Conwy Families First Research Report

Conwy Children and Young People's Partnership

This report has been written for:
Conwy CYPP (Families First Project Board),
to assist in the development of Families First projects

Final version February 2012

Contents

Executive summary 3

1 Research methodology 3

2 Findings 4

Service areas and themes 4

Concepts: Families' reasoning about their experiences 8

3 Next steps 9

Quantitative data analysis 10

Summary 10

1 Methodology 10

2 Findings 12

3 Geography of need in Conwy 14

4 Themes 16

Housing and homelessness 16

Mental and emotional health 16

Education and learning 17

Social Services 17

Parents' needs 17

Family breakdown and domestic abuse 18

Money and finances 18

Employment 18

Misuse of drugs and alcohol 18

Children with disabilities 18

5 North Wales needs assessment 19

6 References 21

The lived experiences of vulnerable families in Conwy: A qualitative study for Conwy Families First programme 22

Summary 22

1 Introduction 27

2 Background 27

3 Methodology 27

Sample 27

Data collection 28
Analysis 28
4 Findings 29
4.1 Service areas and themes 29
4.1.1 Housing and Homelessness 29
4.1.2 Mental and emotional health 32
4.1.3 Education and learning 35
4.1.4 Social Services / child protection 39
4.1.5 Parenting 41
4.1.6 Relationships, family breakdown and abuse 43
4.1.7 Poverty, money and benefits 46
4.1.8 Employment 48
4.1.9 Drugs and alcohol 50
4.1.10 Communication and information 51
4.1.11 Children with Disabilities 54
4.2 Concepts: families' reasoning about their experiences 61
4.2.1 Crisis or turning points / triggers (and intervention/prevention) 61
4.2.2 Coping strategies 64
4.2.3 Parents' childhood experiences 67
4.2.4 Evaluation of who or what is responsible for a situation 68
4.2.5 Engagement with services 72
4.2.6 Support networks 74
5 Conclusion 77
6 Feedback 77

Annexe 1: Qualitative Research and Interviewing 78
Annexe 2 - Information sheet and Consent Form 81

Conwy Families First Research Report

Executive summary

Families First is a new Welsh Government programme that aims to achieve better health and wellbeing, education and employment for families living in poverty. Each local authority is being asked to try new ways to enable everyone who supports families to work better together and so prevent families from developing more complex needs. A key element of the programme is support for families of children with disabilities.

1 Research methodology

There are four strands to the research undertaken to develop Conwy's Families First programme to allow us to 'triangulate' and compare the findings from the different methods.

1. Quantative data collection: identifying vulnerable families by collecting data on vulnerable families known to the following services: Revenues and benefits; Social Services; Health; Education; Youth Justice Service and HOST (homelessness service).

Each service provided a list of parents, children, young people or families including names, dates of birth and postcodes so we were able to cross reference each list against the other; find out the numbers of families using multiple services and map the data to find concentrations of need in the county. Each service signed up to an Information Sharing Protocol which explained how the data was to be used and stored.

2. Consultation with professionals: We held two visioning days to inform the programme, one in February and one in October 2011. We also took ideas for the transition year projects and the initial Families First Action Plan from the work with the Core Aim Groups, and strategies developed by the partnership. Particularly the Play Strategy; Social Inclusion Strategy, Parenting Joint Commissioning Plan and Conwy Children and Young People's Plan 2011-14.

3. Qualitative data collection: This strand focuses on the lived experiences of vulnerable families in Conwy – their perceptions of their experiences and needs (and, in some cases, the professionals working with them). This included listening to their stories, their experiences of services, and their perspectives on what might have prevented or helped their situation (qualitative interviewing). The examples and perspectives provided in this study will bring to life the quantitative data about families in Conwy, and will help to shape future provision for them.

The study took place among 33 families and 12 professionals. The sample covered families with varying involvement from services, and with varying family circumstances, including children with disabilities. Due consideration has been given to quality and ethics, including transcribing, anonymising data, coding, and developing an analysis framework.

4. Service profiling: Investigating and mapping the services available to children, young people and families. Based on the data collected, the Families First Project Board will choose strands to be profiled, to identify duplication and gaps in service provision. For example, while the research shows a need for bereavement support services, it may be that the real need is to raise awareness about existing services or to improve coordination. If there is a need for a new project, this could be developed as a pilot with Families First Funding.

2 Findings

- There are 6,000 families in Conwy using one or more services (based on 13,300 individual records)
- 4,700 of these families use one service only, 900 use two services, 230 use three services and 100 use four or more services.
- 60% of the families are in receipt of benefits
- 97% of families using 5 or more services are in receipt of benefits
- Areas along the coast show the greatest concentration of need (particularly the wards of Tudno, Glyn and Kinmel Bay), with smaller pockets of deprivation spread throughout the rural areas.

Service areas and themes

Housing

- There are 220 families using Conwy's homelessness service, 4% of all the families.
- Homelessness was an issue for 15% of families who used five or more services.
- Housing issues were a common theme for the families interviewed, ranging from concerns about being able to afford appropriate housing, to the quality of the housing available, and the impact that this has had on the family. A number of families commented on the support and information available to them with regard to housing, and some suggested ways in which this could be improved.

Mental and emotional health

- Mental and emotional health features strongly in the interviews, ranging from parents' own needs, to the mental health of their children. A number of examples demonstrate the barriers to seeking and gaining support for mental and emotional health issues, including lack of engagement with services, the stigma attached to seeking help, and the availability of services. The families also demonstrate the causes of mental and emotional health problems; for example, family circumstances, family breakdown, bereavement, domestic abuse, and caring for children with disabilities.

Education

- Fixed or permanent exclusion was experienced by children in 70% of families using 5 or more services and 45% of those families had one or more children in alternative education.
- Of those families using 5 or more services 39% have a child with Special Educational Needs and 30% with School Action Plus.
- Some of the families were completely satisfied with the education received by their children.
- Themes that emerged from families' experiences include school attendance and engagement with education (causes include negative experiences, family breakdown, motivation, peer influence, lack of confidence, unstable school placements, and lack of support); aspiration and overcoming stigma; and additional learning needs.

Social Services

- There are children in need (known to Social Services) in over 59% of families using 3 or more services, and 76% of families using 5 or more services. This is the services used most commonly by families after receiving benefits.
- The families interviewed have experienced varying levels of intervention or contact with **Social Services**, and had different stories to tell in terms of their experiences.
- Some of the families taking part in the study via avenues other than Social Services, give an interesting perspective on their expectations and perceptions of the service, whilst those who had more of a personal experience of the service raised the following issues: confusion around the child protection system, and the importance of continued support and intervention.

Parents' needs

- Parenting skills and support and other needs are a common theme in the study, with most of the families interviewed referring to it in one form or another.
- Although the families came from a wide variety of backgrounds, socio-economic status, and circumstances, parents generally felt that support with their parenting (formal or informal) would be beneficial.

- Families identified some issues that have prevented or encouraged parents to access formal parenting programmes (for example, stigma, lack of engagement, support to attend, and availability and accessibility). This list is reflected in the consultations carried out with professionals.
- The study also illustrates the importance of more informal parenting support, including the value of support from their extended family, support networks, and peer support.
- Parents often described their own needs interchangeably with the needs of their children, suggesting that they felt that their needs (met or unmet) as parents have an impact on the family as a whole.

Family breakdown and domestic abuse

- Domestic abuse featured in just over half of the families using 5 or more services, and in with around 700 of the families altogether on the database.
- Family breakdown and domestic abuse within relationships has been experienced by a number of those taking part in the study, with negative impacts on parents, children, and family circumstance (such as employment and financial situation, and children's emotional health and wellbeing, and education)

Money and finances

- There are around 3,200 families in Conwy in receipt of benefits or some kind, which is 60% of the families receiving one or more services and 97% of families using 5 or more services.
- The vast majority of families taking part in the interviews spoke about **money and finances**, the general theme being that they didn't have enough to provide fully for their families for various reasons and in various contexts.
- The majority of the families were in receipt of some kind of benefits, although this does not necessarily reflect the number of parents who were in employment (for example, parents may be in paid work but still receive disability living allowance).
- The study provides an interesting insight into the impact of poverty on families (for example, on their health and wellbeing, and housing). A number of the families shared their experiences of the systems that are in place to support them financially, including the importance of information and advice, and describing problems around "systems".

Employment

- The unemployment rate (Claimant count) in Conwy County Borough for November 2011 was 4.0%. The rate has remained above 3.5% for three years.

- This featured in the vast majority of the family interviews. In particular, families provided an interesting insight into the influencing factors on their employment, whether chosen or involuntary (for example, lack of confidence, alcohol dependency, finding a job, rurality and access, home circumstances, lack of flexibility, and lack of appropriate childcare). In addition, parents of children with disabilities identify the employment issues that they face.

Misuse of drugs and alcohol

- Substance misuse was an issue for 5% of the families on the database and 33% of those using five or more services.
- In the interviews families tended to describe the trigger or circumstances surrounding the issue. For example, drink as a way of blocking out difficult circumstances such as a partner leaving, and children being put into care; drug dependency following a bereavement; peer influence; and boredom / lack of provision for young people.

Information

- A recurring theme throughout the study has been the lack of **information** provided/available to families, and the lack of **communication between services and agencies**.
- Parents described how they acquired information through friends, family, and neighbours, rather than through professionals, or how they received information through professionals more by accident than by design.
- They felt that there should be a better system in place for where information comes from, and expressed frustration with the timeliness of information, and the need for communication and cooperation between services. Generally, parents felt that there should be one clear source of information available to them.
- This concern was also reflected at the visioning days held with professionals, such as this comment from the day in February “A lot of good work going on including specialist services and skills sets but there is a need to co-ordinate it better to increase information about it”

Children with disabilities

- There are around 700 families with a child with special educational needs on the database. This is 7% of all families and 45% of families who use 5 or more services
- A high proportion of families who took part in the study had children with disabilities, including children with physical disabilities and learning disabilities. Despite the wide range of circumstances described by these families, there were some clear common

themes: experiences of diagnosis and provision; respite; impact on money, finances and employment; impact on siblings; parents' fears; and stigma (experienced both internally and externally) associated with disability.

