidence, acknowledgement must be given to the safety and appropriateness of collective participatory work for some young people. The level of attention afforded to safeguarding is always important but for marginalised young people who are already vulnerable the efforts to protect are necessarily greater. Key workers are aware of this but literature does not always expose this. The immense pressure on practitioners to safeguard can potentially constrain collective participation and undermine a child's right to be involved in decision making (Davies, 2008). Undertaking qualitative research with

marginalised young people should be treated no differently than practice based participatory activity. Following safeguarding and consent procedures should not be seen as a barrier to ensuring voices are heard but should be positively viewed as a process that ensures safe and fair practice.

How organisations and professionals understand and value participation, and how they view the young person's ability to effectively engage are important to consider. Davies (2008, p. 13) highlights how a deficit view of the child can impact on whether they are judged capable of contributing to decision making, and refers to Government speak regarding children with special educational needs, and the need not to 'overburden them with decision making'. Curtis et al (2004b) suggests that children's competences are simply different and by no means inferior and simply require thoughtful consideration regarding the best methods of engagement. In this research the passion and commitment of the key workers, who have embraced participation as an integral part of day to day work, appears to hold participatory activity together for those young people potentially marginalised by society. They evidently value the young people's contributions and show persistence in ensuring they remain engaged. However, the theorisation of children as passive, dependent people who need protection and provision needs to be further challenged (Tisdall, 2008). There is evidence in this research that limitations are placed on the active participation of some vulnerable young people in the name of safety and care. Key Workers understandably want to ensure that vulnerable young people are not placed in unsuitable and potentially compromising situations, and are responsible in their safeguarding duties. There are risks associated with group work primarily. Individual behaviours can be challenging to manage, with many young people more than comfortable to share their views, personal circumstances and even sexual practices and experiences within the group setting. Equally, many young people are deemed too vulnerable to take part in a group and require additional support before this can occur. Whilst this does not prevent the young person's views being sought, it may prevent fuller exposure to debate, as occurs in group settings, thus potentially reducing the personal development which results from group work. There is a fine line between protection and retaining adult power, and practitioners should be encouraged to make every attempt to engage young people in collective voice sharing. Often it is difficult to determine where advocacy, care and participatory work start and finish especially for those young people who have only shared their views through one to one work. However, the key workers clearly attempt to facilitate a seamless route along a continuum as described in 9.4, and where the possibilities of participation are presented, will aid people to take part where appropriate.

As a researcher / practitioner it has been necessary to find appropriate ways to analyse and share findings and develop practice on route, as explained in Chapter 5. The analysis has been the most challenging part of this research, ethically, professionally and personally. There are a multitude of ways a researcher can choose to analyse narratives, with decisions linked to the research question and one's theoretical and epistemological position (Riessman, 1998). Making a choice as a novice narrative researcher is difficult. The researcher wanted to truly and fairly represent the views of the sample group whilst making sense of the first person accounts. Ensuring the shared experiences were not lost in the translation to data meaningful in practice has been challenging. Riessman (1998, pp 61) advises against reading simply for content or to evidence prior theory. Lieblich et al's (1998) two dimensional model helped develop the researcher's own systematic approach to analysis, even though huge amounts of data were generated. The primarily 'holistic' approach to analysis employed helped maintain a contextual focus on the analysis, and allowed for the impacts on the young people's to be understood in context, which has been important in understanding differences between mainstream and marginalised young people.

Research embedded in practice, produces practical dilemmas regarding the timely sharing of findings, and the most appropriate dissemination strategy. The dilemma between researcher and practitioner exposure to data, knowledge generation and specifically, when to share what, were particularly challenging.

This was further compounded by the researcher's belief that each story shared is important and is a potential learning aid, but with an understanding that robust interpretation is essential to drawing conclusions or inferences from the data. The 'holding on to information' which could potentially inform practice was difficult, and at times information was relinquished anonymously to help develop, for example, the Participation Principles (Appendix 4). Informing practice in this iterative way is difficult but important.

Whilst this research could stand outside of the practice environment, the close involvement with frontline practitioners has aided iterative learning as a two way process, and has also resulted in greater theoretical sensitivity (Glaser 1978). Greater awareness of developmental need has occurred through extensive reading of the diverse literature on offer, closeness to practice through for example the Participation Operational Group and direct work with young people, and finally and most importantly the researcher's relationship with the front line practitioners who work with the young people.

As the researchers mind expands and thinking develops, and is drawn further into academic thinking, it becomes essential to find tangible methods to take learning back into practice that draw on the new thinking. Creation of the process and the outcomes models of participation developed in this research provide tools from which the findings can be discussed, and thinking further developed.

### 9.8 Organisational and professional ethos

The participatory experience is evidently linked to numerous confounding factors. An organisation's ethos towards participation can be particularly challenging where multi agency working is the norm. Professionals used to working in certain ways can struggle with a partner organisation's understanding. As marginalised young people are often in contact with many agencies this is an important public health issue. A shared ethos and multi agency commitment to participatory activity is therefore essential across organisations if these young people's health, well being and life chances are to be improved through participatory practice. In

this research some of the key workers felt unsupported in their work and felt managers were lacking real knowledge regarding the participatory process. Senior management commitment is seen as one of the most important actions an organisation can take in promoting participation (Tisdall et al, 2008), and is cited as an important factor in ensuring sustainability (Kirby et al, 2003).

An unexpected aside was the exposure of practical resources, personal capacity and safety issues which impacted directly on key workers ability to facilitate collective participation with marginalised young people. These emerged in natural, explanatory conversation as key workers completed the participation framework. This resulted in variations regarding the type of participation on offer with a particular gap exposed between children excluded from school and those in contact through health and social care. The resource commitment in this specialist area of work was poor and participation focused on advocacy in the education field. The debate of these and other issues in the research environment can leave practitioners with much to reflect on. The key workers interviewed from education were no less committed and passionate than other workers, emphasising a fragile system in engaging with children excluded from school, with reliance on the key workers' personal commitment rather than robust organisational sign up.

Much of the participation work focuses initially on work related to young people's rights. This work is done both one to one and in groups, and concentrates on their right to be heard. Many of the young people describe 'being looked down on' by society, and struggle with the stereotypes imposed on them. Many are inspired to share their voices to help break those stereotypes and be treated as a young person and not a label. Most of the young people who are marginalised are brought together to share their voices because they fit in to a certain group. Even though they work hard in that group to improve things for people in the same circumstances as themselves, the stereotypes and societies views of them create potential barriers to participation. These are further exacerbated by the

continued negative portrayal of young people in the media. This view is supported by new research (Clark et al, 2008) exposing the impact and influences of media portrayal of young people, which highlights that negative media can impact on the way young people view themselves; can create stereotyping causing older people to be intimidated by all young people; and affects the way young people dress and socialise. Organisations, particularly statutory ones, have a responsibility and opportunity through participation to help break those stereotypes, thus improving outcomes for young people.

It is hard to remove all prejudices. However by understanding better the context behind the 'labels' in advance of the young people's interviews the researcher's own stereotypes were challenged. Additionally, awareness of one's language and self presentation in working with the young people is heightened.

The qualitative nature of this research exposes the difficult upbringings and associated behaviours that often further exclude or marginalise the young people. This behaviour is strongly linked to their family and social experiences of childhood. Conversely, it is also their behaviours and actions which may result in them being more visible to health, education and social carers, and give them the opportunity to voice their opinions, sometimes for the first time in their lives. Tisdall et al (2008, p. 343) demonstrates how over time children and young people have acted in a participatory capacity irrespective of Government drivers and Children's Rights agendas. They refer to children's and young people's behaviours such as going to or absenting themselves from school, as a method of personal influence and self expression. This is contrary to the formalised definitions of participation. However, having listened to the young people's stories, the author now believes that many of these vulnerable young people start their voice sharing informally through their own societal marginalisation and their subsequent often negative behaviours, which may in turn fuel the creation of negative stereotypes and media. Often the first voice shared is a response to the circumstances they find themselves in, for example abusive behaviour towards a

teacher. Contact with the key workers appears to offer them the opportunity to formalise the voice sharing that has informally already occurred. This contact may also provide a first impartial listener and therefore the encounter can be a therapeutic one.

The key workers are the primary enablers of participation work. The relationship between the key worker and young person plays an important part in driving successful participation. The attributes of key workers described in chapters 7 and 8; result in young people having access to positive and passionate role models. Whilst many professionals understand the techniques and skills required to engage with young people, it is the experience, in depth knowledge and ongoing working relationship that these specialist workers have with their specific group which appears to impact positively on the young people being able to share their views. Additionally, the young person's preparedness, ability and willingness to share their voices can often be attributed to the key workers commitment and passion so evident in the stories told, which is further enhanced through their advocacy role. As such a strong, trusting relationship is built up between the key worker and the young person.

The interest and passion that the key workers have for these young people often emerges through their efforts to be inventive in the way they deal with difficult issues or in the way they draw on previous experience and limited resources to ensure that young people can take part. Many of the key workers either work with or remain in contact with the young people over long periods of time, and although not always as the direct key worker, this helps maintain trusting relationships. The longevity of contact may occur as a result of limited alternative resources, the intense needs of some of these young people or less then robust exit strategies which are required to strengthen transition into adulthood. The present model of working is intense and resource intensive, especially where movement to collective work is limited. To ensure key workers are not overwhelmed with demands for continued help over long periods of time organisations need to consider multiple methods of continued support.

The main skill is not so much about knowing the techniques but is more about knowing the young people. Each young person has exposed through their stories diversely complex and unique lives. However, commonalities have occurred across many stories, such as the experience of poor parenting or a lack of positive adult role models in childhood. Such experience further highlights the need for some of the exemplary key worker skills and attributes exposed in the research. A strong advocacy role, and the key workers ability to deliver health, education or social care or support in a flexible way, have all resulted in the young people being exposed to positive adult role models.

Finally, organisations have a responsibility to monitor the quality of their provision, and this should not be confined to service delivery, but should also be focused on methods used to improve it, such as research, audit and participatory practice. Stories reveal a huge variety of work undertaken with young people, such as creating new policies, sharing views about the nature of services, and individual care. However, there is no specific or clear method of measuring the quality of the participatory work. Few key workers or young people state that views were sought regarding what the experience of sharing their voice was like and how the experience could have been improved. This compounded the researcher's initial concerns and the reasons behind this research, that often the views of young people are sought, but rarely is the participatory process examined for the impacts on young people or to ask young people how the process could be improved. Cavet and Sloper (2004, p 318) also suggest a deficit in examination of the process of participation. There were only rare instances where some personal reflection on the process is instigated by practitioners, and this tends to be fairly superficial. Additionally, organisations need to get better at monitoring who is being asked to voice share to ensure diversity of those engaged.

#### 9.9 Conclusion

The time invested in these young people potentially has huge benefits for organisations and society. As young people and future adults, the participation experience, the training, new skills development and knowledge will lead to an increase in cultural, human and social capital. The process potentially provides building blocks for the future as framed in figure 14. In this research there is some evidence of young people involved in participation becoming future employees e.g. two young people gained employment in the teenage pregnancy service demonstrating that their skills and unique knowledge were recognised during the participatory activities. Others spoke of the importance of sharing their experiences on job applications, how they saved certificates and training materials on personal files, others shared their aspirations for the future often triggered by their new found self confidence and skills development.

Children and young people are often excluded from civic engagement and are not seen as key stakeholders in local communities often due to their age. Morrow (2003, p176) suggests that this may potentially have impacts on adult engagement as children growing up retain negative impressions of democratic institutions. This heightens the importance of early participation by children and young people, not just in knowing that they can have a voice, but also in preparing them early in methods to have an effective one.

In the models developed and described each is reliant on the other for success in assuring that marginalised young people have meaningful, fulfilling and positive experiences through participation. The initial one to one engagement builds trust and confidence, imparts information and knowledge and where necessary further supports through advocacy. Through a process of gentle capacity building via the development of new skills and knowledge, the young person's power to act independently increases. Power is felt and the young person begins to feel good about themselves through the key worker's positive affirmation as shown in Figure 14. The combination of 'Participation as power' and capacity building increases marginalised young people's opportunities and the effectiveness of their voices being heard and taken seriously.

Once young people are involved there appears to be an 'addictive' element to staying engaged, which evolves from taking part once, doing well and receiving positive feedback regarding their efforts. Many of the young people describe movement from one to one engagement with key workers to presenting their stories at conferences both locally and nationally. This movement takes huge courage on the part of the young person, but also demonstrates the level and longevity of commitment of key workers in building confidence and skills.

As they experience practice change and see real changes aligned to their expressed views they experience 'Participation as therapy'. This increases the emotional well being of these young people, and helps them reflect on self and others. The positive sense of well being appears to keep the young people engaged and leads to further participatory work. The initial and continued participatory activity exposes individuals to cultural difference and diversity, new ideas and debate, and through practical experience results in further building of capacity. This new sense of achievement and well being gives the young people the potential to build resilience and helps support them in times of difficulty.

The model of the processes of participation seen in figure 12 and the strong link between advocacy and participation seen in figure 13 have the young person's needs and present capacity embedded at the centre of them. Alternatively, the outcomes model positively promotes young people's participation as strongly impacting on the building of social capital. The researcher suggests that by selling participation within this outcomes framework, organisations will concentrate less on their legal obligations and more on investment towards better outcomes for children and young people. Outcomes are diverse, and cross health, education and social need, making investment in them relevant across disciplines. Both models, when used together, help build life skills and with each participatory experience the building blocks become a sustainable health improvement method and one that should lead to increased human, cultural and social capital within communities as seen at the top of figure 14.

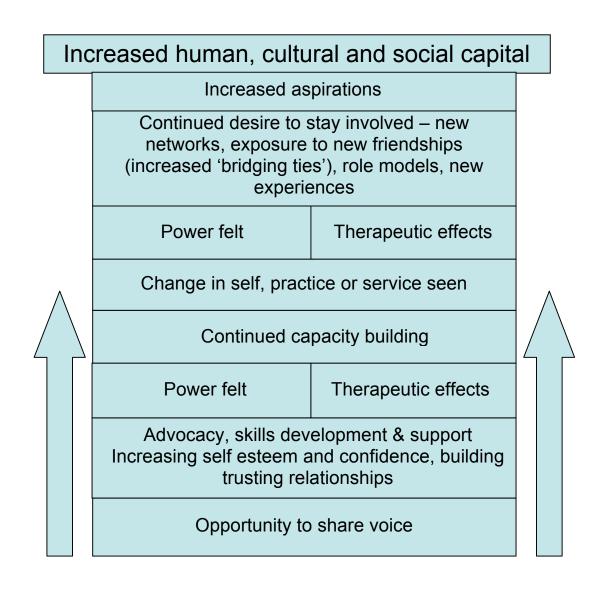


Figure 14: Participation Building Blocks

The ability to act as researcher and practitioner allows for a constant movement between theory and empirical data. As a public health practitioner in a unique position situated in and across organisations, the closeness to practice allows for real life to be viewed and influenced on a day to day basis. As a researcher, time is set aside to ensure a structured thoughtful approach, to allow time to consider theories and interpretations. Movement between the two positions is both enviable and stressful. Practitioners begin to look towards the research practitioner as the informed and the solution finder, when in reality, the researcher practitioner is a learner and investigator and is as reliant on the

sample and subjects as she is on the books and the theory. This mutual on going learning provides a positive arena to share the developed models in practice, specifically as an interactive, participatory learning opportunity. Models can be used alongside anonymised case studies.

Chapter 10 concludes the study and summarises the thesis findings. Policy and practice implications and recommendations are discussed alongside the dissemination strategy.

### **Chapter 10 – Conclusion**

### **10.1 Introduction**

The following is a summary of the findings generated from this research. The findings are separated between those impacts and outcomes relating to the young people and those relating to the key workers. These are followed by some recommendations and implications for policy and practice, and finally the future research implications are highlighted as a result of this research.

## 10.2 Findings relevant to young people

For marginalised young people to be assured meaningful, fulfilling and positive experiences when sharing their voices the process of participation needs to differ from that used with mainstream young people. The following areas require consideration:

- Marginalised young people need a larger degree of preparation before they can safely and comfortably voice share in an open arena;
- Advocacy is an essential component of participatory activity for young people living more complex and challenging lives. This needs to be on going to ensure that young people are supported and able to remain involved even when their circumstances become unstable;
- Participation needs to flexibly move between one to one and group work
   (in line with the young person's changing needs) and is important in
   building and maintaining trusting relationships with adults;
- Group work or collective participation appears to develop social networks and improve communication skills especially those of debate and tolerance. The social side of group work is very important to many and as new friendships emerge continued attendance and sign up to activities appears to be a driver to take part;
- The impact of participation results in a wide range of positive outcomes for marginalised young people e.g. new skills and knowledge, behaviour change often role modelled and learnt through key workers;

- Some direct impact on services was apparent but evidence to demonstrate how young people directly influenced change was limited.
   There were some examples of how young people could influence action planning, promotional literature relating to services and care systems;
- Marginalised young people were often able to affect the way professional and public perceptions of them were characterised in the media by the sharing of self stories through conferences and art;
- Participation has a strong therapeutic effect important in helping increase young people's self esteem and confidence. This is seen in children with disabilities who have been involved in participation (Lightfoot and Sloper, 2001) and may be more relevant and accentuated in young people living complex lives;
- There appears to be a knock on effect of one piece of participatory work leading addictively to another, although limited reasons defining why emerge from the young people's accounts. At best this can be attributed to the 'feel good factor' felt as a result of taking part;
- Rewarding young people to take part appears to be a bonus but not the main driver for taking part. Many reap the benefits of learning new skills and knowledge and become involved in the hope that it will increase their future opportunities specifically in relation to future work. Although rewards attached to voice sharing are viewed positively by the young people, it is often the notion of 'helping others like themselves' that attracts them and keeps them engaged. Certificates and training opportunities are also viewed positively;
- Many young people are more aspirational as a result of their participation and consider the opportunity, learning and skills development in relation to possible future careers and job applications;
- The young people are offered opportunities to take part as a direct result of their complex and vulnerable circumstances, often because they fall into a certain category of vulnerability e.g. a teenage parent, a looked after

- child. However, there is strong evidence to suggest that young people do not want to be labelled and simply want to be seen as a young person;
- Labelling can further marginalise young people, however, often funds to assure participation are linked to labelled groups;
- Democratic and proactive community development methods are primarily used when working with marginalised young people, however, often participation is adult initiated and service driven. More efforts need to be made to focus participation on issues that are important to and initiated by the young people. This is in line with thinking across the country (Badham, 2004, p146).
- Access for some young people in a large geographical county can also act
  as a barrier to regular attendance to meetings, and this coupled with
  material deprivation can, without the right insight and resources, further
  marginalise young people living difficult lives.

# 10.3 Findings relevant to the key workers

Key workers exhibit immense knowledge about the groups of young people they specifically work with, and have a good understanding of the challenges these young people face

- Key workers highlight a diverse range of constraining factors for the young people which are often related to individual's circumstances. However, factors that emerge across stories relate to;
  - The need to build self esteem and confidence and trusting relationships prior to collective voice sharing
  - The need for skills development some of which would be relevant to all young people taking part e.g. interviewing skills; however, ground rules or working agreements are important in some settings and are suggested as a good practice, where individuals may share inappropriately. This is linked to safeguarding;
  - Safeguarding issues pose specific constraints for some of the more vulnerable young people and may limit their collective voice

sharing. The level of attention afforded to safeguarding is always important but for marginalised young people who are already vulnerable the efforts to protect are necessarily greater. Key workers are aware of this. However it is rarely discussed in the literature;

- Access issues can be problematic in a large county where transport and material resources limit access for some
- The key workers demonstrate immense drive and passion to help improve things for the young people and actively facilitate opportunities for young people to share their voices. At times there appears to be an over reliance by organisations on this passion and hard work, rather than making a small investment in resources which could make a huge difference to the key workers. Resources to support participatory activity are very limited in some areas specifically in working with children excluded from school
- Key workers need more acknowledgement of the nature of their work in relation to participation and the immensely challenging circumstances that create potential barriers for them to make and maintain contact, motivate and support young people to take part. Key workers at times feel unsupported by their line managers and feel they do not appreciate the degree of complexity of the lives of the young people and the efforts required to maintain contact;
- Some professionals find the young people's honesty and openness difficult to acknowledge for fear of negative press and the impact on the organisation. This can result in young people's views and work being modified;
- The key workers interviewed valued the research interview experience as it gave them an opportunity to share and reflect on their work, and consider how they could improve practice. The research interview gave them time out, and an ally in the research/ practitioner to help support their passion;

- Often work with the broader community needs to occur before the active engagement of the young people can take part. This is specifically the case for travelling communities;
- A finding that emerged from the research, practice contact and knowledge was the multi disciplinary approaches adopted by professionals in ensuring young people's voices are heard. Working in partnership and across agencies to ensure and facilitate participatory activity is essential to good public health practice as it reduces duplication and acts as a strong enabling factor (Orme et al, 2007, pp 63-82). Most strategies to improve health result from improvements to people's economic and social status and the actions of individuals and communities not just Government intervention. Health and social care staff often undertook participatory activities together e.g. sexual health policy development with young people in the looked after system, teenage pregnancy action planning with social care, nursing and community development workers. This was strong across health and social care but appears to need development in the education field. There is now an emerging evidence base regarding the benefit of multi-agency / multi-disciplinary working on the outcomes of children and young people (Kurtz & James, 2002; Atkinson et al, 2002; Sloper, 2004 & NfER, 2004).

Organisationally, clear systems and structures need to be put in place to ensure that the young people receive robust feedback regarding how their voices have been used to develop and or change services, and where information has been disseminated. The lack of understanding regarding what has happened as a result of their voice sharing indicates that the feedback loop needs to be strengthened but does not imply that no actions were taken. The FACT needs to clearly state the proposed outcomes of participation e.g. clearly state the overarching aims and what impacts they expect to see. It is also important to measure how the participation is changing the organisation not just the direct service. The 'Turn up the Volume' principles will help the organisation achieve

this; however, this should not simply be a tool for frontline workers but should be embedded in the organisation at all levels.

# 10.4 Policy and practice implications and recommendations

Through the latter stages of this research journey the researcher has been involved in helping to develop principles of participation for children and young people for the Families and Children's Trust (Turn up the volume, December 2008, FACT – see Appendix 5). This in turn may help to measure the quality of the participation undertaken. However, with work being undertaken across both statutory, community and voluntary sector agencies measuring quality is inherently difficult where sign up to scrutiny is a potential deterrent. Questions arise around who assesses who, and concerns arise regarding the level of funding and resources available to not just undertake participatory work but also in evaluating practice.

During this research a great deal of discussion about the need for training of frontline staff to ensure high quality and diverse participation has occurred in practice. Whilst there is some need for advanced understanding of participatory methods, the training need is less about increasing front line workers' understanding of the variety of skills and techniques out there, but more about raising awareness amongst middle and senior managers and challenging their ethos and philosophies relating to participation. There is also an urgent need for managers to raise their awareness regarding the need for further investment in the 'preparatory work' exposed in this research which has particular relevance to work with marginalised young people. In this way managers will be better placed to fully support their staff via greater understanding of the time consuming and emotive nature of such work. Tisdall (2008, p. 420) suggests that theorising about children and young people's participation has been too child focused. Organisationally, consideration needs to be given to what time and resources can be and should be invested in considering how we engage audiences in decision making from service delivery to commissioning. Organisations need to have

clearer structures and more robust ways of working in place to ensure the voices of those more marginalised by society and the organisation's present systems can be heard and acted upon.

Equally important the support for practitioners via day to day supervision appears undeveloped in some of the professional groups. Nurses have traditionally been encouraged to seek regular supervision but many of the non nursing staff appeared to have limited peer support. This was often exposed after the interview had finished and was not tape recorded, and emerged as a direct result of the story told. Two of the participants directly stated that this research gave them a rare opportunity to discuss their practice and emotive issues emerging from it. Whilst not part of this research design, key workers were offered an opportunity to come together after the research interviews were complete. Two action learning sets were set up with high attendance in both. The action learning sets were set up to both offer on-going support but also to help externally validate some of the initial research findings. This further developed the researcher's knowledge but also re-emphasised the need for peer support.

**Recommendation 1:** Group supervision, action learning sets or individual peer support should be available to practitioners working with marginalised young people. This will help challenge and develop practitioners and service provision.

During the interviews with professionals working with young people excluded from school, data collection methods via individual needs assessment with the children were revealed. To ensure that the collective views of these young people can be heard the researcher has developed a database offering a tool to collate the individual views for collective analysis via content analysis. This is now being managed within the education department rather than public health, but offers a picture of the collective needs of this group previously missing. Additionally, advocacy for this group has been strengthened over the past year though a pilot project with Save the Children. To ensure the continued strengthening of the

voice of children excluded from school, work needs to continue to secure and develop the advocacy function, to ensure continued work with children 'at risk' of exclusion rather than those who have already been excluded.

**Recommendation 2:** Where young people are unable to meet collectively frontline practitioners should be actively encouraged to seek individual views and compile collective views for consideration at service development meetings. Managers through training and organisational structures need to be receptive to the views of young people gathered in this way.

At times the complex and unpredictable lives that many of the young people lead either temporarily or permanently excludes them from being able to share their voices via universal provision. Their geographical movement (different foster carers, different schools) also interrupts their engagement with more specialist services. To a certain extent key workers, as gatekeepers, remain the holders of power even though their intentions are, through the participatory process, to relinquish some of it to the young people. The key worker often decides who will be consulted and who takes part. These decisions are based on professional concern and knowledge of the young person as to whether they are suitable and ready. Training will help debate professional views regarding young people's capacity to take part challenging the deficit view of the child, Davies (2008, p. 13).

Many key workers are positive role models for the young people through their advocacy and participatory work. This was particularly evident in the stories from teenage pregnancy, looked after children and young carers. Key workers are clearly constrained by resource limitations particularly in moving from individual to collective group work. This is most evident with the children excluded from school, where even wall space is borrowed to display the children's work due to limited venues to meet collectively in some parts of the county.

**Recommendation 3:** Equitable and transparent systems for the selection of young people into participation need to be in place with key workers both facilitators and gatekeepers to participation. The FACT Strategic Participation Group needs to consider how a wider group of more challenging and vulnerable young people can be supported to move into collective participation, and for young people to have a clearer say in whether they are ready to do so or not. Whether organisations choose to use the FACT's 'Turning Up the Volume' new participation principles or existing tools, training needs to take place to empower participating organisations to acknowledge and understand the principles, challenge their own practice with young people and at the very least self assess.

#### 10.5 Further research

- Exploring the 'feedback loop' and how young people learn about the outcomes of their involvement affecting service change, and how they can contribute to setting the research agenda.
- Explore young people's views regarding participation at an individual and a collective level.
- Explore in more depth practitioners ability to relinquish decision making to the young people

#### 10.6 Dissemination

As a direct result of the presentation of key findings from this research to a practice and academic audience dissemination will be via the Participation Strategy Group (FACT) and the communications team (NHS North of Tyne). Both have corporate responsibility for ensuring the public are listened to and engaged with. All participants will be offered a summarised copy of the research findings as recommended in narrative research.

The models of participation discussed in Chapter 9 will be used as a basis of practice based training with frontline workers, specifically those working with more vulnerable groups. Additionally, the findings and methods employed will be shared with academic students across health, social care and education.

# References

Action for Children; Young Carers, (2009). Available at <a href="http://www.actionforchildren.org.uk/content.aspx?CategoryID=403">http://www.actionforchildren.org.uk/content.aspx?CategoryID=403</a> (Accessed 15 July 2009)

Alderson, P 'In the genes or in the stars? Children's competence to consent. *Journal of medical ethics*, 1992,18,119-124.

Arnstein S R 'The ladder of citizen participation' *American Institute Planners Journal*; pp. 216-224; July 1969.