Concepts: Families' reasoning about their experiences

A number of interesting concepts have arisen from the study, which don't necessarily fit into one service area. These are overarching concepts which provide some useful insights into questions such as "why" and "how".

- Crisis or turning points / triggers (and intervention/prevention) is an interesting concept emerging from the study. A number of families taking part in this study have identified or reflected upon a turning or trigger point in their circumstances which has either changed things for the worse or for the better. These provide a useful insight into the role and importance of intervention and prevention. Crisis and trigger points include family breakdown, bereavement, domestic abuse, losing employment, losing accommodation, change in schooling situation, and diagnosis.
- The way that the families told their stories and the language that they used gives an interesting insight into their attitudes, and their coping strategies or mechanisms. Discourse analysis has provided a brief look at how different families see their situations, how they cope with them, and the varying levels of resilience. These included coping strategies such as willingness to ask for help, acceptance, remaining positive, taking one step at a time, gratitude, identity, reflection and hindsight, humour, fight/battle, and being realistic but hopeful.
- Parents taking part in the study often referred to their own childhood experiences, and how this has contributed to or influenced their situation in some way. This provides an interesting insight into the importance of breaking unhelpful cycles and patterns within families from one generation to another. Examples used in the study are around domestic abuse, being in care, and unstable / complex family circumstances.
- Families would often provide an evaluation of who or what is responsible for a situation (consciously or unconsciously) whilst telling their stories. They would try to make sense of why a situation has occurred, and where to attribute blame. While some families blamed external factors, others could see their own contribution and mistakes. Some families would take it upon themselves to solve a problem, even if it hadn't necessarily been of their own making, whilst others would feel that the responsibility lies completely with the services working with them. For example, peer influence, things to do, lack of suitable school placements, heavy case loads, lack of continued support, not asking for help, home circumstances, problems with 'systems' and lack of intervention/prevention prior to point of crisis.

- A common concept emerging from the study, “engagement with services” gives an important insight into the success or failure of interventions and provisions. Families often described their own, or their children’s attitude towards services, positive or negative, and how this impacted on their situation. Establishing a good relationship with professionals was often seen as a key factor.
- The majority of the families taking part in the study referred to their support networks (or lack of). References include family and friends, as well as support from services, community groups, or informal groups. These were seen in the context of their ability to cope with their situation. Many described the loneliness and isolation they felt as a result.

3 Next steps

The data collected has been used to inform the overall focus of Conwy’s Families First Action Plan and detailed information will be used to inform the development of Families First funded projects including Team Around the Family. The themes will also be used to focus future Children and Young People’s Partnership project development, research and service profiling. The findings will be shared with partners and other services and will provide an ongoing resource for them. The data around vulnerable families can be refreshed periodically to provide up-to-date information about local need and the qualitative research methodology we have developed can be adapted for further in-depth research into specific themes.

Partneriaeth Plant a Phobl Ifanc Conwy
Conwy Children & Young People's Partnership

Conwy Families First Research Report

Quantitative data analysis

Summary

- There are 6,000 families in Conwy using one or more services (based on 13,300 individual records)
- 4,700 of these families use one service only, 900 use two services, 230 use three services and 100 use four or more services.
- 60% of the families are in receipt of benefits
- 97% of families using 5 or more services are in receipt of benefits
- Areas along the coast show the greatest concentration of need (particularly the wards of Tudno, Glyn and Kinmel Bay), with smaller pockets of deprivation spread throughout the rural areas.

1 Methodology

We collected data on families who were known to the following services:

- Revenues and benefits: Families receiving out of work benefits
- Social Services: Children in Need (Children on the Child Protection Register, Looked after Children)
- Health: Substance misuse (parents);
- Probation: Parents known to the probation service
- Education: Children receiving free school meals, children receiving alternative education, pupils with a statement of Special Educational Needs; School Action Plus
- Youth Justice Service: Young people in custody, committed crimes and open cases.
- HOST: Homeless families

Each service provided a list of parents, children, young people or families including names and postcodes so we were able to cross reference each list against the other. Each service signed up to an Information Sharing Protocol which explained how the data was to be used and stored.

We combined all the lists by matching names and postcodes, date of birth or first line of address and then combined all the records into families based on the surnames and postcodes. There were 13,300 individual records, which when they were combined, gave a total of 6000 families. This is likely to be a slight over estimate of the total number of families as not all the records included enough data to allow us to cross reference them into families. All records have been included in the data analysis but we were not able to map those without postcodes or those records that were out of county. We were able to capture some of the families where children and parents have different surnames by cross-referencing our list with the free school meals list, which included full names of both children and parents.

For the final analysis, the Revenues & Benefits list was combined with the Free School Meals list. This is due to the similarity between the eligibility criteria for Benefits and Free School Meals; to include both separately could therefore lead to double counting and/ or a falsely high indication of multiple service users in Conwy. Similarly, three datasets from the Youth Justice Service were combined to reflect the fact that names on the lists were users of a single umbrella service.

2 Findings

There were around 6000 families on the final list. The following tables summarise the data collected about the families. There also are many other questions that can be asked of the large multi-dimensional dataset we have now collected as they arise.

Table 1: Number of families known to each service

Service	Number of families	% of all families
Receiving benefits	3602	60
Domestic abuse	712	12
Youth Justice Service	707	12
Children in need	691	12
Pupils with statement of special educational needs	405	7
Children in need (known to health)	403	7
School Action Plus	308	5
Fixed or permanent exclusion	293	5
Substance misuse	293	5
Homeless families	220	4
Children receiving alternative education	71	1
Total	5970	100

Table 2: Number of families who receive one or more services

Number of services	Number of families
1	4721
2	915
3	235
4	66
5	19
6	9
7 +	5
Total	5970

Table 3 Services used by families in each band

	Most common service used										Least common	
Number of services used*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**Total**
1 Service	Benefits	Youth Justice Service	Children in need (health)	Domestic abuse	Children in need	Substance misuse	Special educational needs	School Action Plus	Exclusions	Homeless	Alternative education	
Families (number)	2612	509	305	304	259	178	161	161	112	112	8	4721
Families (%)	55%	11%	6%	6%	5%	4%	3%	3%	2%	2%	0%	
2 Services	Benefits	Domestic abuse	Children in need	Special educational needs	Youth Justice Service	School Action Plus	Homeless	Exclusions	Children in need (health)	Substance misuse	Alternative education	
Families (number)	695	277	236	143	105	94	84	83	50	47	16	1830
Families (%)	38%	15%	13%	8%	6%	5%	5%	5%	3%	3%	1%	
3 Services	Benefits	Children in need	Domestic abuse	Special educational needs	Exclusions	Youth Justice Service	Substance misuse	School Action Plus	Children in need (health)	Alternative education	Homeless	
Families (number)	201	131	81	66	51	44	36	30	30	20	15	705
Families (%)	29%	19%	11%	9%	7%	6%	5%	4%	4%	3%	2%	
4 Services	Benefits	Children in need	Domestic abuse	Special educational needs	Exclusions	Youth Justice Service	Substance misuse	School Action Plus	Children in need (health)	Alternative education	Homeless	
Families (number)	62	40	33	22	24	24	21	13	9	12	4	264
Families (%)	23%	15%	13%	8%	9%	9%	8%	5%	3%	5%	2%	
5 Services	Benefits	Youth Justice Service	Children in need	Exclusions	Domestic abuse	Alternative education	Substance misuse	Special educational needs	Children in need (health)	School Action Plus	Homeless	
Families (number)	18	14	13	13	10	8	6	4	4	3	2	95
Families (%)	19%	15%	14%	14%	11%	8%	6%	4%	4%	3%	2%	
6 Services	Benefits	Youth Justice Service	Children in need	Exclusions	Domestic abuse	Alternative education	Substance misuse	Special educational needs	Children in need (health)	School Action Plus	Homeless	
Families (number)	9	6	7	7	2	4	3	6	3	5	2	54
Families (%)	17%	11%	13%	13%	4%	7%	6%	11%	6%	9%	4%	
7 or 8 Services	Benefits	Youth Justice Service	Children in need	Domestic abuse	Exclusions	Alternative education	Special educational needs	Children in need (health)	Substance misuse	School Action Plus	Homeless	
Families (number)	5	5	5	5	3	3	3	2	2	2	1	36
Families (%)	14%	14%	14%	14%	8%	8%	8%	6%	6%	6%	3%	

*The percentage figure is the percentage of families who use that number of services

3 Geography of need in Conwy

Areas along the coast show the greatest concentration of need (particularly the wards of Tudno, Glyn and Kinmel Bay), with smaller pockets of deprivation spread throughout the rural areas. Additional maps can be created as needed to answer specific questions about the geography of need in Conwy.

Table 4 below shows the number of families in each ward who use one or more services. The number of households with dependent children is included from the 2001 census to give a rough indication of the proportion of vulnerable families in each ward to the total number of families with dependent children.

Table 4: Number of families using one or more service by Electoral Division

Name	Number of families using one or more service (2011)	All households with dependent children (2001)	% of families using one of more services
Tudno ED	303	645	47
Glyn ED	299	545	55
Kinmel Bay ED	293	705	42
Rhiw ED	220	682	32
Colwyn ED	219	546	40
Llysfaen ED	198	450	44
Mostyn ED	185	385	48
Llandrillo yn Rhos ED	185	649	29
Pensarn ED	164	351	47
Pentre Mawr ED	161	356	45
Pant-yr-Afon/Penmaenan ED	160	300	53
Gogarth ED	144	293	49
Conwy ED	144	500	29
Abergele Pensarn ED	141	219	64
Gele ED	112	404	28
Mochdre ED	110	233	47
Marl ED	104	427	24
Eirias ED	104	428	24
Craig-y-Don ED	100	277	36
Crwst ED	85	219	39
Towyn ED	84	241	35
Penrhyn ED	80	495	16
Deganwy ED	69	347	20
Gower ED	61	150	41
Pandy ED	58	209	28
Llansanffraid ED	54	278	19
Betws yn Rhos ED	49	118	42
Llanddulas ED	48	177	27
Bryn ED	39	225	17
Capelulo ED	34	168	20
Caerhun ED	33	204	16
Trefriw ED	31	148	21
Betws-y-Coed ED	30	234	13
Llansannan ED	29	230	13
Eglwysbach ED	21	177	12
Llangernyw ED	20	151	13
Uwch Conwy ED	17	156	11
Uwchaled ED	13	157	8
Total	4201	12479	100

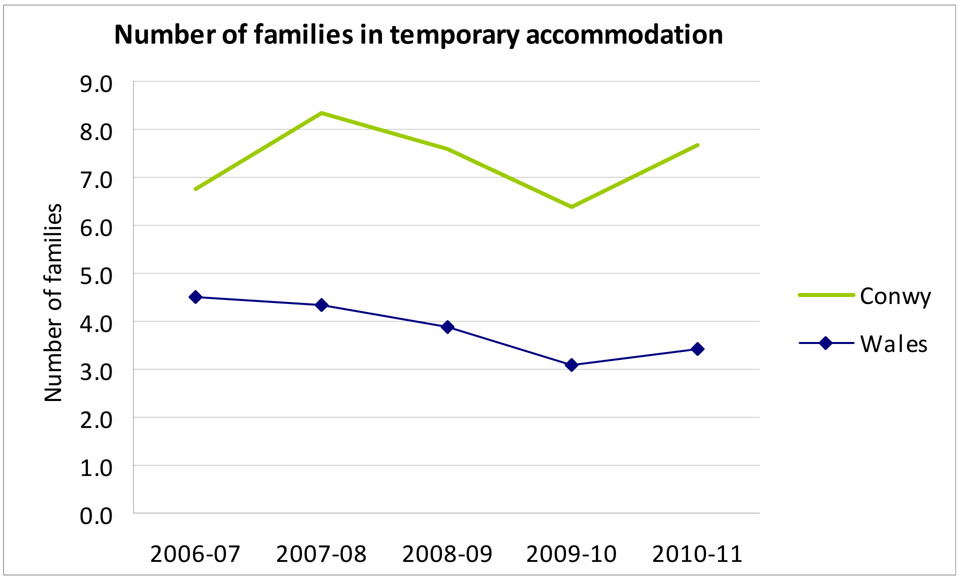
Source: Census 2001 (number of households)

4 Themes

The qualitative research identified the following themes. Below each theme is information from the quantitative research to show their prevalence in the wider population.

Housing and homelessness

- There are 220 families using Conwy's homelessness service, 4% of all the families using one or more services.
- Homelessness was an issue for 15% of families who used five or more services.
- The rate of families per 1,000 in temporary accommodation has been consistently above the Welsh average for the last 5 years and in 2010-11 the rate was 7.7 in Conwy compared with the Welsh average of 3.4.



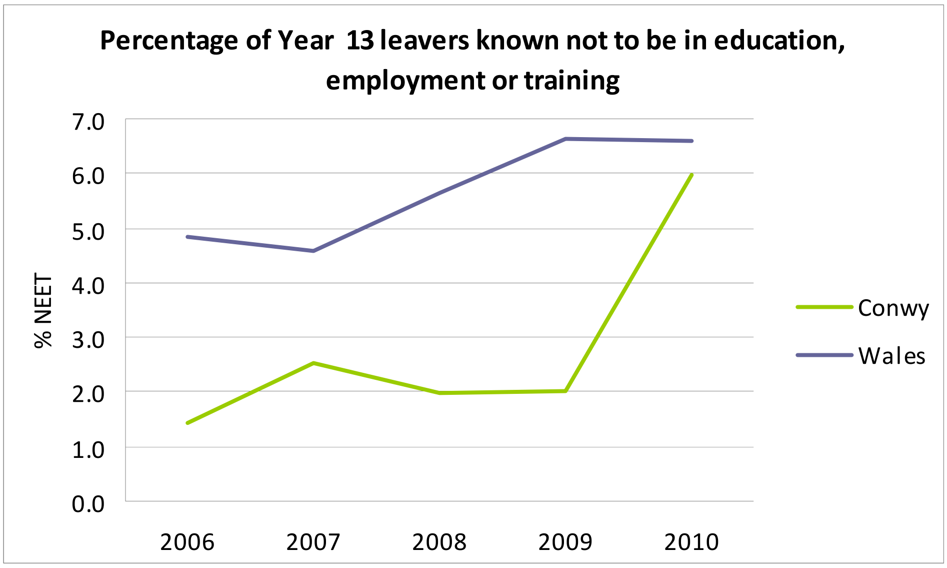
Source: Homelessness Collection, StatsWales

Mental and emotional health

- The Welsh Health Survey (Welsh Government, 2010b) asks respondents a number of questions about their mental health and combines them into the Mental Component Summary (MCS) scores. Higher scores indicate better mental health. The combined data for 2009 and 2010 for Conwy gives an age-standardised score of 51.1, a little higher than the Welsh Average of 49.9.
- Data is not currently collected on the prevalence of mental and emotional health in Conwy in a way that we could incorporate into the overall dataset on vulnerable families. The project board agreed not to conduct a survey to collect the data at this stage.

Education and learning

- Fixed or permanent exclusion was experienced by children in 70% of families using 5 or more services and 45% of those families had one or more children in alternative education.
- Of those families using 5 or more services 39% have a child with Special Educational Needs and 30% with School Action Plus.
- Children and young people in Conwy achieve good standards and very few learners leave school without a recognised qualification (Estyn Inspection, 2011). However, the percentage of Year 13 leavers known not to be in education, employment or training rose dramatically in 2010 although is still below the Welsh average.



Social Services

- There are children in need (known to Social Services) in over 59% of families using 3 or more services, and 76% of families using 5 or more services. This is the services used most commonly by families after receiving benefits.

Parents’ needs

- The average number of births in the Conwy County Borough is 1120 each year based on the last five years (ONS, 2009).
- Around 110 births each year are to mothers under the age of 20, which is 10% of the total (ONS, 2010).
- There are around 50 children who start to be looked after each year (Welsh Government, 2010a).

- Research conducted with parents in Conwy showed that 45% of those surveyed said that they had felt like they needed support, help and advice and parenting at some point and of these 83% said that they did get the support they needed[1] (Conwy CYPP, 2010).

Family breakdown and domestic abuse

- Domestic abuse featured in just over half of the families using 5 or more services, and in with around 700 of the families altogether on the database.

Money and finances

- There are around 3,200 families in Conwy in receipt of benefits or some kind, which is 60% of the families receiving one or more services and 97% of families using 5 or more services.

Employment

- The unemployment rate (Claimant count) in Conwy County Borough for November 2011 was 4.0%. The rate has remained above 3.5% for three years.

Misuse of drugs and alcohol

- Substance misuse was an issue for 5% of the families on the database and 33% of those using five or more services.

Children with disabilities

- There are around 700 families with a child with special educational needs on the database. This is 7% of all families and 45% of families who use 5 or more services.

---

[1] Data from a survey of parents attending groups such as the National Autistic Society Support Group, Young Mums, Gingerbread (Single Parents), Mind, Youth Justice System in a selection of urban and rural areas in Conwy. 156 parents completed questionnaires.

5 North Wales needs assessment

A similar exercise has been carried out by the consultancy firm Cordis Bright with other North Wales local authorities. The indicators used were fairly similar (see table 5 below) although a different methodology was used to capture the data. In Conwy information currently held by services was cross referenced, whereas the Cordis Bright exercise collected information about families directly from a sample of professionals who work with families. The Conwy methodology identified 6000 families using one or more service and 1250 using two or more services; compared to 720 families identified in Denbighshire and 1,440 identified in Flintshire (p25, Cordis Bright: 2011).

Table 5: Comparison between Conwy and Cordis Bright principal indicators of vulnerability

Cordis Bright criteria	Conwy criteria
No resident parent in the family is in work	Benefits data
The family lives in temporary, overcrowded or poor quality accommodation	Homelessness data
No parent in the family has any academic qualifications	
The mother has a mental health problem	
At least one parent has a longstanding illness, disability or infirmity that limits their daily activities	
The family has a low household income (below £287 per week)	Benefits data
The family cannot afford certain food or clothing items	Benefits data
There is evidence of domestic violence in the household	Domestic abuse data
There is evidence of substance misuse in the household	Evidence of substance misuse in the household from health.
	Children in Need known to Social Services (including Children on the Child Protection Register and Looked After Children)
	Children in Need (known to Health)
	Education: Children receiving Alternative Education, Special Educational Needs and School Action Plus data
	Youth Justice Service data

Table 6 below presents the information about the prevalence of indicators in families using different numbers of services in the same format as the Cordis Bright reports. This allows some comparison with the data from other North Wales Authorities and shows some similar findings (p10, figure 3, Cordis Bright: 2011). For instance, both show a high proportion of families where no resident parent is in work and the family has a low household income. The quantitative data from the other North Wales authorities also confirms some of the findings from Conwy's qualitative research such as a high prevalence of temporary, overcrowded or poor quality accommodation and mental health problems among disadvantaged families.

Table 6: Prevalence of indicators by whether a family displays five or more or three or more principal indicators

Indicator: (Red cells are indicators that 50% or more families display, orange cells are indicators which more than 25% display, yellow are indicators which more than 10% display and white cells are those which less than 10% display	Families using 5 or more services	Families using 3 or more services	Families using 3 or 4 services	Families using 1 or 2 services
Receiving benefits	97	88	87	59
Children in need	76	59	57	9
Youth Justice Service	76	28	23	11
Fixed or permanent exclusion	70	29	25	3
Domestic abuse	52	39	38	10
Children receiving alternative education	45	14	11	0
Special educational needs	39	30	29	5
Substance misuse	33	20	19	4
School Action Plus	30	16	14	5
Children in need (known to health)	27	14	13	6
Homeless families	15	7	6	3

Source: Conwy's Families First data; format taken from the Cordis Bright report

6 References

Cordis Bright, 2011. Families First Pioneers: Mapping of Vulnerable Families

Office for National Statistics, 2009. Number of live births in Conwy [online] Available at: www.conwy.gov.uk/statistics [Accessed 13 September 2010]

Office for National Statistics, 2010. Live births by year and UA (age of mother) [online] Available at: http://www.statswales.wales.gov.uk/ Reference: 010749 [Accessed 1 February 2010]

Welsh Government, 2010a. Children starting to be looked after by local authorities, by need for care, year ending 31 March (SSDA903) [online] Available at: http://www.statswales.wales.gov.uk/ Reference: 024424 [Accessed 1 February 2010]

Welsh Government, 2010b. Welsh Health Survey (2010) [online] Available at http://wales.gov.uk/topics/statistics/theme/health/health-survey/results/?lang=en [Accessed 16 February 2012]

Conwy Families First Research Report

The lived experiences of vulnerable families in Conwy: A qualitative study for Conwy Families First programme

Summary

This study focuses on the lived experiences of vulnerable families in Conwy – their perceptions of their experiences and needs (and, in some cases, the professionals working with them). This included listening to their stories, their experiences of services, and their perspectives on what might have prevented or helped their situation. The study was requested by Conwy Children and Young People’s Partnership (Families First Project Board), in order to provide an insight into the needs and views of families living in Conwy.