Arnstein S R (2004) *A ladder of Citizen Participation*. Available at: <a href="http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html">http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html</a> (Accessed 18 May 2007)

Atkinson P (1997). The self as a soliloquy. *Sociological quarterly*, 35, pp. 521-532.

Atkinson M, Wilkin A, Stott A, Docherty P & Kinder K (2002). Multi agency working (LGA Research Report 26): A detailed study. National Foundation for Educational Research. Available at: <a href="http://www.nfer.ac.uk/research-areas">http://www.nfer.ac.uk/research-areas</a> (Accessed 20/09/09)

Badham B (2004) 'Participation – for a change: Disabled young people lead the way'. *Children & Society: Vol. 18, pp.143-154.* 

Barnardos (2007) Available at:

www.barnardos.org.uk.what we do/working with children and young people/y oung carers.htm (Accessed 14 June 2006)

Berridge D, Brodie I, Pitts J, Porteous D & Tarling R (2001). The independent effects of permanent exclusion from school on the offending careers of young people. RDS Occasional Paper No71. The Home Office. Available at <a href="http://www.homeoffice.gov.uk/rds/pdfs/occ71-exclusions.pdf">http://www.homeoffice.gov.uk/rds/pdfs/occ71-exclusions.pdf</a> (Accessed December 2008)

Blaikie N (1993), Approaches to social enquiry. Polity Press, Cambridge.

Blenkiron P (2005) 'Stories and Analogies in Cognitive Behavioural Therapy: A Clinical Review'. *Behavioural and Cognitive Psychotherapy*. 33:pp.45-59. Cambridge University Press.

Booth T & Booth W (1997). Making connections: A narrative study of adult children of parents with learning disabilities, in Doing Disability Research, edited by Colin Barnes and Geof Mercer. Leeds, The Disability Press, pp 123-140. Available at:

http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/chapter%208.pdf (Accessed 14 July 2009)

Borbasi S, Jackson D & Wilkes L (2003). Fieldwork in nursing research: positionality, practicalities and predicaments. *Journal of Advanced Nursing*, *51*(*5*), *493-501* 

Borland M, Hill M, Laybourne A & Strafford A (2001). Improving consultation with children and young people in relevant aspects of policy making and legislation in Scotland, Glasgow. University of Glasgow.

Bowling A (1997). Research Methods in Health – Investigating health and health services. Open University Press, Buckingham.

Bradley B (1989) *Visions of infancy: a critical introduction to child psychology.*Cambridge: Polity Press.

Bristol Royal Inquiry Report (2001) Available at: <a href="http://www.bristol-inquiry.org.uk/final-report/index.htm">http://www.bristol-inquiry.org.uk/final-report/index.htm</a> (Accessed 10th September 2008).

Bruner E M (1984). Introduction: The opening of anthropology. In S Plattner & E.M. Bruner (Eds), *Text, Play, and story: The construction and reconstruction of self and society – 1983 proceedings of the American ethnological society* (pp 1-16) Princeton, NJ: American Ethnological Society.

Bugge K E, Salvi H & Darbyshire P (2008). 'Children's Experiences of Participation in a Family Support Program when a parent has incurable cancer'. *Cancer Nursing* Vol 31, No 6

Bugental D B and Happaney K. (2000) 'Parent-Child Interaction as a Power Contest'. *Journal of Applied Developmental Psychology* 21(3): 267-282

Carr J, Matheson D & Tipene-Leach D (2001). "Hard to reach populations" in Pencheon D et al (Ed), *Oxford Handbook of Public Health Practice*. Oxford University Press, Oxford, pp226.

Cavet J & Sloper P (2004). The participation of children and young people in decisions about UK service development. *Child Care, Health and Development* 30, 613-621.

Children's Society (2004). Available at:

http://www.childrenssociety.org.uk/all\_about\_us/what\_we\_do/participation/4348.a sp (Accessed 22/04/08)

Clark C, Ghosh A, Green, E & Shariff N (2008). Media Portrayal of Young People – impact and influences. National Children's Bureau. Available at: <a href="http://www.participationworks.org.uk/news/young-people-publish-research">http://www.participationworks.org.uk/news/young-people-publish-research</a> (Accessed 30/08/09)

Clarke C & Proctor S (1999). 'Practice development: ambiguity in research and practice. Methodological Issues in Nursing Research'. *Journal of Advanced Nursing*. 30(4):pp.975-982. October 1999.

Coad J, Flay J, Aspinall M, Bilverstone B, Coxhead E, Hones B (2008). 'Evaluating the impact of involving young people in developing children's services in an acute hospital trust'. *Journal of Clinical Nursing*, 17, pp.3115-3122.

Coffey A (1999). The Ethnographic Self. Sage, London.

Cohen D & Prusak L. (2001). *In good company. How social capital makes organisations work*. Boston Harvard Business School Press.

Cortazzi M (1993). *Narrative Analysis; Social Research and Educational Studies Series: 12.* The Falmer Press, London.

Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N & Tyrer P. Systematic Review of involving patients in the planning and development of health care. *Volume 325 30 November 2002, pp 325:1263 [Online]* Available at <a href="http://www.bmj.com">http://www.bmj.com</a>; (Accessed: 24 April 2008)

Crist J D & Tanner C A (2003). 'Interpretation / analysis methods in hermeneutic interpretive phenomenology'. *Nursing Research Volume 53(3) pp.202-205* 

Curtis K, Roberts R, Copperman J, Downie A & Liabo K (2004a). "How come I don't get asked no questions?" Researching hard to reach children'. *Children and Family Social Work*, *9*, *pp167-175*.

Curtis K, Liabo K, Roberts H & Barker M (2004b). 'Consulted but not heard: a qualitative study of young people's views of their local health services'. *Health Expectations*, *7*, *pp 149-156*.

Curzon L B (1992). *Teaching in Further Education – an outline of Principles and Practice*, p98. From Maslow's 'Self actualization and beyond' in *Challenges of Humanistic Psychology*, (ed.) J. Bugental (McGraw-Hill, 1967)

Cutler D (2002). Taking the initiative; promoting young people's involvement in public decision making in the UK. Carnegie Young People's Initiative. Available at <a href="http://www.carnegie-youth.org.uk">http://www.carnegie-youth.org.uk</a> (Accessed 11 December 2008)

Davies L, Williams C, Yamashita H & Ko Man-Hing A (2008) Inspiring Schools - Impact and Outcomes: Taking up the challenge of pupil participation. Available at <a href="http://www.carnegie-youth.org.uk">http://www.carnegie-youth.org.uk</a> (Accessed 11 December 2008)

Davis M & Edwards R (2004). 'Setting the Agenda: Social Inclusion, Children and Young People' in Scotland in 2002-2003, *Children & Society, Volume 18 (2004)* pp.97-105

Denzin N K (1989). Interpretive Biography. Sage Publications, London

Denzin N K & Lincoln YS (Eds) (1998). Collecting and interpreting Qualitative Materials. Sage Publications, London

Department of Children, Schools and Families (2007). *The Children's Act;* Building brighter futures – summary. The Stationary Office, London

Department of Children, Schools and Families (revised 2008). *Children's Trusts:* Statutory Guidance in Inter-agency cooperation to improve the well being of children, young people and their families. The Stationary Office, London Available at:

http://www.everychildmatters.gov.uk/\_files/48459BE871A3D2E3C71501D44FA6 OBF.pdf (Accessed 11December 2008).

Department for Education and Skills (2001). *Learning to listen; Core Principles* for the involvement of Children and Young People. Children and Young People's Unit. Available at:

http://www.dfes.gov.uk/listeningtolearn/downloads/LearningtoListen-CorePrinciples.pdf (Accessed: February 2004)

Department for Education and Skills (2004a). *Children's Trusts: Statutory Guidance in Inter-agency cooperation to improve the well being of children, young people and their families.* The Stationary Office, London

Department for Education and Skills, Every Child Matters (2004b): Available at: <a href="http://www.everychildmatters.gov.uk/resources-and-practice/IG00200/">http://www.everychildmatters.gov.uk/resources-and-practice/IG00200/</a> (Accessed August 2005)

Department of Health (1989). *Quality Protects*. London: The Stationary Office, London.

Department of Health (2000a). *The NHS Plan: A plan for investment, a plan for reform*. The Stationary Office, London.

Department of Health (2000b). *Patient Advice and Liaison Services*. The Stationary Office, London.

Department of Health (2001). *A guide to involving young people in teenage pregnancy work* Teenage Pregnancy Unit. London.

Department of Health (2004). *National Service Framework for children, young people and maternity services; core standards*. The Stationary Office, London.

Department of Health (2006a). *Our health, our care, our say*. The Stationary Office, London.

Department of Health (2006b). *A stronger local voice*. The Stationary Office, London.

Department of Health (2007a). You're Welcome Quality Criteria – making health services young people friendly. The Stationary Office, London.

Department of Health (2007b). *Local Involvement Networks*. The Stationary Office, London.

Department of Health (2007c). Developing a core set of competencies. World class commissioning competences. Available at: http://www.dh.gove.uk/worldclasscommissioning (Accessed January 2009)

Dick S & Cunningham G (2000). *Nothing about me, without me*. The report of a practice based study of approaches to effective user involvement in individual acre in one agency, Edinburgh. The consultation and involvement trust, Scotland. Available at: <a href="http://hdl.handle.net/10065/567045">http://hdl.handle.net/10065/567045</a> (Accessed 11 December 2008)

Ecclestone K & Hayes D (2009). *The Dangerous Rise of Therapeutic Education*. Routledge, Oxford.

Edwards R, Franklin J & Holland J (2003). *Families and Social Capital: Exploring the issues*. Economic and Social Research Council, South Bank University.

Ezzy, D (1998) 'Theorizing Narrative Identity: Symbolic Interactionism and Hermeneutics'. *The Sociological Quarterly*, 39, 239-263

Faculty of Public Health (2001). Available at: <a href="http://www.fphm.org.uk">http://www.fphm.org.uk</a>. (Accessed 1 June 2005).

Families and Children's Trust Northumberland (2008). 'Turn up the volume' - Participation Principles for children and young people. (Unpublished)

Field P A & Morse J M (1996), *Nursing Research: The application of Qualitative Approaches* 2<sup>nd</sup> Edition. Chapman and Hall, London.

Fielding, M (2004). Transformative approaches to student voice: theoretical underpinnings recalcitrant realities. *British Educational Research Journal* 30:295-311.

Frank A W (2000). 'The standpoint of the story teller', *Qualitative Health Research, Vol. 10 No.3, pp.354-365* 

Gadamer H G (1976) *Philosophical Hermeneutics* (D E Linge, (Ed) and Trans). Berkeley: University of California Press.

Gadamer H G (1979) *Truth and Method (2<sup>nd</sup> English Edition)*. Sheed and Ward Ltd: London

Gilbert N, (Eds) (1993), Researching Social Life. Sage Publications: London.

Giorgi A. (1992) 'Descriptive versus interpretive: competing alternative strategies for qualitative research'. *Journal of Phenomenological Psychology 28, pp.235-260.* 

Glaser BG (1978) *Theoretical Sensitivity.* Sociology Press, Mill Valley, CA. Griffith (1996) 'Educational Citizenship and Independent Learning: Children in Charge 6' in John M (2003) *Children's Rights and Power: Charging up for a new century, Children in Charge 9.* Jessica Kingsley: London.

Goodley D (1996). 'Tales of the Hidden Lives: a critical examination of life history research with people who have learning difficulties, *Disability & Society, 11:* 3,333-348.

Hart R (1992). *Children's Participation; From Tokenism to Citizenship.* Innocenti Essays, NO.4, Florence. UNICEF International Child Development Centre, 44.

Hart R (1997) Children's Participation: The theory and practice of involving young citizens in community development and environmental care. Earthscan: London.

Heaton J & Sloper P (2006) *National survey of Patient Advice and Liaison*Services (PALS) in England: children, young people and parents' access to and use of PALS. Social Policy Research Unit: University of York

Hill M (1997).' What children and young people say they want from social services'. *Research, Policy and Planning, 15, 17-27*. In Curtis K, Roberts R, Copperman J, Downie A & Liabo K (2004). 'How come I don't get asked no questions? Researching hard to reach children. *Children and Family Social Work, 9 pp167-175*.

Holloway I (1997) *Basic concepts for qualitative research*. Blackwell Science Limited, Oxford.

House of Commons Select Committee (2007) *Public and Patient Involvement in the NHS; Third Report of session 2006-07, Volume 1.* Report, together with formal minutes, House of Commons, 22 March 2007.

IPPF (2004) Setting standards for Youth Participation – Self Assessment Guide for Governance and Programmes. International Planned Parenthood Federation. Available at: <a href="http://www.ippf.org/">http://www.ippf.org/</a> (Accessed 30/08/09)

John M (2003) Children's Rights and Power: Charging up for a new century, Children in Charge 9. Jessica Kingsley, London.

Johnson C, (1998). 'The essential principles of action learning'. *Journal of Workplace Learning. Volume 10, Number 6/7, pp296-300.* 

Kashefi E & Mort M (2004) 'Grounded Citizens' Juries: a tool for health activism'. Health Expectations, Volume 7, Issue 4, pp. 290-302.

Kidd M C (2004) 'Road to equality' *Public Health News.* 13 September 2004.

Kirkby P & Bryson S (2002). *Measuring the magic: Evaluating and researching young people's participation in public decision making.* Carnegie Young People's Initiative, London.

Kirkby P, Lanyon C, Cronin K & Sinclair R (2003) *Building a culture of participation: Involving children and young people in policy, service planning, delivery and evaluation: A Handbook*. Department for education and skills, London.

Koch T (1995). 'Interpretative approaches in nursing research: the influences of Husserl and Heidegger'. *Journal of Advanced Nursing* 21, pp.827-836.

Kurtz Z & James C (2002). What's New: Learning from the CAMHS Innovation Projects, London, Department of Health.

Lansdown G (2001). *Promoting children's participation in democratic decision-making*. Florence Italy: United Nations Children's Fund, Innocenti Research Centre.

Lewis A (2008). 'Silence in the context of child's voice'. *Children and Society, Volume 24, pp14-23.* 

Lieblich Amia, Rivka Tuval-Mashiach and Tamar Zilber (1998). *Narrative Research; reading, analysis and interpretation*. Thousand Oaks, CA. Sage Publications.

Lightfoot J and Sloper P (2001). Involving children and young people with a chronic illness or physical disability in local decisions about health services development: Phase one: report on national survey of health authorities and NHS Trusts. University of York, Social Policy Research Unit.

Lindesmith A R; Strauss A L & Denzin N K (1999). *Social Psychology* (8<sup>th</sup> Edition). Sage Publications, London

MacDonald R & Marsh J (2002) Youth, the 'Underclass' and Social Exclusion. ESRC database <a href="http://www.regard.ac.uk">http://www.regard.ac.uk</a> Available at: (Accessed 8 February 2004)

Maggs-Rapport F (2000). 'Combining methodological approaches in research: ethnography and interpretive phenomenology.'\_Journal of Advanced Nursing 31(1)219-225.

Maslow A (1954). *Motivation and personality*. New York, Harper.

Maslow A, (1971). *The farther reaches of human nature.* The Viking Press, New York.

Matthews H, (2001). 'Citizenship, youth councils and young people's participation'. *Journal of Youth Studies, Vol. 4, No.3 pp. 299-318* 

McGill I & Beaty L (1992). *Action Learning – A practitioner's guide*. Kogan Page, London.

Moen T (2006).'Reflections on the Narrative Research Approach'. *International Journal of Qualitative Methods 5 (4)*. <a href="http://www.ualberta.ca/~ijqm/">http://www.ualberta.ca/~ijqm/</a> (Accessed 16 June 2008)

Morrow V (2003). 'Improving the neighbourhood for children' in Christensen P & O'Brien M (Eds) *'Children in the city: Home, neighbourhood and community'*. Routledge Falmer, London, pp. 162- 183.

Munn P (2000), 'Social Capital, Schools, and Exclusions' in Baron S, Field J & Schuller T (Eds) 'Social Capital – Critical Perspectives'. Oxford University Press.pp.168-181

National Statistics First Release (2007) Available at: http://www.dfes.gov.uk/rsgateway/DB/SFR/s000741/SFR27-2007.pdf (Accessed 16 June 2008) National Statistics Social Analysis and Reporting Division (2001). Available at: <a href="http://www.statistics.gov.uk/socialcapital/downloads/soccaplitreview.pdf">http://www.statistics.gov.uk/socialcapital/downloads/soccaplitreview.pdf</a> (Accessed 1 November 2009)

National Youth Agency (2005). Available at: <a href="www.nya.org.uk/">www.nya.org.uk/</a> (Accessed 22 April 2008)

National Youth Agency (2008) What's Changed. Available at: <a href="https://www.nya.org.uk/whatschanged">www.nya.org.uk/whatschanged</a> (Accessed 12 December 2008)

NCH Available at: <a href="www.nch.org.uk/information/index.php?i=244">www.nch.org.uk/information/index.php?i=244</a>. (Accessed 13 January 2005)

NCH (2007). Working with Children; facts, figures and information, 2006-7. NCH/Guardian Book Series. Sage Publications Ltd: Society Guardian.

NfER (2004) Qualitative Study of the Early Impact of On Track. National Foundation for Educational Research. Available at: <a href="http://www.nfer.ac.uk/research-areas">http://www.nfer.ac.uk/research-areas</a> (Accessed 20/09/09)

Office of the Prime Minister; *Citizen's Juries* (2007). Available at: http://www.number10.gov.uk/output/page13164.asp. (Accessed 15 May 2008)

Office of Public Management (2001) Signposts – A practical guide to public and patient involvement in Wales. National Assembly for Wales.

Oldfield, C & Fowler, C. (2004). *Mapping Children and Young People's Participation in England*. National Youth Agency, Leicester.

Orme J, Powell J, Taylor P & Grey M (2007). Public Health For the 21<sup>st</sup> Century: A new perspective on policy, partnership and practice (2<sup>nd</sup> Edition). Open University Press, Maidenhead, England.

Osler A, Street C, Lall M & Vincent K (2004). *Not a problem? Girls and Exclusion*. New Policy Institute and Centre for Citizenship Studies in Education, University of Leicester. Joseph Rountree Foundation.

O'Toole T, Marsh D & Jones Su (2003) 'Political literacy cuts both ways: The politics of non participation among young people'. *The Political Quarterly Publishing Co.Ltd. pp.349-360.* 

Patton M Q (1990). *Qualitative Evaluation and Research Methods* (Second Edition). Sage Publications, London.

Percy-Smith B & Malone K (2001). Making children's participation in neighbourhood settings relevant to the everyday lives of young people'. PLA notes: Children's Participation – evaluating effectiveness. October 1991 – pp. 18-23.

Porter S (1996). 'Qualitative Research' in Cormack D.F.S. (ed.) *The Research Process in Nursing* 3<sup>rd</sup> Edition. Blackwell Science, Oxford, pp.113-122.

Public Health Core Competencies <a href="http://www.fphm.org.uk">http://www.fphm.org.uk</a>

Putnam R D (1993). 'Making democracy work: Civic traditions in modern Italy'. Princeton University Press.

Putnam R D (1995) 'Bowling Alone: America's Declining Social Capital', *Journal of Democracy* 6:1 Jan, 65-78.

Putnam R D (2000) Bowling *Alone: The Collapse and Revival of American Community.* New York: Simon and Schuster.

Research and Information (Infonet), Northumberland County Council. Available at <a href="http://www.northumberland.gov.uk/default.aspx?page=1585">http://www.northumberland.gov.uk/default.aspx?page=1585</a> (Accessed 11 December, 2008)

Riessman C K (1993). *Narrative Analysis; Qualitative Research Methods Series* 30. Sage Publications, London.

Riley J & Jones L (2002). *User and public involvement in health services: a literature review.* Partners in Change, the Scottish Human Services Trust.

Riley T & Hawe P (2005). 'Researching practice: the methodological case for narrative enquiry'. *Health Education Research*, Vol.20 no 2, pp. 226-236. Oxford University Press.

Save the Children (2005) *Practice Standards in Children's Participation*. International Save the Children's Alliance, UK.

Scottish Parliament Equal Opportunities Committee 2001, Official Report, Scottish Parliament, Edinburgh, 5 June.

Seaman P & Sweeting (2004). Assisting young people's access to social capital in contemporary families: a qualitative study. *Journal of Youth Studies*, *7*(2) *pp.* 173-190.

Shenton F (1999). *Evaluation of County Durham 'Investing in Children Initiative'*. Durham, University of Durham.

Shenton F (2004) 'Everyday Participation: A practical guide to youth involvement', UK Youth, London.

Shephard C & Treseder P (2002) Spice it up! Practical tools for engaging children and young people in planning and consultations. Save the Children, Swansea.

Silverman D (1993) Interpreting Qualitative Data Methods for Analysing Talk, Text, and Interaction. Sage, London.

Sinclair R & Franklin A (2000). *Young People's Participation; Quality Protects Research Briefings*. National Children's Bureau. Research in Practice, Making research Count, Department of Health

Sinclair R (2004). Participation in Practice: 'Making it meaningful, effective and sustainable'. *Children and Society, Vol 18 (2004) pp. 106-118.* Published on line at www.interscience.wiley.com Accessed 13 November 2007

Sloper P (2004) 'Facilitators and barriers for co-ordinated multi agency services' *Child Care, Health and Development, 30:6, pp. 571-580.* 

Smart H, Titterton M & Clark C (2003). 'A literature Review of the health of gypsy / traveller families in Scotland: the challenges for health promotion'. *Health Education* Volume 103: Number 3, 2003, pp. 156-165.

Strauss A (1987). *Qualitative Analysis for Social Scientists*. Cambridge University Press, Cambridge.

Strauss A & Corbin J (1990). Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Sage Publications, London.

Taylor F (2005). A Fair Hearing? Researching Young People's Involvement in the School Exclusion Process. The Save the Children Fund.

The Acheson Report (1998). Available at: <a href="http://www.archive.official-documents.co.uk/document/doh/ih/part2b.htm">http://www.archive.official-documents.co.uk/document/doh/ih/part2b.htm</a>
Accessed 15 June 2002

The Children's Act (2004). Available at:

<a href="http://www.everychildmatters.gov.uk/resources-and-practice/IG00200/">http://www.everychildmatters.gov.uk/resources-and-practice/IG00200/</a>
(Accessed 8th October 2008)

Thomas K W & Velthouse B A (1990). 'Cognitive elements of empowerment: An 'Interpretative model' of intrinsic task motivation'. *Academy of Management Review, Vol 15, No. 4, pp.666-681.* 

Tisdall E K M, Davis J M & Gallagher M (2008) 'Reflecting on Children and Young People's Participation in the UK'. *International Journal of Children's Rights* 16; pp.343-354.

'Turn up the volume': *Participation principles for children and young people* (2008) (Unpublished). Families and Children's Trust, Northumberland.

United Nations Convention on the Rights of the Child (1989), Geneva.

Van Manen M (1990). Researching lived experience: human science for an action pedagogy. State University of New York Press.

Vygotsky L S (1978). *Mind and Society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Wade H and Badham B (2005) *Hear by Right* (second edition). The National Youth Agency in partnership with the Local Government Association, Leicester.

Walker L O (1995) *Strategies for Theory Construction in Nursing* (3<sup>rd</sup> ed). Prentice Hall International, London.

Wall TD, Wood S J & Leach D J (2004). *International review of industrial and organizational psychology. Chapter 1: Empowerment and performance.*<a href="http://media.wiley.com/product">http://media.wiley.com/product</a> [Accessed 01/09/09]

Wansbeck Council for Voluntary Services (May 2002). 'Gypsy Joe from Mexico; The experiences of travelling people from three sites in Northumberland'. A report from the young travelers action research team', NCH

Webb E (2002). 'Health Services: Who are the best advocates for children?' *Archives of Disease in Childhood; Sept 2002; p.87, 3.* 

Webster's Third International Dictionary (1966). Springfield, MA, Merriam-Webster.

Whiting E & Harper R, (2003). Young People and Social Capital. Office for National Statistics. Available at:

http://www.statistics.gov.uk/downloads/youngpeople\_final.pdf (Accessed 8 October 2008)

World Health Organization (1986) Ottawa Charter for Health Improvement. WHO, Geneva.

Williamson C (1999). 'Reflections on health care consumerism: insights from feminism'. *Health Expectations*, *2*, *pp.150-158*. Blackwell Science Ltd.

Zimmerman D H & Wieder D L (1971) 'Ethnomethodology and problems of order' in Douglas J D (1971) *Understanding Everyday Life.* Routledge and Kegan Paul, London

# **Appendix 1- Information sheet and consent form for participants**



#### Information Sheet for young person

### Finding out about young people's experiences of participation and involvement

#### About the researcher

My name is Dawn Scott. I am a nurse working for Northumberland Care Trust. I am also a student studying at Northumbria University. This project is part of my work and my studies. If you agree to meet with me I will have an identification badge with me to prove who I am.

#### What is the project about?

I am studying how we involve children and young people in planning their care and services. I am particularly interested in finding out what it is like for young people to be asked and to share their views about local services or things that affect them.

Some young people live in different and sometimes difficult circumstances. They might not attend school regularly, they might have to look after someone at home, friendship groups might change because of their circumstances, they might move about the country a lot, or they may have had difficulties in their families. Seeking the views of children and young people who live in different or unusual circumstances is important.

#### Why have you been chosen?

Not all young people have had the opportunity to share their views. In the past you have been asked to share your views about either your individual care or broader service issues, with people who provide your care. I would like to know how you became involved, what it felt like to share your views and how it could be improved. In the past we have not been very good at asking people what it was like to be asked for a point of view. We feel we can learn something from your experience.

I am also going to ask some professionals who provide health, education and social care what involving young people felt like for them.

#### How does the researcher know about you?

I do not presently have any information about you. I have asked health, social care and education workers to select someone who has been involved in sharing their views about their individual care or our services.

Your key worker has agreed to give you this information on my behalf and answer any questions you might have. If you agree to take part in the project you will need to sign the enclosed consent form. The consent form needs to be signed by your parent or carer as well as you. Only then will your information be passed on to me. If you do not want to take part I will not be given your name or contact details.

Please take time to think about whether you want to take part. You will need to discuss it with your parent(s) or carer, maybe with your friends and others before you decide.

#### How do you take part?

The interview will take approximately <u>one to one and half hours</u>. If you are happy to take part, you will need to pass your consent form, signed by you and your parent or carer to me, via your key worker. Alternatively you can send it directly to me by post.

Once I have received your consent form I will contact you. I would like to visit you at your home, school or other place preferred by you and your parents or carers. It would be interesting to find out a bit about you. I would therefore like to hear your story, how you became involved in sharing your views and what that experience felt like. I would also like to know how you think we could improve things so young people have more opportunities to share their views about their own care and about how services are provided.

#### Why undertake this project?

Organisations such as Northumberland Care Trust have a responsibility to involve children and young people and others in how we develop our services. As an organisation we also feel very strongly that if we do this, we should do it well. We are good at asking adults what they like and dislike about services and are getting better at asking young people. We have not however asked people how they feel about being involved – what the experience of involvement was like.

By sharing your views about what it felt like to be involved we can put in place a good system of involvement that ensures all groups of people have a chance to share their views and shape our services in a positive way.

#### **Sharing Information**

I would like to tape record your story and take some notes. This allows me to examine all the stories together and gather information from them.

Once I have listened to the stories and read the notes, I will write a report. Individuals will not be named or identified in the report. Once the stories have been examined and written into a report I will destroy all the tapes and notes. The tapes will be kept safe until I have completed my degree.

As a nurse, if you share information with me that I think needs to be followed up with another professional, such as another nurse or a doctor, then I will talk this through with you and explain why I need to share the information.

#### Saying 'no' to taking part

If you do not want to take part that's OK. It is also OK for you to change your mind even if you have already agreed to take part. If you change your mind after you have shared your views and before I have written up the report, I will destroy your tape and notes, and I will not use them for my project. This will not affect your care.