Families First is a new Welsh Government programme that aims to achieve better health and wellbeing, education and employment for families living in poverty. Each local authority is being asked to try new ways to enable everyone who supports families to work better together and so prevent families from developing more complex needs. A key element of the programme is support for families of children with disabilities.

This study and report is part of wider research, which includes data collected about the number of vulnerable families in Conwy, service profiling, and consultations with professionals. All of these have and will inform the development of Families First in Conwy.

Methodology

The study took place among 33 families and 13 professionals. Most of the family interviews took place with a parent or both parents, and one interview with a grown up sibling. The sample covered families with varying involvement from services, and with varying family circumstances, including children with disabilities. Despite this, a number of common themes and concepts emerged from the study. These are set out in this report, and are summarised as key points below.

Data collection for this study was achieved through qualitative interviewing, with due consideration given to quality and to ethics. All interviews were conducted face-to-face, (using a semi-structured approach), were transcribed from the audio recordings, and family names have been anonymised. A qualitative data software package (Nvivo 9) was used to manage and structure the data, including developing an analysis framework through coding. This was informed by a constant comparative, thematic approach. The study has sought to take an open minded approach to the data, allowing it to speak for itself, rather than impose preconceived ideas and theories.

Main findings

This qualitative study has provided a wealth of data on a number of themes, service areas, and conceptual ideas. The following points provide the main conclusions from each of the sections within the report.

Service areas and themes:

- Housing is a common theme, ranging from concerns about being able to afford appropriate housing, to the quality of the housing available, and the impact that this has had on the family. A number of families commented on the support and information available to them with regard to housing, and some suggested ways in which this could be improved.
- Mental and emotional health features strongly, ranging from parents' own needs, to the mental health of their children. A number of examples demonstrate the barriers to seeking and gaining support for mental and emotional health issues, including lack of engagement with services, the stigma attached to seeking help, and the availability of services. The families also demonstrate the causes of mental and emotional health problems; for example, family circumstances, family breakdown, bereavement, domestic abuse, and caring for children with disabilities.
- Many of the families, although not all, referred to their children's education; some were completely satisfied with the education received by their children. Themes that emerged from families' experiences include school attendance and engagement with education (causes include negative experiences, family breakdown, motivation, peer influence, lack of confidence, unstable school placements, and lack of support); aspirations and overcoming stigma; and additional learning needs.
- The families interviewed have experienced varying levels of intervention or contact with Social Services, and had different stories to tell in terms of their experiences. Some of the families taking part in the study via avenues other than Social Services give an interesting perspective on their expectations and perceptions of the service, whilst those who had more of a personal experience of the service raised the following issues: confusion around the child protection system, and the importance of continued support and intervention.
- Parents' needs, whether in terms of parenting skills and support, or otherwise, are a common theme in the study, with most of the families interviewed referring to it in one form or another. Although the families came from a wide variety of backgrounds, socio-economic status, and circumstances, parents generally felt that support with their parenting (formal or informal) would be beneficial. Families identified some issues that have prevented or encouraged parents to access formal parenting programmes (for example, stigma, lack of engagement, support to attend, and availability and accessibility). The study also illustrates the importance of more informal parenting support, including the value of support from their extended family, support networks, and

peer support. Parents often described their own needs interchangeably with the needs of their children, suggesting that they felt that their needs (met or unmet) as parents have an impact on the family as a whole.

- Family breakdown and domestic abuse within relationships has been experienced by a number of those taking part in the study, with negative impacts on parents, children, and family circumstance (such as employment and financial situation, children's emotional health and wellbeing, and education). Often these were seen as triggers or turning points for families into further problems.
- The vast majority of families taking part in the study spoke about money and finances, the general theme being that they didn't have enough to provide fully for their families for various reasons and in various contexts. The majority of the families were in receipt of some kind of benefits. The study provides an interesting insight into the impact of poverty on families (for example, on their health and wellbeing, and housing). A number of the families shared their experiences of the systems that are in place to support them financially, including the importance of information and advice, and describing problems around those systems.
- Closely linked to money and finances, the theme of employment also featured in the vast majority of the family interviews. In particular, families provided an interesting insight into the influencing factors on their employment, whether chosen or involuntary (for example, lack of confidence, alcohol dependency, finding a job, rurality and access, home circumstances, lack of flexibility, and lack of appropriate childcare). In addition, parents of children with disabilities identify the employment issues that they face.
- Misuse of drugs and alcohol were discussed by some of the families taking part in the study. Most of these described the trigger or circumstances surrounding the issue. For example, drink as a way of blocking out difficult circumstances such as a partner leaving, and children being put into care; drug dependency following a bereavement; peer influence; and boredom / lack of provision for young people.
- A recurring theme throughout the study has been the lack of information provided/available to families, and the lack of communication between services and agencies. Parents described how they acquired information through friends, family, and neighbours, rather than through professionals, or how they received information through professionals more by accident than by design. They felt that there should be a better system in place for where information comes from, and expressed frustration with the timeliness of information, and the need for communication and cooperation between services. Generally, parents felt that there should be one clear source of information available to them.

- A high proportion of families who took part in the study had children with disabilities, including children with physical disabilities and learning disabilities. Despite the wide range of circumstances described by these families, there were some clear common themes: experiences of diagnosis and provision; respite; impact on money, finances and employment; impact on siblings; parents’ fears; and stigma (experienced both internally and externally) associated with disability.

Concepts: families’ reasoning about their experiences

A number of interesting concepts have arisen from the study, which don’t necessarily fit into one service area. These are overarching concepts which provide some useful insights into questions such as “why” and “how”.

- Crisis or turning points / triggers (and intervention/prevention) is an interesting concept emerging from the study. A number of families taking part in this study identified or reflected upon a turning or trigger point in their circumstances which has either changed things for the worse or for the better. These provide a useful insight into the role and importance of intervention and prevention. Crisis and trigger points include family breakdown, bereavement, domestic abuse, losing employment, losing accommodation, change in schooling situation, and diagnosis.
- The way that the families told their stories and the language that they used gives an interesting insight into their attitudes, and their coping strategies or mechanisms. Discourse analysis has provided a brief look at how different families see their situations, how they cope with them, and the varying levels of resilience. These include coping strategies such as willingness to ask for help, acceptance, remaining positive, taking one step at a time, gratitude, identity, reflection and hindsight, humour, fight/battle, and being realistic but hopeful.
- Parents taking part in the study often referred to their own childhood experiences, and how this has contributed to or influenced their situation in some way. This provides an interesting insight into the importance of breaking unhelpful cycles and patterns within families from one generation to another. Examples used in the study are around domestic abuse, being in care, and unstable / complex family circumstances.
- Families would often provide an evaluation of whom or what is responsible for a situation (consciously or unconsciously) whilst telling their stories. They would try to make sense of why a situation has occurred, and where to attribute blame. While some families blamed external factors, others could see their own contribution and mistakes. Some families would take it upon themselves to solve a problem, even if it hadn’t necessarily been of their own making, whilst others would feel that the responsibility lies completely with the services working with them. For example, peer influence, things to do, lack of suitable school placements, heavy case loads, lack of continued support, not asking for

help, home circumstances, problems with ‘systems’ and lack of intervention/prevention prior to point of crisis.

- A common concept emerging from the study, “engagement with services” gives an important insight into the success or failure of interventions and provisions. Families often described their own, or their children’s attitude towards services, positive or negative, and how this impacted on their situation. Establishing a good relationship with professionals was often seen as a key factor.
- The majority of the families taking part in the study referred to their support networks (or lack of). References include family and friends, as well as support from services, community groups, or informal groups. These were seen in the context of their ability to cope with their situation. Many described the loneliness and isolation they felt as a result.

1 Introduction

The purpose of this study is to discover the lived experiences of vulnerable families in Conwy, in their own words. Listening to families' stories as they see them provides a unique perspective – families' own interpretation of what has happened to them, why, and how. The study aims to find out families' perceptions of their needs, experiences of services, prevention, and possible solutions.

As such, this study brings to life and illustrates other data collected (this report is part of wider research, which includes data collected about the number of vulnerable families in Conwy, service profiling, and consultations with professionals.)

2 Background

This study was requested by Conwy Children and Young People's Partnership (Families First Project Board), during its first year, in order to inform decision-making and developments with regard to Families First projects.

Families First is a new Welsh Government programme that aims to achieve better health and wellbeing, education and employment for families living in poverty. Each local authority is being asked to try new ways to enable everyone who supports families to work better together and so prevent families from developing more complex needs. A key element of the programme is support for families of children with disabilities.

The board requested a wide scope to the study and research questions in order to gain an overall perspective of families' views and experiences. The results of this study are intended to be used alongside quantitative data collection, and data from service profiling.

3 Methodology

Data collection for this study was achieved through qualitative interviewing with families and in some cases with the key worker or professionals working with the families. Due consideration has been given to quality and to ethics whilst undertaking this study. For further information please see **Annexe 1**.

Sample

The sample (n=33 families and n=13 key workers/professionals) was selected purposively, and includes a wide range of respondents in terms of the number of services they are/have been involved with, and their circumstances. The study only includes individuals able to give informed voluntary consent.