#### Any questions?

If you have any further questions you can ask your key worker to contact me, or you can contact me directly. My work number is 01670 394443 or I can be emailed on <a href="mailto:dawn.scott@northumberlandcaretrust.nhs.uk">dawn.scott@northumberlandcaretrust.nhs.uk</a>

THANK YOU FOR READING ABOUT THE PROJECT



#### Information Sheet for Parents or carers

## Finding out about young people's experiences of participation and involvement

#### About the researcher

My name is Dawn Scott. I am a nurse consultant working for Northumberland Care Trust. I am also a student studying at Northumbria University. This research project is part of my work and my studies.

#### What is the study about?

I am studying how we involve children and young people in planning their care and services. As an organisation we have a responsibility to involve the public and patients in how we deliver services. Much of my work is focused around developing services for children and young people and therefore seeking children's and young people's view is very important. We are quite good as an organisation at undertaking 'involvement' work, but we do not fully understand what that experience is like for people.

I am planning to talk to both staff and young people who have experience of involvement work to determine what being involved meant to them. What the barriers and constraints were, and how we can improve our involvement work in the future.

I am particularly interested in seeking the views of young people who have experienced some difference or difficulties in their lives. Children who care for a family member, those who have been excluded from school, teenage mothers, children in care and gypsy / traveller children.

#### Why choose these children and young people?

These very children and young people, because of their health, education and social circumstances might have greater need to influence services because they do not fit into the norm that many of our services are built and based on. It is important that our services meet the needs of all people.

#### Why undertake this project?

Organisations such as Northumberland Care Trust have a responsibility to involve children and young people and others in how we develop our services. As an organisation we also feel very strongly that if we do this, we should do this well.

We are good at asking adults what they like and dislike about services and are getting better at asking young people. We have not however asked people how they feel about being involved – what the experience of involvement was like.

#### What will your child / the young person be asked to do?

I will be asking young people to share their experiences of involvement with me in the form of a story. Their experience of involvement with a key worker may have been at an individual level about their care or it may have been as part of a consultation exercise. I will ask the young person's permission to tape record what they say and I will be taking some notes.

#### What about confidentiality?

All the information collected will be kept confidential. Individuals will not be named or identified in any reports or publications produced. The tapes and notes will be kept safe and secure and will be destroyed once the report is written and I have finished my degree.

As a registered nurse, if I become aware of any issues that cause me concern during the interview, I am obliged to share my concerns with an appropriate professional.

#### How can you help?

The interview will take approximately **one to one and half hours**. We would like your permission to talk with your child / the child in you care. His or her views and experiences are as important as anyone else's. If you agree a consent form must be completed / signed before I can proceed. Your child will receive information about the research and will also consent to take part. The consent form requires both of your signatures before I can contact you.

I will only contact you and the young person once I have a signed consent form. We can then arrange a suitable place for me to hear the young person's story.

#### What will happen to the research project findings?

I will have to complete a report for my University studies and a copy for Northumberland Care Trust. A summary of the findings will be distributed more widely to help influence the way people who work in health; education and social care undertake public and patient involvement work. It is also hoped that some of the work will be published.

If you need to discuss this further before making a decision I am happy to clarify any of the above or answer any additional questions you may have.

I can be contacted by telephone on 01670 394443 or via the email at the following address <a href="mailto:dawn.scott@northumberlandcaretrust.nhs.uk">dawn.scott@northumberlandcaretrust.nhs.uk</a>

Please note that any decisions you make will not affect any services that you or your child (or the child in your care) receives either now or in the future.

Thank you for finding time to read this information.



# Consent form for parents / carers and young people Finding out about young people's experiences of participation and involvement

I have read the information sheet and understand the nature and purpose of the study. I understand that my child is free to withdraw from the study at any time without having to give a reason for withdrawal, and that this decision will not affect the services my child or family receive now or in the future.

I understand that the information supplied will be kept confidential, safe and secure, and that no information, which could identify the young person, will be released to anyone outside the research team.

I give consent for my child / the child in my care to take part in this research

project (Plea	ise tick	appropriate	DOX)
YES		NO	
If 'Yes', do y	ou nee	ed any further	information?
YES		NO	
Do you agre	e to the	e interview be	eing tape-recorded?
YES		NO	
Name of chil	d / you	ing person	
Signature of	parent	t / carer	
Signature of (If appropriate		young perso	n
Contact deta			
Address			
Tel Number	(Day).		Tel Number (Evening)
Please retur	n this f	orm to Dawn	Scott, Nurse Consultant, Public Health,

Northumberland Care Trust, Merley Croft, Morpeth, Northumberland, NE61 2DL



# Information Sheet for Key Workers of Northumberland Care Trust or Northumberland County Council

## Finding out about young people's and key worker's experiences of participation and involvement

#### About the researcher

My name is Dawn Scott. I am a nurse consultant working for Northumberland Care Trust. I am also a student studying at Northumbria University. This research project is part of my work and my studies.

#### What is the aim of the research project?

As an organisation we have a legal responsibility to involve the public and patients both in their individual care and in how we shape services. Much of my work as a nurse consultant is about developing services for children and young people. Seeking the views of children and young people is important to this work.

This research aims to examine the experience of involvement or participation work of both marginalized children and young people, and their key workers. I hope to examine the facilitation and advocacy experiences of key workers and he participation experiences of the young people themselves.

#### Who are the children in the sample?

Children and young people aged between 11 – 18 years old who have been involved in participation or consultation work within the past two years. Children who are:

- Teenage mothers
- Young Carers
- Part of the traveling community
- In 'looked after' care, or have been,
- Excluded from school.

#### Who are the Key Workers?

Professionals from across health, social care and education who work directly with the children and young people in the sample above, and who have helped them engage in participatory / involvement work.

#### What will you be asked to do?

I would like to talk to you about any involvement work you have undertaken with your specific client group. I will help you place those activities onto a framework of public and patient involvement and we will talk about what each of those activities involved and what the experience was like for you as a practitioner. The interview will take approximately **one to one and half hours** 

I will ask you to select a very positive experience of involvement work and a not so positive experience. I would like to tape record our meeting as you share your story and experiences of these involvement activities. I would also like you to highlight a few young people who you think would be suitable for me to talk to. I want to hear their stories and experiences too.

Some of the young people who fall into the sample have experienced difficulties in their lives, and whilst I am keen to hear their views, I do not want to inappropriately select a young person onto the study. I would therefore be reliant on your professional judgement in selecting a suitable young person to talk to. We can discuss this further during the interview.

Once I have started to analyse some of the data, you will be called back into a focus group with other professionals, where the broad anonymised findings will be shared. It is hoped that key statements will be debated and those present will collectively look at ways to improve public and patient involvement for marginalized children and young people.

#### What about confidentiality?

All the information collected will be kept confidential. Individuals will not be named or identified in any reports or publications produced. The tapes and notes will be kept safe and secure and will be destroyed once the report is written and I have completed my degree.

#### What will happen to the research findings?

I will have to complete a report for my University studies and a copy for Northumberland Care Trust. A summary of the findings will be distributed more widely to help influence the way people who work in health; education and social care undertake public and patient involvement work. It is also hoped that some of the work will be published.

#### Consent to take part

If you agree to take part in this research you will need to sign and return the enclosed consent form. Once I receive your signed consent we can arrange a mutually agreeable date, time and venue for me to listen to your experiences. If you do not wish to take part in the research project, I would appreciate it if you could send back the consent form declining the offer.

#### This research has been granted ethics approval.

If you need to discuss this further before making a decision I am happy to clarify any of the above or answer any additional questions you may have. I can be contacted by telephone on 01670 394443 or via the email at the following address <a href="mailto:dawn.scott@northumberlandcaretrust.nhs.uk">dawn.scott@northumberlandcaretrust.nhs.uk</a>

Thank you for finding time to read this information.



## Consent form for Key Workers of Northumberland Care Trust or Northumberland County Council

### Finding out about young people's experiences of participation and involvement

I have read the information sheet and understand the nature and purpose of the study. I understand that I am free to withdraw from the study at any time without having to give a reason for withdrawal, and that this decision will not affect my employment now or in the future.

I understand that the information supplied will be kept confidential, safe and secure, and that no information, which could identify me will be released to anyone outside the research team.

I give my consent to take part in this research project (Please tick appropriate

box)			
YES		NO	
If 'Yes', do y	ou nee	ed any further	information?
YES		NO	
Do you agre	e to th	e interview be	eing tape-recorded?
YES		NO	
Name of Ke	y Work	er	
Signature of	Key V	Vorker	
Name of em	ploying	g organisatior	1
Contact det	tails		
Address			
Tel Number			Email

Please return this form to Dawn Scott, Nurse Consultant, Public Health, Northumberland Care Trust, Merley Croft, Morpeth, Northumberland, NE 61 2DL

### **Appendix 2- Prompt card for young people**

What did you like about sharing your views?

# Did you get feedback?

What happened to the information?

How did you get involved?

Did you feel listened to?

What would you change?

What type of participation?

Did you learn anything new?

Appendix 3- Key workers completed public and patient proforma by sample

#### **Main Dimensions of Public and Patient Involvement**

Teenage Pregnancy	INFORMATION	FEEDBACK	INFLUENCE
INDIVIDUAL  Preparation stage – young mums Info giving re nature and process of involvement	<ul> <li>Face to face information giving about a range of services</li> <li>Prep for prep basis</li> <li>YP directory of services leaflet Sexual Health Services</li> <li>Confidentiality statement – influenced by young peoples comments</li> <li>Information leaflets for psychosexual service, GUM service</li> <li>Confidentiality statement leaflet – feedback loop so young people can commence on design</li> <li>Contraceptive service advertising</li> <li>Young persons contraceptive service</li> </ul>	<ul> <li>Sexual health clinic forms – encouragement to complain</li> <li>When a problem is shared suggestions on how to make things better (if realistic try and change things)</li> <li>Via HIV/AIDS Social Worker</li> <li>SRE – Q &amp; As furry box- Write any Q or worry to guide the lesson</li> <li>Suggestion box boxed – sexual health clinics</li> <li>Forms and confidentiality statement designed by young people (Feedback moving into influence)</li> <li>Young people designed evaluation form</li> <li>Evaluation of SRE</li> <li>Individual consultation about health visitors</li> </ul>	<ul> <li>YP service advertising</li> <li>Contraceptive clinic</li> <li>Help structure lessons</li> <li>Healthy snacks after schools</li> <li>nice furniture</li> </ul>
COLLECTIVE	<ul> <li>Young person confidentiality statement</li> <li>Young person drop in at Point to illustrate what's available - Influenced by young persons comments</li> <li>Galaxy Radio / SH Media group / Website (feedback on services)</li> <li>Parenting group - 10 week course (coquet children centre)</li> </ul>		<ul> <li>Health Trainers Scheme</li> <li>Influencing, Interviewing and recruitment</li> <li>Teenage Pregnancy Strategy</li> <li>Away Day, Action Planning,</li> <li>Selection</li> <li>Action being taken in school. Meeting to implement - Young people feed back to professionals</li> <li>Launch of FACT at Kirkley Hall (suggested outline – Young people worked I/c that) - Sharing their priorities</li> <li>(Evaluation and reflection in between two groups)</li> </ul>

Traveller's	INFORMATION	FEEDBACK	INFLUENCE

INDIVIDUAL	<ul> <li>Traveller's advocacy project. (Children's Fund)</li> <li>Children's advocacy worker / participatory Worker – what skills would this worker need</li> <li>Health Improvement Specialist one to one contact / visits</li> <li>Health Visitor contact when required</li> <li>Information re process of research input to families and young people (x 5 families)</li> <li>Verbal info</li> <li>Sent out letters / explanations</li> <li>NVQ portfolio in participatory research</li> <li>information and views sought to help keep a family on an illegal site</li> <li>1:1 support from health improvement team</li> </ul>	Consultation with young travellers group participatory Worker – what skills would this worker need	
COLLECTIVE	<ul> <li>Information re health visitor services</li> <li>Research reports</li> <li>Tomasha. East is East – issues of identity. Choreographer, DJ, Script Writer, Song Writer</li> </ul>	<ul> <li>Aims towards communities consultation</li> <li>Arts worker – Pegswood</li> <li>Gypsy Joe from Mexico (Participatory Action Research) - Children's participation re: culture / changing involvement in children's centre</li> <li>Fun day and Artwork to help develop children's Centre - Steering group guiding work</li> <li>Presentations as part of Our Part – lead to research which helped to form Young peoples equality group - 24 young people – weekend at Otterburn Hall</li> <li>Connexions research</li> <li>Specific training for interviewing</li> <li>Work better – copy of report actions</li> </ul>	<ul> <li>Young people on interview panel for advocacy worker and young people created scenario for interview - partial power to select</li> <li>Young people helped write report</li> <li>Young people's equality group aims towards policy influence</li> </ul>

	INFORMATION	FEEDBACK	INFLUENCE
Young Carers			
INDIVIDUAL	Young carer + Mum – workshop  Given general information about young carers	Produced Art work for leaflet - The children chose colour combination for leaflets and poster	Involved in professionals Training on mental health issues with LA Talked at school Published in Young Carers National Magazine
COLLECTIVE	Conferences around County. Young Carers Awareness raising Film making	X 3 young carers spoke at Connexions Conference telling their stories (individual and collective)  Trinity Youth Consultation (limited services in South of County) presently trying to set up a young carers forum	Influenced services & development plan  Info exchange – Regional young carers group  Pilot services re: drugs and alcohol (caring for parents with substance misuse)