The respondents were targeted and invited to take part mainly through the services that they use (some through the data collection process (n=21), some through an invitation sent out to a selection of families on the Revenues and Benefits data base (n=10), and some through other contacts (n=2). The sample:

- includes mothers (n=31), fathers (n=10) and siblings (n=1). Eight of the interviews had both parents present;
- represents families residing in rural (n=9) and more urban/coastal (n=24) areas;

- comprises a mix of housing situations such as families living in social housing (n=22), private rented accommodation (n=7), and owned homes (n=4);
- represents various employment status - at the time of the study, 12 households had neither parent in paid employment; 9 households had at least one parent in paid employment, and 13 households had one or both parents as full-time carers of their child with a disability;
- comprises various family make-ups, including single parents (n=13), and a wide variety in terms of the number of children, and children's ages (early years, primary aged, teens, and grown up children);
- includes families who have moved into Conwy from other counties (from within and outside of Wales) (n=18);
- comprises families with children with disabilities, including physical and learning disabilities (n=13);
- and includes families who use a high number of services, ranging to those who are in receipt of a low number services.

Data collection

All interviews were conducted face-to-face and in a mainly one to one situation. Some families chose to have a key worker or a family member with them during the interview.

A semi-structured interview schedule was used, informed by the research aims agreed by the Families First Project Board. A rolling hypothesis technique was used, approaching interviews with a relatively open structure, and homing in on key emerging themes (from earlier interviews) during later interviews. A flexible approach was needed during the interviews because families were so different to one another in terms of their ability to tell their story, and in terms of their background and circumstances.

Audio recordings of interviews were made and transcribed, with respondents' permission.

Analysis

All interviews were transcribed from the audio recordings, and family names have been anonymised. Field work notes were written by the interviewer, and memos and notes made during the analysis of the interviews. A qualitative data software package (Nvivo 9) was used to manage and structure the data. Following initial reading of transcripts and notes, an analysis framework was developed which was used to structure the data under identified headings (codes). This was informed by a constant comparative, thematic approach. Validity of identified themes was checked across the whole data set, and themes can be linked back to the data extracts. The study has sought to take an open minded approach to the data, allowing it to speak for itself, rather than impose preconceived ideas and theories.

4 Findings

The families taking part in the research each had a very different story to tell, and a different way of expressing and telling their story. Some were able to reflect on their experiences and provide their own interpretations of events, while others simply told their story. The interviews were, on the whole, rich and full of interesting and useful data for the study.

The study has a wide scope, interviewing families from all sorts of backgrounds and situations. The research questions were also very wide (for example, "tell us your experiences", "needs", "prevention"). This has provided a wealth of data on a number of themes, service areas, and conceptual ideas. It is possible to undertake a more in-depth study on each one of these. However, this report seeks to present the data collected in a useful structure as a first step to inform and influence decisions around Conwy's Families First provision.

The findings have been split into two sections:

- Service areas and themes
- Conceptual ideas

Some things to note:

- All names have been changed
- This qualitative study has provided a vast amount of material and the main themes and issues have been demonstrated within the findings. However, there is scope to use the data further, and the study highlights areas that may be worth pursuing more specifically and in more detail.
- Some of the families refer to past experiences, where improvements may have already been made to the issues that they raise. Also, quotes from families may not always be factually accurate. However, these have been included as useful insights into families' experiences and perceptions.
- Each section includes illustrative (but not exhaustive) quotes from the families, many of which represent a number of other families' experiences taking part in the study. Where there is an exception to this (a rogue, but interesting case) this will be stated.

4.1 Service areas and themes

4.1.1 Housing and Homelessness

Housing is a common theme for a number of families taking part in the study. This ranges from concerns about being able to afford appropriate housing, to the quality of the housing available, and the impact that this has had on the family.

Impact of housing situation on families

The study provides an insight into the various impacts (positive and negative) that a housing situation can have on families.

A mother living in council housing describes the impact of inappropriate housing on her family's health and wellbeing:

"Problem with it was it had damp, which I told Conwy Council over and over… again. It took a year before they finally turned around and says "Ok, yes there is damp", and by this point…I had moved my daughter into the other room, and … my bedroom was my living room … I must admit, now I never realised how much affect it has on your health until I moved out... Mainly colds, you have so many less colds… less sniffles… less coughing …

me and my daughter were constantly cold after cold after cold after cold; you wouldn't have a gap." (F9)

These families describe the expense and insecurity of living in private rented accommodation:
(F2) - *"Looking to get on the housing list, because we do pay a lot of money to live here. And if you add it to the bills and everything else, the wages just don't make up…. It's the insecurity of private renting as well…If he decided to sell, or you know, move back in, or something like that, we could be homeless in a month. And when you've got three kids…I think you're a lot safer when you rent off social housing."*
(F6) - *"It's just the fact that they can't… work miracles to provide a house for me and my kids... I've been off and on for the last years trying to obtain… a housing association property and nothing's been available. So hence I've been forced to like rent all these years, at £5.95 [an hour], and that's where my wages are going...People are needing money and a lot of people are having to sell up. …You know I've felt for the children, I've had to like, you know, move them from place to place to place."*
(F21) - *"We've had to move out because the house went up for sale and that…if it's in the council, it's cheaper isn't it; the whole thing, everything about it is better… You get some bad landlords out there."*

In contrast, this mother describes the impact of some of the difficulties associated with living in social housing on herself and her son:
"Just to have that space and have a base really…It doesn't feel like home, we're very cramped… it doesn't matter what you do, it still doesn't distract from the fact that you're from the flats. And there's a lot of stigma that comes from [that]. My seven year old's noticed that already in school; he said "I'm getting the mick taken out of me…" and I said "It doesn't matter where you come from, it's who you are, and… how you're brought up." But, for a child I think that's quite hard to understand…" (F24)

Reflecting concerns expressed by others, this family describes problems with the area in which their family has been placed, and the influence and impact that this may have on their children:
"I was miserable for years on [names housing estate] - I absolutely hated it….There's just so many horrible people up there, people from big cities who are just rough; the council just put them there "oh there's nowhere else to put them"…My kids - I won't even let them play out - they go to school and after school club and in the evenings they'll stay in with me or their friends will come round…I'd just let them play in the garden." (F5)

A young mother describes the expense of providing an appropriate home for her family:
"…kitting it out and trying to decorate it, I've been in my new flat because I had to move from my one bedroom flat to a two bedroom because of my son. Been in it for…nearly three years and I still haven't decorated my kitchen, his room, the bathroom, the hallway. I've only done the living room and my room….I can't afford to carpet or laminate my living room or my hallway." (F23)

A social worker describes the difficulties caused for a family with children in care, by lack of co-operation between services:
"The main issue…is housing. They live in a three bedroom property, with a family of ten people… As far as housing are concerned, Amber[2] *has made herself intentionally overcrowded by having eight children…. We can't, as a result, revoke care orders on children - no court in their right mind would agree for ten people in a three bedroom property - and as such we are in a no-win situation. There isn't a need for [these children to be looked after children], only because of the housing situation, which is extremely frustrating for Amber. And extremely frustrating for us."* (F17)

---

[2] All names have been changed

Another situation is described by F14 where better communication and co-operation between services was needed in order to smooth the transition for looked after children into independent living.

In contrast, a mother describes the positive impact that being in appropriate housing will have for her children to return from care (and the support provided):
"My housing situation is alright…We haven't touched drugs for ten months now… we give clean urine samples all the time… They said we've got a good chance now to keep the house, and the house we've got is gorgeous. They spent 58 grand on it last year, putting on all solar panels… new fitted kitchen, new bathroom, brand new carpets….So it would be perfect for the kids…" (F16)

Reflecting frustrations expressed by a number of families with children with disabilities, this mother describes the impact on her family of years of seeking adaptations to their house in order to make it safe and viable for their child with autism (living in social housing). She describes, amongst other things, dangerous fencing and concrete posts in the back garden (which have caused a number of injuries), lack of safety guards on heating, the temperature of the house affecting her son's condition, and the challenges of keeping a house clean with a child whose disability causes regular soiling. In summary, the mother felt that the housing providers …
"…need to be educated, in the respect that, you know, I'm not somebody who's trying to take the mickey out of them. I'm trying to adapt this house to make it safe for my child, and sometimes it's not just the resources that I lack, [there are some things] they could only do, and you need permission for. But, they wouldn't give it, and that's what I don't understand." (F10)

Housing support and information

A number of families commented on the support and information available to them with regard to housing, and some suggested ways in which this could be improved.

A mother describes a complicated system for accessing social housing:
"But…I think it will be more hard work, and we'd probably have to wait a long, long time… And it's just so complicated over here… I got the forms and thought "oh no, this is going to take forever." … "I'm going to pay £650 a month for the next seven years"…If you just had one form that got sent to all the different housing associations…and then you just hear off them as and when a property that suits you comes up." (F2)

A mother describes her own childhood experiences of becoming homeless at 16 and how better support could be provided for those in similar situations:
"More support for children … when they get kicked out of the home at 16… They don't know anything about working, benefits or just life in general; they're left to their own devices…I don't know maybe have a support worker in place, or someone that can sit down with them and say "well this is what you need to do, this is how you fill the form out. Don't sleep on the street, you know, we can organise it"…" (F5)

A key worker describes a father not coping with the demands and responsibilities of renting a house, and being made homeless as a result:
"I know he [father] has had problems with drink and drugs in the past…he does get very frustrated with things. And if he had an outlet, or an avenue to… or somebody to support him…Obviously he has been overwhelmed with running a house because he's lost his home…If he had support in some areas, then maybe that would alleviate the stress…That would improve his parenting because then he wouldn't be so stressed about the other things…you kind of get a sense that he's drowning with things." (F19)

4.1.2 Mental and emotional health

Mental and emotional health features strongly in a number of the families' experiences. These ranged from the parents' own needs, to the mental health of their children. A number of examples demonstrate the barriers to seeking and gaining support for mental and emotional health issues, including lack of engagement with services, the stigma attached to seeking help, and the availability of services. Other examples demonstrate the causes of mental and emotional health problems.

Barriers to seeking and gaining support

These mothers talk about their perceptions of receiving mental health support, and the stigma attached to it:
F9 - *"I wouldn't have wanted that [counselling], because when I was younger I was a bed wetter and they tried all different tactics with me, counselling included…It's not a nice…I wouldn't like to look back on my life and see myself as "I got counselling when I was younger…I was counselling throughout my whole life"… I don't like that idea….Then again, I'm the kind of person who, I don't like to rely on everyone else; I'm very independent."*
F12 - *"I'd love to have someone to turn to and sort myself out… 'cause I feel my life's been a battleground…you are constantly addressing yourself, because I've had reactions off people and they've not understood it…I've been kind of wounded, and I think you just kind of bottle yourself into this small space, where you don't say anything because you're worried about how people are going to react…"*

A mother suffering with depression and anxiety describes her reluctance to receive professional help:
"I'm supposed to be on medication, but again, it's the whole getting to, going to the doctor thing….At first I was having counselling, but I stopped. But…[family support worker] helps me; it's all down to her basically….When I came out of hospital I [met] …with the mental health people…I missed one appointment and I haven't heard anything from them since…it's probably my own fault, 'cause I missed the appointment….well, in a way I'm kind of glad, 'cause I don't really want to go back there…"
The family support worker describes how she feels the client would benefit from engaging with a professional with more specific expertise:
"Somebody who has the expertise to be able to support her with the depression…She was on medication but she stopped taking it…she ran out and she hasn't got herself sorted… I've offered and offered and offered, I think she doesn't want to be on them…." (F21)

A mother describes the downward spiral of alcohol dependency, depression, and suicidal thoughts; and her reluctance at that point to receive help with her mental health:
"I'd go through the motions of crying and thinking what have I done to myself, what have I done to the family…the bitterness would come and the anger...Eventually I thought "what is the point in living?"; …I would think of buying panadol because I'm bound to need it at some stage…I'd wake up in the mornings [after taking an overdose]…I'd be so embarrassed…and they'd be like "there's a psychiatrist coming round"… "I'm not seeing no psychiatrist" and I'd sign myself out and I'd be off…." (F3)

A mother describes her daughter's struggles with mental health, accessing services, and engaging with the support provided:
"I pestered Social Services and CAMHS …took months for them to get involved. It took two overdoses before they did anything. The waiting list is just horrendous. I got her rape counselling…she stopped going because she couldn't handle it…they closed the case. She was seeing a psychologist through CAMHS…kept missing the appointments because she couldn't handle it…they closed the case. Social services rang me three weeks ago to close the case…That's just another knock…more rejection…she was really upset and she said 'Mum, even they've cut me off now' ... At 15 that's the way she's sees it…as an adult you think "fair enough", but a child sees it as "oh they don't care either"." (F5)

Causes and triggers for mental health:

The same mother describes her own mental health struggles, the impact of a difficult relationship with her mother, and a similar pattern emerging between her daughter and father:
"As a young person myself… I was mixed up about my mum. I still get upset about it now… but I've learnt to deal with it... But Jessica needs to get to that point where she's like 'right well that's just the way my dad is and that's the way he's always going to be and I have to learn to deal with that'. But at the moment she's like 'he isn't, he does love me; he will change.' It's sad to watch it because I've been there myself and I know how bad she feels, think that's why I get so upset." (F5)

A mother describes the effect of family breakdown and domestic abuse on her mental health:
"I had ended up with what they call unexplained infertility and they ended up putting it down to the stress of the divorce and the custody battles, my body just shut off. I lost most of my hair, I got alopecia, my hair fell out and people thought I was having treatment for cancer and all sorts. It was just stress….but it all led to counselling believe it or not." (F4)

Parents describe the effect of their children being taken into care on their mental health:
"They've treat this family [as] though we're criminals, [as] though we've done something wrong, and we haven't, we've just tried moving forward in life. It's caused me depression, it's caused mum depression… and all we're trying to do is think of our children and think, "why have they been took away from us?" but we can't think for a reason why." (F18)

A sibling describes the impact of trauma and being put into care on her brothers' mental health:
"Jim has always been very quiet…He's had a lot of trauma as a child…got locked in a bedroom, Mick set fire to the bedroom…Jim's took a lot of beatings at the hands of Mick… which is why he has the DID *[dissociative identity disorder]…they put it down to childhood trauma…My mum wasn't in any stable mind…she gave them up…they had a lot of anger towards my mum at first…But I do think… instead of just shoving them into care…they all needed some form of counselling....they saw a psychiatrist, but that was only for their diagnosis…I don't think they had any actual one-to-one child therapy, which I think they probably could have done with as children. Even now, I think they could do with some sort of counselling to help them deal with being put into care."* (F14)

This is one example of many where bereavement (and lack of counselling) impacts on a parent's mental health. Here, a father describes the effect of bereavement on his ex-wife:
"Suddenly…her mum died…she went to pieces…She was just bottling it all up…and it was making her ill. …and I was telling her "just go and see a doctor"… she wasn't having any… just… two fingers up to me, and two fingers up to everyone else. She was just in a world of her own. Her head went..." (F19)

The following families describe in particular the strain on their mental and emotional health caused by having a child with a disability:
A mother describes the impact of her autistic son's behaviour on her mental health:
"A few years ago I was on anti depressants because…I couldn't cope with him, and they…send him home and say "can you not bring him to school for a few weeks?" And then you're just stuck at home and … I used to try and get him into activities, he used to get kicked out, and you just end up stuck…It feels like you know, you're wound up…you do feel like you're on your own." (F13)
A father describes the stress caused by his disabled daughter being bullied:
"Camilla started at the village school, which in hindsight was a mistake…she was bullied…And that actually did have an effect when she went to high school because she was ostracised and the kids were horrible to her; so the first few years of high school were hard, emotionally, on top of having a disabled child. For us, as parents, that was the hardest thing." (F26)

Parents describe the impact of looking after a child with a severe disability on their mental health:

"It was stressful for us 'cause Carl would be out at work all day, I'd be home with a very poorly child …I'd do all the nights because she's up a lot at night, because I knew he had work, to try and take some of that off him. So he's going out stressed, coming in … to a stressful atmosphere here. …A lot of time we were at loggerheads…It was just the stress we were under because of the financial situation." (F33)

Similarly, a mother describes the strain caused by looking after a child with a disability, and the emotional support that would have been useful at the time of diagnosis:

"When I had the bad news about the adaptations…my boss said to me 'take as much time off as you need'…I volunteer. He says it's more important that my mental health is good. I've got vertigo through stress, it's just every day is a battle… I think support for the parents - you have the diagnosis and then all of a sudden you have physios, you have an occupational therapists, you have speech therapists, you have social workers and all these things are thrown at you. Maybe it was available for me but because you don't think at that time, some kind of grievance counselling to help parents understand…" (F28)

4.1.3 Education and learning

Many of the families, although not all, referred to their children's education; some were completely satisfied with the education received by their children, and therefore did not have a great deal to say about it. However the following themes emerged from the study.

School attendance and engaging with education
The following examples provide an interesting insight into the factors that influence school attendance and whether children and young people engage with education, and suggest the importance of intervention or prevention to overcome disadvantage in education.

A mother describes how a **negative experience** has affected her son's school attendance from an early age:
"I feel we're getting bullied by the teacher…The first week he was in school he'd been having wee accidents, but he's only three…they had him stood on a piece of newspaper…and they'd left him for 25 minutes like that; and I'm sorry but if that's not neglect, what is? They don't see they've done anything wrong…He said that the teacher was laughing at him, calling him a naughty boy, everybody was laughing at him in the class…Since then he never wants to go into school. He hates it now…still keeps mentioning about the newspaper." (F22)

A mother describes the impact of **family breakdown** on her school attendance as a teenager:
"I was a bit of a rebellious teen…They managed to get me into [secondary school] before the start of year nine…I went there for three and a quarter days; didn't get along with the people there, didn't enjoy it…kicked off a big storm and refused to go back. Within a month or so they managed to get me into [different secondary school]. I was there for about six months, but I ended up having lots of panic attacks and wasn't in there much because of them. I think that's probably down to the pressure of my parents breaking up and everything, 'cause I took it quite hard." (F9)

A mother describes her difficulty in **motivating** her daughter to attend school:
"Polly is a nightmare…her attendance - it's really low - 'Lazyitus' …I have to call her for an hour solid before she gets out of bed. She's either late or not attending….she makes the excuse she's not well, or headache or period pain…. She doesn't realise I have to deal with this on a day to day basis…I said to her time and time again "if you don't start attending school, I'm going to end up in prison". She says I won't but she doesn't get it … "I'll lose you, I'll lose Rebecca, and I'll lose Tom"." (F31)

A father describes his difficulty in encouraging his son to attend school, partly due to **peer influence**, and his own **childhood experiences**:
"He's just all right…he's in middle sets in everything in school… just getting him to school is… he's a pain…, just 'cause all his mates are always off up here, he just tries to blag me he does. But because of like how I was brought up, what I went through with my dad… that's my weakness with him." (F19)

A mother describes the impact of the **trauma** caused by having an abusive father, and having been the victim of a violent crime, on her daughter's schooling:
"Then since then she's had lots of mental health issues…Jessica's behaviour… she wasn't going to school. She was a 'straight A' student before all this happened, never had a phone call off the teachers about her behaviour before any of this, no complaints about her." (F5)

A social worker attributes **low confidence and motivation** levels to his client's low attendance and lack of engagement:

"One of the most difficult to engage is probably Sean…He is currently drifting at the minute. He's not interested in engaging in any education, training or employment. We have set up lots of opportunities for him, but when it's come to start them, he's changed his mind, or backed out. I'm not sure whether that's a confidence thing, or if he's, basically, just plain idle. I suspect, because he has got a degree of learning difficulties, in terms of basic maths and english, it could be a confidence thing. But, he's very reluctant to do anything about that, even." (F14)

Parents of a child with learning disabilities assign **lack of understanding** on the school's part as the main factor in their son's school attendance, although they may suggest responsibility on both sides:
"It's the school's fault, but I got told, because he was having absences…I get threatened…getting these nasty letters…phone calls… and I'm trying to tell them the difficulties but they don't want to know. So they tell me about all these fines…end up in prison….He hates school…it's all because of them…[He gets] really agitated, so upset in the morning and then the minute he's there, he calms down, he knows "I've got to get over it", and then, when he comes home, he starts doesn't he?" (F30)