Looked After	INFORMATION	FEEDBACK	INFLUENCE

INDIVIDUAL	1:1 information re: sexual health (2 way process – identify high risk young people) Telephone and direct contact Health Assessment summary and letter to young person - Explanation on an individual basis - social / medical health assessment Information profile Re Foster Carers Video- Experiences of other young people in care Health Assessment / Sexual Health Leaflet Care leavers pathway plans – aspects of personal life, accommodation, choice Finance - 16 – 18 year olds benefits Information pack "What's your problem" Making complaints, advocacy service, information who's who	YP speak 1:1 with KWs Re: Views of services external to care system KW will feedback to service provider or support young person to feedback Questionnaire: views at leaving care stage (but poor response (attempt to consult countywide as inequitable at present) Leaving care questionnaire	Now able to access sexual health services herself  Bring information back to Looked After Service – feedback to relevant services  Support to put it in writing Can make a 'no' decision for sharing health assessment Newsletter
COLLECTIVE	Drafted young people sexual health policy Connexions provide young people's interview formats to prepare them to take part in interviewing for new staff Book produced by children on foster carers (house and person) Articles written by young people "listen up" reference group Arts festival – leaving care Parent and carers new information pack	Focus group (participation officer) LAC Focus Group Before summer project pre consultation re sexual health policy Consultation Lake District 2002 to develop sexual health policy (Art Work developed by young people also, once policy developed) Care leavers group Now working towards young persons sexual health policy (peer support) Realised need for peer support programme 'A PAUSE' programme Exeter, customised to look after young people Involved in developing campaign to attract foster carers Produced video Re YPs experience in care Care leavers art exhibition in Gateshead Sage	Young person on interview panel for new participation officer (influenced final decision Interviewing for residential care officers – decisions Re Questions they wanted to ask  Development of sexual health policy – for staff (draft taken back to young people and professionals) Feedback at the Point Wrote young people policy with the young people themselves (3 weeks) Pocket money – influenced change Shared the need for peer education – that should then influence service delivery Influenced age related materials being produced

Excluded	INFORMATION	FEEDBACK	INFLUENCE
-Adiada	1111 0111111111	1 2255/1011	=0=0=

INDIVIDUAL	Letter of confirmation Re Commencement of tutoring Booklet about EOTAS Tuition Plans and venues Parent Partnership Information leaflet 1:1 meeting – completion of 'Where do we go from here' – Individual views captured Re Exclusion (Presently no feedback loop) One to one to ensure the family / child knows their rights and understands the appeals process Information Re: appeals process and options advice to parents Key contact card ACE booklet	<ul> <li>'Choyses' Education Support Programme, mentoring sessions as a group - get the award for attendance (limited group feedback)</li> <li>Tuition – can suggest options for days out</li> <li>Monthly feedback report and 6 weekly review to check everything is OK</li> <li>Young person invited to own review (very few attend) –need independent advocate</li> <li>Evaluation sheet being developed for parent, child and multi agency partner</li> <li>Developed student self assessment booklet</li> <li>Young persons mentoring session with EOTAS</li> <li>Young peoples booklet to evaluate quality of service</li> </ul>	<ul> <li>Parental involvement in pupil discipline meeting and attendance to Governor meetings (rare attendance)</li> <li>Limited options so limited influence</li> <li>KW can also help influence decisions / writes report for EOTAS</li> <li>Children with Special Educational Need's have advocates working with them – can influence</li> <li>Have not reflected on any yet</li> </ul>
COLLECTIVE	Statistics – EOTAS, YOT Rule setting (group agreement before go on outings)	Rule setting is agreed and formulated with young people	KW influenced policy
Poweioro Cros	PRU – lots of people who go back into mainstream don't settle. No outreach work	Research – permanently excluded re: excluded not localised provision	

Barriers – Group work = Risk Assessment / level of paper work – very challenging behaviours when in groups / limited venue. Undertake individual needs assessment but do not pull the information together into collective information to help change servic

#### Appendix 4: Quote referencing

Each quote is referenced with a code.

#### **Key Workers**

KW will refer to a key worker, and their area of practice will be coded as follows LA = 'Looked After' Children; TP = Teenage Pregnancy; TR = Travellers; YC = Young Carers, and EX = Children excluded from school. The numbers '1' and '2' relate to whether they were the first or second person interviewed in their area of special practice. Hence a **KWLA1** code refers to the first key worker interviewed for looked after children.

#### Young People

YP will refer to a young person, and their area of need will be coded as follows LA = Looked after Children; TP = Teenage Pregnancy; TR = Travellers; YC = Young Carers, and EX = Children excluded from school. The numbers '1' or '2' relate to whether they were the first or second person interviewed within that category. Hence a code **YPLA1** refers to the first young person interviewed in the looked after children cohort.

Appendix 5- Participation standards developed alongside this research (See Turn up the Volume disc – attached)

Appendix 6 - Summaries and initial analysis of young people's interviews

#### **Summary of Analysis - YP EX 1**

#### Stage 1

#### Background

EX 1 is a 15 year old boy who lives with his family in Ashington (urban environment). Mum and dad work, his older sister is taking 'A' levels at school. No apparent home problems.

#### **Epiphanies**

- Moving to year 10 behaviour change
- > Relationship with Peer Group peer pressure to act out
- Relationship with teachers negative (although liked PE teacher who treated him with respect)
- Exclusion bored, lost and uninspired
- Advocacy role of Key Worker
- Securing Training and practical work placement

#### Initial impression / assessment

This interview and the subsequent story varied considerably from the others. Firstly, whilst the young man was keen to take part, information in the form of his story was hard to gain. During this interview the narrative was difficult to obtain and the researcher found that question after question needed to be asked to gain any insight into this young man's life.

Part way through the interview it becomes apparent that he has no concept of participation and involvement work, and has not been involved in sharing his voice at any meaningful level throughout his experience of being excluded.

The difference in this story is 'the isolation' one feels from the shared experience and the lack of participation at a collective level. All work, if any has been on a one to one basis, and appears education or training focused.

There appears to be no evidence of any participatory work being on offer, and this is confirmed when the researcher asks him to share his participatory experiences. In some ways, this young man did not meet the selection criteria, i.e. that those selected should have been involved in sharing their voices within the past year. However, the researcher has chosen not to remove the interview to highlight the difference in only working one to one with a young person or as reflected in this story as an advocate and not a participation worker.

#### **Self-descriptions**

'Bad', 'Disruptive', 'Daft', a victim, bad and quick tempered. Examples of both through the text (additional comments)

#### **Personal Outcomes for YP**

Gaining an advocate (key worker and connexions worker) to act on his behalf when relationships have broken down. (Break down of relationships due to his behaviour, and to find him alternative educational and vocational opportunities). Support to secure training opportunities

Future Job Opportunity

#### **Outcomes for others**

No immediate outcomes for other excluded children as there appears to be no involvement in assessing the collective needs of this group. This instigated action from the researcher to work with Re-integration Officer to develop the one to one booklet assessing individual needs and expectations and to set up a database to start to keep the collective views of these young people. Also researcher involved in shaping a Save the Children Project to support young people excluded from school and break the cycle of re exclusion.

## Relationships and significant others (often linked to epiphanies)

Wants to please family – looking forward to telling his dad that he has secured some training

Relationship with Key worker(s) – links to support needs / process etc Good relationship with Re-Integration Officer and connexions staff – although not perceived by young man as participatory work.

## **Aspirations**

To be in practical work

#### Issues

Lack of group participation work and limited 1:1 work (limited support opportunities and alternative education). Hated Choyses Programme at college – boring.

## Stage 2 - Analysis Epiphanies within story

Movement from class in school with peers to another class would have impacted on his behaviour and potentially prevented his exclusion. Exclusion linked to his behaviour – accepts this but feels that he was labelled early on and was always blamed for others behaviour too.

Pleased to have secured a training opportunity (on the day of the research interview) and saw this as an opportunity for future work – optimistic.

**Stage 3 - Examine findings across stories** – Little opportunity to share his views regarding the exclusion and his future needs and no collective opportunity to do so. Similar poor participation experience / opportunity as other excluded young person - advocacy more than participation.

Feels labeled

## **Analysis - Young People EX 2**

## Stage 1

## Background

EX 1 is a 15 year old girl who has had a turbulent home life. She has a mother, sister and 2 brothers. Her biological dad is gay and she has lived with her mother and step father in violent circumstances.

She describes a happy childhood but difficult teenage years.

## **Epiphanies**

- Difficulties in managing her emotions moving into her teenage years
- Relationship with mother (mum could not choose between violent partner and daughter)
- Step dad's domestic violence and unpredictable behaviour
- Being hit by step father (also offensive verbally)
- Biological father's sexuality
- Intermittent residential care and movement between different carers
- School Changes / change of friendship groups and bullying
- Overdoses (specifically final attempt) Wake up call
- School Exclusion
- Being able to stay permanently with Nana

## Initial impression / assessment

This young woman has matured through exposure to very difficult and challenging circumstances

She takes responsibility (on reflection) for previously poor behaviour

She recognises that pressure from her peers has lead to at times her own poor behaviour

She has strong negative feelings about the use of illicit drugs and alcohol (having lived with a step father who used cannabis and alcohol)

She is non judgemental and is accepting of her dads sexuality but expresses difficulties associated with this.

She has experienced residential care, movement between parents and schools. She has built an incredible amount of resilience over time, although in low times overdoses were the chosen option

## **Self-descriptions**

Makes friends easily

Quick Tempered

Feels 'stupid' having taken overdoses

Felt 'stupid' getting excluded

'It's hard to know that I have been so evil'.

Now – 'Happy go lucky 15 year old teenage girl who wants everything and is very demanding. I don't get everything I want but I like to try'.

#### **Personal Outcomes for YP**

Very little participation around exclusion or even later decisions in her life around her care – feels she could share her views one to one with re integration officer. Through previous peer support training feels she could help others (has supported cousin regarding suicidal feelings).

## **Outcomes for others**

None revealed as very little opportunity to share voice

## Relationships and significant others (often linked to epiphanies)

Close to girl in residential care (similar experience to EX2)
Residential care officers (2 specific people mentioned as important)
Nana and granddad are straight with her and praise her and have provided a stable and permanent home life after many moves.

Relationship with Key worker(s) – links to support needs / process etc Very positive view of Re integration Officer (key worker link for this research) even though she has not had a huge amount of time with her – trusts her.

## **Aspirations**

To get GCSE's

To get E2E (Education to Employment grant) and move to A levels at Newcastle College.

To be a Residential Care Officer

#### Issues

The fact that her mother could not choose between her daughter and her boyfriend (now regrets the way she has treated her mum!)

Endless moves / fraught and uncertain home life

Knew overdoses would lead to an action (reaction) and an offer of support. However, got a 'wake up' call when finally hospitalised and very ill on last attempt Regrets being excluded from school

Feels she and her family should have been given more chance to discuss exclusion

**Stage 2 - Analysis Epiphanies within story** –Many of the negative family relationships and circumstances could be linked to her behaviour at school, and her subsequent exclusion. Very little opportunity to express her feelings and state her views which may have sequentially worsened her behaviour and impacted on the next negative event.

Living with her Nana has introduced some stability and a first opportunity to properly reflect on her circumstances.

**Stage 3 - Examine findings across stories** - Limited opportunity to share her views and thoughts particularly regarding her exclusion and also her social placements.

## Analysis of YP TP 1

## Stage 1

## Background

Spent childhood in rural Northumberland now lives in urban environment with long term Foster Mother. TP1 is in a secure and loving relationship with partner and father of her child. She is a bright and intelligent young woman although at interview was initially very quiet and guarded.

## **Epiphanies**

- Describes a 'very hard' upbringing -Experienced very poor parenting abandoned with siblings by mother.
- Support of Nana
- ➤ Negative experience of school Re-visiting school and confronting previous behaviour (teacher remembered her as a 'bully')
- > Relationship with Peers at school encouraged their poor behaviour
- Movement into foster care geographically distanced from home (positive and life changing opportunity)
- > Relationship with Foster Mum (positive and stable)
- New school and peer / friendship groups behaviour changed
- Relationship with partner of 7 years
- > Being a mum
- Sure Start Midwifery support
- Participation experience

## Initial impression / assessment

Very reserved and quiet at beginning of interview (unsure what to share). Bright young woman – has achieved 'A' and 'B' grades at her GSCEs and also started 6<sup>th</sup> form before having to leave due to pregnancy.

Poor relationship with own father, lots of unknown brothers and sisters and told in childhood that her father tried to drown her as a baby

Relationship with birth mother poor in childhood – mum abandoned them and Nana looked after them – more recently relationship with mother has improved and been re-established

Did not like school (701) describes her poor behaviour and why she got excluded.

Movement into foster care has been permanent and positive (will maintain support with foster mother as a care leaver). This coincided with movement into a school where she could build new positive relationships.

Embarrassed about behaviour at school but still blames others.

Very good relationship with partner of 7 years (who works full time and supports his TP1 and her son), but wants her own home not to move to his as wishes to maintain own independence.

Positive about motherhood (easier than expected) and remain aspirational about own future (although son a priority)

## **Self-descriptions**

Describes her actions at school and although embarrassed by these actions places the blame on others.

Young mum (sometimes judged by others)
Anti abortion

# **Personal Outcomes for YP**

Getting her opinions heard (speaking up for self)
Listening to others views (those in same situation as her) – gaining insight into their views and gaining mutual support
Ensuring grown ups know how teen mums feel
Impressed and pleased with self

#### **Outcomes for others**

Ensuring grown ups know how teen mums feel – Sharing our views

# Relationships and significant others (often linked to epiphanies)

Partner- 7-year relationship with father of her child. Made personal choices with partner regarding pregnancy and given lots of information regarding choices via good GP support.

Foster mum not family – 1:1 relationship gave her the attention she needed. Continued support from foster mum into independent living.

Maintains relationship with birth mother and Stepbrothers and sister.

Midwife and staff at Sure Start– midwife linked her to Sure Start and first chance to share her voice and meet a new friendship group as a young mum. Sure start was somewhere she felt she could talk to others when needed and gain new friendships

Relationship with Key worker(s) – links to support needs / process etc Sure start midwife - Attributes – good listener Teenage Pregnancy CDW

## **Aspirations**

Wanted to be a midwife but this is now on hold (although may in the future) – wants to look after baby until he is a year old. Wants to return to her studies and maybe study childcare / crèche work – wants to look after children in own home so she can look after her son.

## Stage 3

Inspired by KW. Self reflection and huge movement onwards. ? maturity / positive and focused outlook. Judgements by society and others Re Teenage Mums.