Some families describe the difficulties caused by **unstable school placements**:
A mother and father describe problems with school attendance with all of their children; this example is about their daughter's provision at alternative education:
"Natalie has now been put down to three half days because her and her friend were messing about so she's been given two days off school, so that didn't help her. They made us get her back into school, now I've got her back in, because she played up a little bit they took two days off her…yet the other girl's got her days still. So that don't help Natalie does it, 'cause it just messes with her head." (F11)
A mother describes her son's behavioural difficulties, leading to unstable school placements, with a knock-on effect on home circumstances such as employment and housing:
"[After being expelled] it was inevitable…that Rupert was going to end up in some trouble…because he didn't have anything to do during the days… When he went from primary to secondary there wasn't a school place for him. So he went a long time…just at home...I can't do anything because I have to stay in with him…But if he could have had a secondary school that was adequate, and settled, it could have been really different… it's too late now really but, it could have been really different….[Current situation] is kind of his fault this time; he's on school strike…He only goes there three mornings a week…. That's why I was kind of pleased that he got himself a little job because it filled up some of his time and he had some money in his pocket… and it was a shame that he wasn't allowed to do it, because he doesn't have enough school hours to fill up a week, you know, he only does 11 – 12:30." (F13)
A sibling describes the impact of her brother being expelled from school at an early age on the family:
"With him not being diagnosed [with a behavioural condition] 'til he was twelve, you know. My mum's eight, nine years of hell with him….I think something should have been done… school wise, when he was six, when he was permanently expelled from school. I think they should have maybe looked into boarding school and stuff then, instead of leaving [it] 'til he was like twelve, thirteen…" (F14)

Aspirations and overcoming stigma

Some families spoke about education as a means of improving their situation:
F14 - *"He's doing IT in college…He's always been one of these that wants to do better than everyone else. He doesn't want to be a stoner sat on the dole….He's been with Social Services to stuff, to prove to other care children that there is another life, if you like. He's been to all sorts of meetings…I think Social Services are…very proud of how far he has come on - considering he didn't go to school."*
F5 - *"Over the years I did various college courses to better myself. Because I didn't want to be another single mother…living on a council estate and doing nothing else….I've done it all*

very topsy tervy and have two grown up kids; I mean I'm 33 now…I'm thinking about going back to Uni…I didn't have the confidence back then to probably have done it. I'd have thought I was incapable…I was told I was thick. It's only through life experience and…going to college, passing courses and thinking "yes I can do it"."

Additional Learning Needs

Families' experiences of the support and information provided with regard to additional learning needs varied greatly within the study (positive and negative). The following quotes illustrate the spectrum of stories and experiences, and the choices made by families.

A mother describes the lack of understanding experienced in a primary school setting around her son's ASD:
"I highlighted stuff that I felt Mike was doing at home and that it was not because he was naughty; it was part of his traits…We had… a 'home-to-school' book….Everything they were writing was negative…he's pushed this kid, he's…shoved this, he's thrown water across the table or he's spilt his dinner….That makes him look like a really naughty child…I went to observe him one day in school and he was good…I sat there that morning and he was in front of the… white boards… doing a story and he was just sat there...looking like a little boy that was lost. I went out crying my eyes out." (F20)

This mother describes the lack of understanding experienced around her son's needs in primary school, and the improvement into secondary school:
"At junior school, I felt that he wasn't getting the support that he needed. … All's we got… was 'there's nothing wrong...' But there is a problem; he's academically behind…he's got no concentration, he doesn't sit and listen, he can't take orders…He wasn't given the support to catch up…They just weren't acknowledging...even when he had his diagnosis off CAMHS… A lot of people still don't recognise ADHD as a medical condition…. But he's moved to high school. I've had countless meetings with them before he started and I think…his educational needs will be put first" (F2)

In contrast, these parents describe a positive experience in terms of support and understanding of their son's physical and learning disability in the primary school, which was lacking in secondary school:
"The school are horrendous…, they just don't want to know…get no help from them….We said we were worried about him going into secondary school… because he was getting all sorts of help from [primary school]. So he went into school…he was getting a bit of help but it soon stopped. We used to go in and call meetings with them and they'd say "no"….He used to have P.E and because he struggles dressing himself… he could have P.E early in the morning and he'd do the whole day with no socks on all day… pants unfastened, he got no help. It was embarrassing for him… degrading for him." (F30)

A father and mother describe how provision and understanding of their son's condition have improved:
"People put it down because it's…an alternative education…but when you go and see it, it was absolutely brilliant and the things that they get to do like building…and catering…he was absolutely made up with it. And he enjoyed going as well, that was the other thing, whereas if he would have been told you've got to go to high school…he didn't want to go there…At first in [secondary school] it wasn't easy...because he wasn't statemented and he was a "naughty boy" and he was in trouble, but…as the years have gone on they've put more and more things into place for him." (F12)

A mother describes her own lack of understanding, and the impact of children travelling to receive provision:
"They do have a statement but to be honest I don't really understand a lot about it. Although we do have meetings with educational psychologists and the school speech and language… [I'm] not 100% sure what's what, but the teacher…met up with the boys in their infant

schools…and had a lot of contact with them and ourselves as well, and the boys spent a day in [primary school] to get used to it, and the input was very good, and I felt confident that she's going to be a very good teacher…They go off in the taxi and it's just a shame 'cause I miss out on picking them up…it just means that they're out of this area where they're going to have friends…and I don't drive…" (F1)

A mother describes the dilemma of making decisions around schooling for her disabled child, and the need for expert advice:
"See the first big, big decision that you have to make…is what school do they go to when they're five…We got it terribly wrong…So I think advice about schooling…a key thing… I do appreciate nowadays that parental choice is everything and… is very precious. But…I had no experience of a disabled four year old when I was making that decision…I could do with a little bit of advice… it's a real dilemma… having made that mistake once, I'm really scared that we get it wrong." (F32)

In contrast, this mother describes how she went against the advice given for the schooling of her child with a physical disability:
"When she was about two…the paediatrician… [was] trying to encourage her to go to mainstream... Mainstream couldn't cope with her…No changing facilities… there would be no support for the one to one…she would be on a different curriculum so she'd be in a separate part of the room…So you're alienating her… she's never going to catch up with her peers…You hear so many times in mainstream, "the one to one's gone off to do the photocopying"… I thought there is no way am I having that; so we said "No, she's going to Gogarth" where I know she'd have the one to one support…and Gayle would get everything that's relevant to her with her peer group and children of like abilities." (F33)

4.1.4 Social Services / child protection

The families interviewed have experienced varying levels of intervention or contact with Social Services, and had different stories to tell in terms of their experiences.

Some of the families taking part in the study via avenues other than Social Services, give an interesting perspective on their **expectations and perceptions of the service**:

Some families express surprise at the level of support received:
F10 - *"I even fostered my own grandchild who was on an 'at risk' register... I still got no assistance, even with that…She was already under Social Services because of her parents, not a serious risk, but the parents were rowing and fighting in front of the daughter, so Social Services felt it appropriate that she had to be put on the register, understandably, of course. And then it came to a head and they removed Serena and they brought her to me…. A lady that came out…I had meetings and everything… I was still working… and I had three little babies…. So, no, I've had none, none, nil, zero support; none."*
F5 - *"[Daughter on the at risk register for sexual exploitation by older men]…I'm shocked actually at how little they will do. I mean there's a stigma attached to Social Services isn't there and people say 'don't ring [them] because they'll take your kids off you. They wouldn't take mine even if I begged them. They're not interested. I think maybe publicising the Social Services more as to what they actually do. They aim to keep children with their parents and I don't think people see that."*

In contrast, this family feels that there is no need to involve more services than necessary in their situation:
"They did put a referral in to Social Services and I received a letter saying, "unfortunately we cannot help you at this time", which I'm quite pleased about because I didn't really want them involved if I could deal with it with CAMHS and with prevent and deter [youth justice service], so Social Services is just another agency that I don't want involved at the moment. If it does become a safety issue with Damon, then something is going to have to be done, but I don't want them involved anyway." (F2)

Some families who took part in the study via contact with Social Services, expressed **confusion around the child protection system**:
"It's just messing us all up, because we're trying to work with them, and they seem to go the opposite way all the time…And I can't see how we can move forward when they keep on going back to the past and changing stuff all the time…That's what I can't get my head around…why, if the children were mainly in danger from day one, didn't they do something sooner…? Why let us try and move forward and prove ourselves if they thought it was too bad…? Why didn't they do something sooner than get our hopes up to move forward, and we thought we were… giving our children the best chance in life when they were just going to come eventually and take our children away from us?" (F18)

"They said [if] I done my three week detox in here, and then do well and then I'd leave, the kids would be returned to me…Then five days before I was due to leave here, they…said they were getting court orders for them. So in that way I feel like I didn't have any sort of support. You know, I've got told one thing, and got told another. So I left here, I thought 'I've lost everything, what's the point?'" (F16)

The same two families expressed the importance of **continued support and intervention** in order to bring them to a position where they can receive their children back from care:
"I've… done well the last twelve months; there's been a major turnaround in myself, people have notice[d]… the difference in me and how motivated I am. It's just I was motivated with my others, it's just I wasn't on a script, I wasn't getting sort helped towards the end, once the kids had been removed from me, it was like all that support just went "whoomph", out the window." (F16)

"When we get the children home…they give us more support, like parenting skills, they can do that for us …and this health and safety course, they can do that for us. To help us to be good parents with the five children…They could get someone to come to the house…" (F18)

(See the sections on Children with Disabilities, Information and Communication, and the section on 'Concepts' for further references to Social Services)

4.1.5 Parenting

Parents' needs, whether in terms of parenting skills and support, or otherwise, are a common theme in the study, with most of the families interviewed referring to it in one form or another. Although the families came from a wide variety of backgrounds, socio-economic status, and circumstances, parents generally felt that support with their parenting (formal or informal) would be beneficial.