## **Analysis - Young People TP2**

## Stage 1

## **Initial Analysis**

Lived with mum, dad and brother in Ashington happily until hit early teens. Parents unable to deal with her behaviour – describes being hit (physically abused) when misbehaving. Conceived first child when she was 14 –did not tell parents until she was 6 months pregnant. Lived with parents until she was 16 years old.

Now at 19 lives independently and is a Young mum of two children.

## **Epiphanies**

- Development in early teens difficult relationship with mum
- Boyfriend in middle school risk taking behaviour
- First Pregnancy Six Months pregnant (unable to tell anyone) –
- Impact of pregnancy all risk taking behaviour stopped, just wanted to look after baby well.
- Father's response to pregnancy (disappointment)
- Loss of friendship group
- Attitude of health professionals made her more determined to prove her worth.
- Positive relationship with Teenage Pregnancy worker the TP Team shown 'interest in her'
- Return to school teacher's response (judgemental) and mother's decision about childcare – felt she should respect her views.

'My mam, my mam, cause she didn't want him to go into crèches and stuff at that age. In a way I had to really respect what she wanted because I still lived under her roof and I didn't want all the arguments and stuff. So I just went along with it'. Lines 246-49

 Left school and studied GCSEs via Teenage Pregnancy Unit – pride in passing exams

## Initial impression / assessment of personality

Determined and capable, feels she must prove herself. Felt 'worthless' when she fell pregnant – now a confident young woman

Self-descriptions - 'classed as a wild child'. 'Cheeky'.

'I'm a good mother'.

I could talk to people, but I didn't want to. I was frightened what was going to happen. I was really frightened, but at that age I was only 14, I was still just a kid myself. And if I look at 14 year olds now I think well, you know, they're not really able to have kids now and I did look back and wonder how I coped. Lines 122-26

#### Personal Outcomes for YP

 Pride in passing exams – possible with support from Teenage Pregnancy Unit

Impact of being able to study in the Young Mum's Group and return of a friendship group

'I never really had many friends around me because they all disowned me, after I got pregnant with J. Just sort of dropped away from me, spoke to me when they seen me. Apart from one, who was a lad and has been friends with me for years and years. He was the only one who still bothers with me. So that's quite hard. So I got my friends back when I went to that Young Mother's Group and I'm still in touch with one of them I see her all the time. So things just got better from then for me.' Lines 300-306

- Increasing confidence and ability to fight for self and baby from a
  position of nervousness and low confidence movement from individual to
  group work, to peer support and then conference presentations
- Interviewing staff opportunity / skills development / taking responsibility
- Gained lots of personal feedback regarding her contribution to the conference

#### **Outcomes for others**

Took on peer support function to prevent other young people from making the wrong decisions

Help set up Young Mums group (changed workers views of what the group should be like)

## Relationships and significant others (often linked to epiphanies)

- Dad's initial rejection on finding out she was pregnant was very difficult
- · Relationship with mum and dad is now improving
- Respects her mum

Relationship with Key worker(s) – links to support needs / process etc Teenage pregnancy nurse and other TP Staff – they listened and did not judge

TP Nurse –different attitude than other professionals

'Got involved with her. She was great. The first day at school she came, I said, I'm not going back to school you can't make me. That was probably the first word I said to her. She said I'm not going to make you. But I went back.' Lines 229-232

## **Aspirations**

Of a future stable relationship

# Stage 2 - Analysis Epiphanies within story -

## Treatment and judgement of professionals

- Attitude of hospital staff towards a young mum.
- Teacher's response when she returned to school

That was quite hard. You could see some of the teachers looking but I though you can look all you want, I don't care, I'm a good mother. Joe was probably about 5 - 6 month before I went back.

Lines 236-38

Possibly could not tell mum due to the physical abuse experienced when ever she did something wrong and due to age of partner

## Affected by fathers response

My dad? He was alright but he said he was disappointed in me and I thought that was horrible....I would have rather been slapped across the face. For him to say that he was disappointed in me just sunk me. Because that does hurt, cause I didn't want him to be disappointed in me. It was just an accident; I didn't mean to do it. It was like I went out and did it on purpose. **Lines 145-153** 

## Stage 3 - Examine findings across stories

School – wrong type of support – also judgemental teachers
Movement from position of low confidence to high
Essential support of key workers
Need for skills development even how to speak appropriately in different audiences

# **Summary of Analysis - Young Persons Interview – YC1 Stage 1**

# **Background**

Environment – Lived in isolated rural community. Mother strong role model.

Father chronically ill

## **Epiphanies**

- Attitude of first head teacher
- Bullying at school
- •Financial difficulties at home
- •Mum's stoic nature, motivation and intelligence
- •Mum's own volunteering work
- •Own difficulty in gaining 1:1 support
- •Taking part in involvement work
- Meeting the Local Authority participation worker
- •Publics attitude towards her dad and mental health problems in general
- •Her own impression of how the public view young carers

## **Initial Assessment of personality of YC1**

Intelligent, confident, self-motivated, resilient, determined, moral, caring and empathetic, loving, modest, passionate, reflective, aspirational and an inherent optimistic

#### Self descriptions

Selfish, annoyed and frustrated, Honest (won't lie), does not swear at home, worried and upset, a feminist, afraid of being judged at school. Used to be embarrassed about dad. Late addition to family (older siblings)

1. Passionately positive – endlessly turns potentially negative situations into positive views or solution focused comments.

Bullying at school - YC had shared a passionate and emotionally charged account of her bullying experiences at first school that resulted from an adult and the children's perceptions of mental health. (This account leads to both the researcher and story teller crying). However, she was still able to move the negative story into a positive outcome.

Words Used (positive)
Self Satisfaction

It makes you feel good about yourself
It actually helped me - you become stronger
It was good (talking about what you think should be changed)
It was interesting (hearing others groups views)

(I can) give my opinion Keeps your mind active

## Personal outcomes for YC1 in being able to share her voice

Therapeutic effects - Time for reflection - on her own circumstances. Feeling a Sense of personal achievement is demonstrated throughout her accounts 'feeling good' about herself.

Increasing own confidence by telling her story publicly Developing own techniques to manage stress - therapeutic

#### **Outcomes for others**

Normalising the young person to ensure visibility as a person not a carer Contributing to change

To change the publics Views of Mental Health by both challenging discrimination and by raising her views about Mental Health discussions being part of the curriculum

As in outcomes for others – attitudinal change – how people view mental health problems, how they view young carers

## Relationships / significant others

Whilst YC1 describes where she lives at the beginning of her account, she speaks about the environment as being good for her dad and her pets, but does not share her own feelings about living there.

Family mentioned in order of text include dad, pets, family in New Zealand, older brother and two sisters and her mum. Mum is mentioned last but it becomes apparent that she has been and is the most significant person in YC1 life.

## Relationships with dad

Negative view of dad sees him as defeatist and sexist

Views her dad as lazy and sexist – she separates this from his mental health problem (this is his personality – and strongly believes it would be there without the mental health problem). Interestingly, this view is so strong that if she could change anything about him it would not be his mental health problem but his attitude towards women.

Views of his illness (Protective nature)

YC1 has a strong sense of political justice and a strong regard for acceptance of difference and diversity because of her life's experiences. She shows a mature political view of what needs to be done to address mental health stigma.

 Increase school curricular activities for young people about mental health awareness

- Positive impact of being able to share her voice is by face to face contact with public and professionals to prove young carers are normal and look normal
- Relationship with Mum

Talks positively about mum throughout the account

Mum has helped educate her about her dads disability, and the political side of her personality is shared again.

Relationship with Key worker (linked to support needs issues)

- Someone who understands (or tries to understand) the social and personal circumstances that surround the young person, who trusts the young person.
- Someone who shows empathy, and responds in times of need.
- Someone who understands children, and who has time to talk, responds to you within a reasonable period of time.
- Someone who is there when you want them to be, saying the rights things, actively interested in you
- Someone who values your opinions and does not enforce theirs (offers options)
- Someone who can offer future possibilities / aspirations
- Available during your transition to adulthood
- Should have to be a mother

# **Aspirations**

To be Prime minister

To study at Cambridge

To not struggle financially (driver)

For Mental Health Disability to be discussed on the school Curriculum alongside racism and physical disability

## Stage 2 – Analysis of Epiphanies in stories

Lack of formal support – support for dad but not family
Disconnected services in participation and service provision
Sensitivity of personal circumstances (care needs to be taken in where this is shared) School not a place where YC1 would want to share her circumstances.
Normalising Young Carers – being a young person not a carer, but conversely being able to share her voice in the right environment (to improve care, systems and therapy).

#### Stage 3

Huge issues regarding 'labels' Helping other Young Carers Therapy Relationship with school

## **Summary of Analysis YP LA1**

# Stage 1 Background

Environment – deprived urban upbringing. Isolated from family life and positive role models as a child due to interrupted care. Parental rejection.

## **Epiphanies**

- Aged 11 years old in care for the first time (just a short time)
- Back with Mum in new but violent relationship (could not cope with violence regularly ran away) – rejected by mum.
- In care for 3 years (Foster care and Care Home 4 placements)
- At 15 years old moved back with mum (still an unsettled relationship)
- Study and educational experiences (School/ Kirkley Hall / E2E) (Link school experiences to YC1)
- Pregnancy with First child Teenage pregnancy group (positive)
- First Job with Teenage Pregnancy Team (past criminal record but first people to believe in her) - Qualification
- Second Child (Decisions re work and home arrangements made on economic basis)
- Participatory Work After care group, teenage mothers group, expression of feelings through art – Sage Conference

Negative memories and opinions of education – started course Diploma in Animal Care at Kirkley Hall – accused of bullying / difficulties with travel – offered E2E 'Hated it' – had high blood pressure during pregnancy so left course.

## My first impressions

Pleasant, resilient (has dealt with major rejection), determined, very self aware and self conscious, pragmatic, aspirational

#### **Descriptions of self**

We = young person and partner – make decisions together

We = young people in care - not really important to society

We = relationship with mother

I = as someone who has had to grow up guickly

I = independent person

I = Teenage mother (very conscious of this)

'We young people in care are not really important' (Poor housing experience) 'I haven't had a childhood – so I am older than some people think I am' 'I am not a typical 19 year old lass'

#### Personal Outcomes of Participation

Proud (458)

Learnt to challenge rather than just moan

Could see links between sharing voice and action (pathway plans)

Connectivity – new friends

Taking more responsibility (1036) Filling in forms to fund some work – working towards constitutional group

### Outcomes for others / service

Pathway plans were changed – felt listened to. Negative outcomes of participatory work -No results from sharing voice – Housing issues

## Significant others

Partner of 5 years

Children's (partners mum) Grandma

After care worker

Mum and Dad had issues – mum's rejection / experience of violence in the family. Physically isolated from mum – Cambois – Cramlington – neither has transport

Key worker(s)

- Treated as a young adult
- Not take things too seriously could have a laugh with them Reminisces about good fun times with residential staff (1161)
- Acted as a guide during participation work, encouraged (Participation work adds to CV).
- Need to be good listeners.

Link to comment from Young Carer (did not want people at school to know).

## **Aspirations**

To work again – but work versus benefits, economical difficulties

#### Stage 2 – Analysis within story

Views of treatment of people in care – not important people (1350)
Barriers to participation – practical – now has two children (999)
Importance of a voice and a chance to make own decisions in a world where many decisions are made for you and lives are fairly public
Importance of private time and time to be a young person not a LAC

## **Stage 3- Examine findings cross story**

Inappropriate school support – no to participation at school

Contradictions- need a voice as a marginalised group, but by placing them in a group it reinforces the labelling / stereotyping.

Future work important

Expression of feelings through art

# Summary of Analysis - Young People - LA2

## Stage 1

## **Background**

Environment – Living in semi rural isolated environment along way from original home. Unpredictable and fraught home relationships. Has younger brother and older sister. Chatty but vulnerable. Easy to talk to and easy to get to know. Very open and willing to share. In love with baby – focus of her attention (given some focus and meaning to her life)

Not well educated – lots of myths and misconceptions shared throughout story and not always aware of the language she uses (swears without thinking). Very reflective – specifically about own previous behaviour

# **Epiphanies**

- Fraught relationships at home
- Went into Care (Looked After System)
- Pregnant at 14- 15 years old
- Breakdown of friendships / personally bullied and ostracised at school / bullying of younger brother
- In Foster care with baby big transition being a mum and having to move
- Breakdown of relationship with baby's father.
- Improved relationship with family members (values relationship with Mum and dad) – dad cares for baby regularly (see significant relationships)
- Participation work Conference in Scotland (expression of feelings through art / story) – See personal outcomes
- Studying at college (getting organised)
- Considering independence

#### Initial Analysis / assessment

Charlotte's life story has no mention of early childhood. She describes her life in relation to her immediate family members, particularly her difficult relationship with her siblings, and latterly her relationship with friends.

Her story starts with a description of her immediate family (at no other point in the hours interview does she describe any other family members such as aunts, uncles, grand parents etc.). Her story quickly moves to the breakdown in relations with all the emphasis of blame on self.

## Self-descriptions

Negative body image and regarding her past behaviour

#### Personal Outcomes for YP

Opportunity to express feelings through Art and sharing of own Story. Has developed a therapeutic way of dealing with her own life stories – often thinks about her circumstances, writes things down, reads them and then burns the paper.

"....it felt good because you can just watch all your dreams or your nightmare go away.

Opportunity to meet people from all over the world Conference in Scotland – sharing of mutual experience (same feelings and similar situations – all in care)

Personal Pride – in feeding back to residential staff

#### **Outcomes for others**

## Relationships and significant others (often linked to epiphanies)

Relationship with family and particularly older sister stronger when she was in care and not at home

Enjoyed being in Children's Home – strong relationship with staff

Describes an improving relationship with mum and dad

## Attributes of Key Worker

- Patience of key worker(s)
- Helped her build confidence
- · Role modelling strong within this story

## **Aspirations**

Describes writing down her story and her readiness for independence— 'I'm beginning to feel that I'm ready for my own place'
Wants to work with children possibly nursery nurse

## Stage 2 - Analysis Epiphanies within story –

• Disruptive at home – fraught relationships with siblings - separateness

Although Charlotte shares moments of great emotional need to be with her family, she rarely places herself comfortably within this family unit. She rarely expresses her relationship with her family as a 'we' relationship. She is separate from them, almost always using the word 'l' in relation to herself both in and out of the family. The heavy use of 'l' gives Charlotte an air of strength and independence from them but one that is not convincingly chosen. However, throughout her story her separateness from them feels physical not emotional. One always senses a great need in Charlotte to be needed by them (or someone) and accepted back in.

The first time she uses 'we' in a family context is when she perceives her relationship with her sister is improving and strengthening and that appears to reinforce her decision to remain in care.

Went into Care (Looked After System)

Charlotte describes going into care at 12-13 years old. There is warmth and happiness expressed about being in care that has not been expressed in relation to living at home. This can only be described as a good experience of being in a children's home. Throughout her accounts of being in the home and the participatory work she was involved in she regularly uses the word 'we' and clearly sees herself as a part of this surrogate family unit. She describes a good relationship with workers (see significant others), disappointment in having to leave and expresses a sense of loss in moving on to foster care.

- Pregnant at 14- 15 years old Making decision and telling family anti abortion
- Breakdown of friendships / personally bullied and ostracized at school / bullying of younger brother
- Improved relationship with family members (values relationship with Mum and dad) – dad cares for baby regularly (see significant relationships)
- Participation work Conference in Scotland (EXPRESSION OF FEELINGS THROUGH ART / STORY) – See personal outcomes
- Studying at college (getting organised)

## Stage 3- Analysis across stories

Importance of the key workers in her life, from both a care giving, loving relationship to role models
Importance of self expression through art

## Summary of Analysis - Young People TR1

# Stage 1

## Background

TR 1 is an 11 year old girl from the travelling community with a good level of education and excellent communication skills. Sometimes she appears older than her years as she considers her answers carefully before she answers them. She attends middle school and aims to and has support from her parents to attend high school and move on to college. She lives with her mum and dad and younger sister on a permanent traveller's site. Her Grand dad is the warden of the site.

Whilst they travel in the summer holidays, they do not let travelling interfere with the education of the girls.

TR1 does not mix with many other children on the site, but has good friends at school. She visits their homes sometimes but friends do not come to the site.

## **Epiphanies**

There is a powerful example of how being involved in sharing her voice has helped her defend her community and challenge discrimination and prejudice. This leads to her exhibiting brave behaviour and as a result she is proud of herself.

## Initial impression / assessment of personality

TR1 is a positive, happy and bright individual. She is intelligent and thoughtful. She is very supportive of her own culture and community. She is happy to discuss her home circumstances with people at school if they ask, but otherwise would not offer this information.

# **Self-descriptions**

Proud

#### Personal Outcomes for YP

Felt 'good'

Increased confidence leading to bravery and pride

Rewards – gift vouchers (although these are not significantly important) Interviewing skills

#### **Outcomes for others**

Greater understanding of the travelling community Information for professionals and others

## Relationships and significant others (often linked to epiphanies)

Key workers

Relationship with police can be tenuous –understands needs to be law abiding but intermittently raises issues relating to the law without prompting

## Relationship with Key worker(s)

Given opportunity to contribute to the writing of 'Gypsy Joe from Mexico' and resented findings at a number of conferences

## **Aspirations**

"To be treat like an equal person"
To go to college

## Stage 2 - Analysis Epiphanies within story -

Opportunities to take part and share voice have most definitely increased her confidence. She is also a very reflective and thoughtful girl possibly as a result of the work she has been involved in.

Separate community

Others people's views of travellers

Some kids have home education

Don't mix with people in the village but are liked by local people

Some people get bullied

Recognises that the travellers who make their homes on illegal sites are different than those on permanent sites – no obvious integration

## Stage 3 - Examine findings across stories

Took part but did not really understand the outcomes of sharing her voice Built confidence and sense of own rights in the process of taking part Increased networking with other travelling children via group work

## **Summary of Analysis - Young People TR2**

## Stage 1

## **Background**

J is a young teenager living within a travellers' community with his mum and dad and his two twin siblings. On the surface he appears to enjoy life and his environmental surroundings. Although he and his family live within a designated site, the family rarely travels in their trailer, but others on the site do. J tells me that those that do 'leave a base' and continue to pay rent, so they can return to the site. Some of his immediate extended family lives on site too, but J's Granny and Grand-dad live in a house nearby.

J attends a local middle school and has many friends. Some are aware that he is from the travelling community, and some are not. J uses his judgement as to who he chooses to share this information with.

Whilst J does go to non traveller friends houses, he has not had any friends back to the site. On asking if he has experienced any problems at school he states that he '...has been alright. But there is not many people know that I am a traveller, but I am not bothered'.

Whilst J appears outwardly comfortable with his circumstances, he shows how he guards sharing his real circumstances with friends.

'I don't tell them what I live in or anything because they still think I live in a bungalow, I said I lived in a bungalow'.

J shares that he used to live in the warden's bungalow, but now appears to stretch the truth in order to protect himself from the potential of being bullied. He shares no experiences of bullying in his account. This worldly wise ability to self protect is expressed throughout the text, and demonstrates great respect for others and resilience.

#### **Epiphanies**

J does not describe any major events during his story. His stable family life has resulted in a positive experience of being a traveller. Education and life long learning appears to be important to the family. J 's mum contributes to some of the interview and once she is happy with me she leaves J and I to continue our conversation in private. However, mainly because of their living environment she is in and out of the room (living area in the day, J's bedroom space at night).

## Self-descriptions

Describes himself as part of a family, as a socialite 'regularly with friends', as a teenager and a pupil.

Examples of both through the text (additional comments)

#### Personal Outcomes for YP

Participation - Involved 'because he knew 'we were going to get something back from it'

Trips out / knowing that someone was going to help us (advocate for them) NVQ3 gained through participatory research training

No longer 'shy'

New Skills – interviewing and communication skills (talking / answering questions in class)

#### **Outcomes for others**

In talking about why he agreed to the research interview with me – 'it was just to find out -it might have made you think better about travellers and make you have a better point of view.'

Trips out / knowing that someone was going to help us (advocates for them)

Agreed to be interviewed - I think it was just to find out it might have made you think better about travellers and make you have a better point of view.

# Relationships and significant others (often linked to epiphanies) Friends

Good relationship with mum (present for some of the interview)

## Relationship with Key worker(s)

Varied – sometimes they are good but sometimes they do not keep their promises (promised computer and mobile phone). Also when interviewing for one post listened to, but not for other

#### **Aspirations**

None shared

#### Issues

Mum raises a good point about loosing intelligence as workers move on. (Line 241)

#### Stage 2

## **Analysis Epiphanies within story**

No major epiphanies shared

#### Stage 3

Skills development and increased confidence

Appendix 7: Table of definitions of participation and advocacy / Attributes of key workers from key worker interviews

Interview Code	Definitions of participation and advocacy	Aims of participation and advocacy	Attributes / skills of key workers in participatory work	Whys?
TR 1	P Its about asking opinions Listening to peoples wants Everyone having an equal voice Not being afraid to use that voice  A Nurturing feelings More supportive	To find a common ground Trying to provide it within the limits and structures we have Everyone's views are respected	Non judgemental Approachable Good listening skills Very approachable and friendly Professional 'Softly, softly Dress awareness' Political and cultural awareness Flexibility from support and information giving (preparatory stage) through to structured information seeking	Gaining Respect It takes time Not frightening them Need to fit in Its about making them comfy with you Meeting them on your level Not taking anything for granted Need to explain everything Build relationships trust and confidence *Gives community ownership
TR 2	P Involvement in research planning and design Engagement / inclusivity Equality of access  A Used if aren't able to speak for yourself or in difficult situations – might not feel able to speak on behalf of another	Not shared	Needs to be perceived by community as OK (respected and respectful) Ability to respect the views and rights of others Need to be able to see the bigger picture Ability to encourage involvement and solutions KW must understand equality and respect, and prejudices. Ability to treat people as equals Ability to undertake training	

From key workers (Travellers) Interviews

Interview Code Code Code Code Code Code Code Code
TP 1  P Equal participation in decision making Influence  A When people express views and opinions on behalf of someone else Get peoples needs met by being their voice Doing it through a third person  A Work  Giving young people the (about gaps and issues) / theoretical knowledge especially in advocacy Good interpersonal skills – listening especially in advocacy Good interpersonal skills – listening especially in advocacy Good interpersonal ethical and consent issues  Important ethical and consent issues  Sound understanding of the rights agenda Ability to gain feedback Awareness of young peoples behaviour in groups and how it differs from adults (Drawing on school nursing experience) Acceptance of
P Equal participation in decision making Influence  A When people express views and opinions on behalf of someone else Get peoples needs met by being their voice Doing it through a third person  P Equal participation in decision making people the ability to people the ability to influence and knowledge that they can influence Influencing service Planning, delivery and evaluation  Good Knowledge base (about gaps and issues) / theoretical knowledge especially in advocacy Good interpersonal skills – listening Sound understanding of the rights agenda Ability to gain feedback Awareness of young peoples behaviour in groups and how it differs from adults (Drawing on school nursing experience) Acceptance of
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(Drawing on school nursing experience) Acceptance of
nursing experience) Acceptance of
Acceptance of
experiential learning
0
and professional
development
Awareness of changing
needs
Ability and desire to receive feedback
TP 2 P To tailor a Honest and open about Making it
Asking people their service to what what we want, what we interesting
opinions, their they say and are doing it for Asking the
suggestions, what they their Being able to constantly opinions a
want from a service requirements reassure suggestion
Ask people their wants Not talking down to to problem
and their needs young people Influence
Ensuring they know service
they have a choice to change /
Doing something on participate improvement their behalf – Ability to use lots of Not looking
negotiating access to methods of for probler
practices for mystery engagement – but 'areas
shoppers awareness of the need potential
to seek views from improvement
different social groups
(representative).
Ability to structure
sessions and ask
specific questions to
directly influence   service
Ability to feedback
Negotiation skills –GPs,
YP YP

From key workers (Teenage pregnancy workers) Interviews

Interview Code	Definitions of participation and advocacy	Aims of participation and	Attributes / skills of key workers in	Whys?
LA 1	P 'Not just listening to them but hearing what they are saying and taking those views into account'.  A Its about not having a set agenda from anywhere else, simply hearing what is said and acting as a mediator as a go-between	advocacy  Mould and inform your practice 'They are the guys that know' To develop work  Ensuring views and feelings are acknowledged Advocacy 'it is much more on a personal level'. For LA kids – in public eye they	participatory work  Very good listening skills Counselling skills Non judgemental Need skills but also awareness of (clients) limitations Tolerance and patience Need skills around building relationships Skills to work through bad language / spec body language Understanding and	Spend time building a relationship  Historically don't trust adults – feel let down personally and professionally  Have to deliver the goods / reliability
LA2	<b>P</b> 'Including and involving	need someone who they trust and can support them  Contributes to	empathy – oodles of empathy Honesty Ability to feedback to other services	Children
	them in anything that affects them' Consultation, interviewing staff, sharing issues and experience  A Involvement leads to the professional advocating for them Can advocate for themselves but may need some support	their record of achievement Being able to effect services Capacity building Training NVQs	to talk to people Not inhibited in putting opinion forwards Able to advocate at a senior level You need different skills to work with young people than you do with adults Helps being a mother, a grand mother and a social worker You need attributes to deal with management, with young people (computer skills) —	Leaving Care Act – Law Connecting with young people
	workers (Looked after Childr		creativity	

From key workers (Looked after Children workers) Interviews

Interview Code	Definitions of participation and advocacy	Aims of participation and	Attributes / skills of key workers in	Whys?
Code	and advocacy	advocacy	participatory work	
EX 1	P Being involved at a practical level and seeing what works  A 'Act as a go-between' Liaise with agencies to get them to meet that YPs needs Promote their [young person's] Rights Articulating needs on behalf of the YP or their family	Talk with them about exclusion — an individual piece of work for that YP	Ability to information share Being able to inform YP of their rights Self Confident in helping people negotiate schools Advocacy skills An honest broker – negotiating with school and family – ensuring families know their rights and school know theirs Be able to challenge Diplomacy Knowledge of other support services (sign poster and referrer)	To make sure that the Young Person's needs are met (although feels that their emotional needs are often unmet)
EX 2	P Engagement Participation to develop self It's not about imposing a set of rules A contractual mutual respect thing Building relationships Negotiation  A Working in a multi agency way – helping the young people to have their views and issues known	So disengaged it's about engaging them in conversation, into a mutually accepted contract, to engage them back into services that suit them and meet their needs  To re-kindle a sense of achievement	Loose your middle classness Masses of patience Positive Ability to change the child's worldview Strong personal motivation Real sense of commitment	To give them a glimmer of hope Getting youngsters to believe in themselves

From key workers (Education Other Than at School workers) Interviews

Interview Code	Definitions of participation and advocacy	Aims of participation and advocacy	Attributes / skills of key workers in participatory work	Whys?
YC 1	P How accessible our services are Giving them a means to get involved To take part Talk about being a young carer  A supporting young people, to say what they want to say, if they are having difficulty in doing that.	Supporting young people to Participate Helping people voice their views when they cannot do so themselves	Knowledge of issues to enable you to advocate for them Listening skills Good facilitation A 3-Way Counsellor Experience of working with C&YP	Raising awareness amongst professionals of issues for them Giving kids a voice
YC 2	P 'it's for young people to be able to be recognised, in who they are and they have recognition for the way they experience life at the moment' To be involved – in decision making  A supportive role rather than just doing it for them Support to share their views	So they understand their right to services 'sometimes young people very much find they have a lot to say but they find it very difficult to say it'	'needs to be somebody that's really going to look at the individual needs as well as the group needs of young people' Flexible We have to have a lot of give and take 'Need to be able to advocate' Knowledge (alcohol and drugs) and experience	To influence service provision Have not traditionally had a voice or felt empowered To empower them

From key workers (Young Carers) Interviews