Formal parenting support - the following examples illustrate parents' experiences of more formal parenting support, in particular the issues that could prevent or encourage parents to access the support.

A mother describes her positive experience of a parenting programme, despite concerns about **stigma**:
"If there's any mums out there…you don't have to be a bad mum to go to it, you see…It's just full of all these wonderful ideas…all these strategies, and you're thinking…'Why didn't I think of that?' and you can't believe it….If anyone ever needs any help, seriously, go to that Incredible Years, or even if you don't need help….I think men should go on it as well, because it's just, it's an amazing course." (F9)

This mother's experience of parenting classes emphasises the **need for engagement** from the parent:
"But, to me it didn't work out, because…you had to do role play and half the time, you were just having a laugh…I come home with a book, that was about it. But, I haven't even read that." (F15)

Support to attend meant that this mother had a positive experience of parenting courses, but she describes a lack of confidence in applying what she has learned:
"I enjoyed them. I really did enjoy them. It's [social worker] that used to take me every week…. I've done them a few times. You know, like they've always said, my parenting skills are brilliant, you know, I know what to do. It's just sometimes, I lack it, do you know what I mean? I could do more." (F17)

A mother describes lack of **availability and accessibility** of parenting support, and the referral systems:
"I've had trouble with the eldest, but the school offer the kids the support but they don't offer the parents any support… I have actually phoned social services again about my daughter…to see whether there was anything I could do, or they could offer me some support, and they said "well there's nothing really we can do unless there's been an incident"…I don't know where to get some advice from or talk to anybody…I had to be referred to do a parenting course for an eleven year old...Why can't it be open for every parent to do? … There should be something…information-wise…" (F8)

A father describes his frustration with **lack of parenting support**, which he feels could have prevented his children being taken into care:
"*Parenting skills, we've asked them can we do them, still waiting, they come back with all sorts of excuses…and that to me is wrong because we haven't been given a chance to prove that we're decent parents…we keep on asking, still waiting….If we'd have had the parenting skills sooner… we would have known what to do…."* (F18)

A mother describes the need for **practical support** with her disabled child as well as theoretical information:
"The council were really good, I had a psychologist, and she was excellent to be honest, and she gave me all the information I needed and gave me, you know, links to where I could find more if I needed, she was excellent, but you seem to be able to get all that kind of information but not practical help, is what the problem is… just like, practical issues that come with children like Rupert." (F13)

Informal parenting support - these parents' experiences illustrate the importance of informal parenting support to complement the more formal provision:

A number of families spoke about their extended family as an invaluable source of support. For example:
"Getting her home and my mum didn't want to intervene too much. I remember that first night of her being at home with us…Me and my daughter's father were…trying to you know calm my daughter, she was crying and she was crying. She didn't want food, she didn't want dummy, she didn't want her bum changed; she didn't need anything…I think my mum had heard me burst into tears…and then she'd come through…and she just picked her up, put her sideways in her arms, pressed her against her side and she went quiet…" (F9)

The following parents describe the value of having support networks with people in similar situations to themselves:
F12 - *"I think the parenting groups were good, we've been to both of them…And we did the teenage one…They really do help you…we did enjoy going to the group sessions as well with people who were often like-minded and had kids the same…That's what upsets me most is that I need somebody to talk to who knows about this to help me...I don't think there is help…I would love to have someone to turn to… to talk to…some support…That's why I like these support things because sometimes in this world, you go through your whole life, and you think "this is only happening to us…everybody else's kids are probably fine"… And then we actually talk to like minded people…"*
F10 - *"I do need some kind of guidance. It's not in the respect of looking after Harry [with autism] and how to look after him…but it was other aspects, just silly things…I've never met any other parents with a child with autism. There's no groups either…in local areas. I'm isolated here. I'm stuck here…Why is there not a local, someone like me, like a mother with a child, to do like a coffee morning, but in their own home?… like all the parents get together. Why has no parent ever thought of that?..."*
F2 - *"As a parent there isn't, apart from CAMHS, there isn't any other support networks, there isn't any groups or anything that….I can go and sound off at Damon's psychologist and I can tell her how I'm feeling… she'll sit and listen to me…I've got friends…they don't know how to tell me to deal with him because they haven't been through it…I think a group, and something set up within the group so that the kids can sort of interact, and go out and do things…It's alright talking to some health professional about it but when they haven't been in that situation - they can offer so much advice, but there's nothing more they can do... But when you speak to somebody that's in that situation…"*
F33 - *"We got the play session once a week…it was nice to go because you met other parents who are in a similar situation. And it was a way, you were communicating and also discussing not your child's needs, but what you would access, what you had found good, relevant. It was mums talking… 'Try this' or 'Speak to your health visitor or social worker or physio about, see if you can get…'. And it was that passing of information through a little group…it would be nice to do that more often."*

The following parents describe how they have had to teach themselves to parent their disabled children:
F20 - *"Now he's finally got to the stage where; we couldn't even take him into places like Tesco's Café and get him to sit still…. We've learnt little new tricks of the trade that we think 'If you give him that to occupy him, or we give him this, he'll sit in the corner'… But we have nobody we can phone and say 'Look we're having this problem with him. We don't know what to do'."*
F26- *"Her sleep patterns were pretty bad; she would only sleep for four hours…that was quite tiring. Obviously…some behavioural aspects in the early days, that we just didn't know how to deal with, and nobody else knew how to deal with. So, we sort of parent intuitively, we just do what we think is right."*

Stigma associated with parenting - stigma is a common theme throughout the study, relating to various issues. The following cases illustrate the stigma associated with parenting:

A parent describes the stigma of parenting a child with behavioural difficulties, and the lack of understanding in communities:
"But there's no sympathy with the kids with ADHD. People just blame the parents, and say it's just bad parenting. But the other two kids are alright, so I can't be that bad. That's the way I look at it." (F2)
A mother describes the reaction she has received from others regarding attending parenting classes:
"Maybe it could give you some help… I don't think it's bad doing a parenting course…some parents probably think 'oooh…I've got to do a parenting course', but I think…every parent needs it…" (F8)
A mother describes insecurity about her parenting, and being seen as an inadequate parent:
"It gets me stressed then it makes me feel like 'what have I done wrong; have I done anything wrong with him; is it me or is it just him been him?' Or is it just because he's two or three; my head's just…" (F23)

Addressing parent's own needs - parents often described their own needs interchangeably with the needs of their children, suggesting that they felt that their needs (met or unmet) as parents have an impact on the family as a whole.

"I'd love to have someone to turn to and sort myself out…I feel my life's been a battleground…you are constantly addressing yourself" (F12)

"I can…come here…speak to other mums…A lot of the mums that I see around town, they look very alone; there's a lot of mums like that, that are struggling. Or the ones that don't look like they're struggling, when you know that they actually, maybe are…And, we all have those days…but just to be able to have a chat with somebody and vent off. Or, have a coffee and a cry or anything you know, just to have somewhere to go." (F24)

"As well as being a mum, you're an adult, you're a wife; whatever, and it's having my own personality. For a long time, I sort of lost that, and especially with having a poorly child, you are just a mum. You are not a person, you are just someone there who goes to the appointments and answers questions and follows guidelines from these people, you know, and it's very difficult." (F33)

"I am a single parent; it's hard to meet people when you have a disabled child…. I need to just have a week go lie on the beach and recharge my batteries so you're fighting fit again but when you're doing it daily daily daily … you forget who Emily is; I'm "Lucy's mum" you know, if that makes sense…" (F28)

(See the section in the report on "parent's childhood experiences" for some examples of how parenting has been affected by the way in which parents themselves were brought up)

4.1.6 Relationships, family breakdown and abuse

Family breakdown and domestic abuse within relationships has been experienced by a number of those taking part in the study, with negative **impacts** on parents, children, and family circumstances.

These mothers describe the impact of family breakdown on **employment and financial situations**:
F10 - *"By this time, me and Billy had split up; he couldn't handle it. He was a postman, couldn't stand the kids crying in the middle of the night…And there wasn't a lot of support*

from Billy whatsoever, so the arguments started to happen, and he left…. I went to see the manager [employer] and I said 'I can't do evenings anymore, because obviously he's left.' And I've obviously got Cara and Harry and Jenny, so I need to find a nursery that will take care of them, but day shifts."
F6 - *"Unfortunately I broke up from my ex-partner…. And I must admit the main element in the family structure has always been the lack of finances. It's been quite difficult struggling financially always, you know. Particularly when I haven't had any assistance from my ex-husband with child maintenance support…in all these years….I've had to live on benefits since we've split up."*

Others described the **impact on their children**:
F3 - *"But of course all hell broke loose… we had an affair, I kept thinking I was gay…My husband was quite jealous and possessive….In between it was all the heartache of the kids seeing me like that, hearing stories about me. I wish it could have been different, Katie was very angry…. But the two youngest were hearing all this."*
F9 - *"Me and him broke up…Abby was still only young…First of all…we were still living together for Abby. And that wasn't working out…And he didn't bother to see her at all to begin with. And she rebelled against that, she may have been a baby, but she knew something wasn't right…I was having a lot of problems with her….It got to the point one day where she was screaming "dad, dad, dad, dad, dad" …and literally I couldn't stop her…..So, I took her… and banged on his door, and he opened the door and burst into tears himself and just cuddled her."*
F8 - *"He wanted to live with his dad, but, see his dad's got a new wife, and he left me, because he got someone pregnant…now they've got three children and Tim's living with his Nan… and we're up here. I can kind of understand why he's… a bit all over the place, but he didn't want to live with me, so… it's his decision. I said "well I'm always here"...It's a bit sad in a way that…he had to make that choice.*"
F19 - *"Obviously I had a hard time and that 'cause…it was killing my kids….he [son] stays with me now, he won't go to his mum because she, that's bond's gone you know, that connection that they had, 'cause she up and went…And the effect it's had on him; his mum going away from him…it killed him. It destroyed him, and it still affects him now…he has got no relationship with her."*

F12 - *"[Social Services got involved]… when their dad left, they basically went wild…"*

These examples illustrate the impact of family breakdown on their **mental health, wellbeing, and ability to cope**:
F4 - *"I had ended up with what they call unexplained infertility and they ended up putting it down to the stress of the divorce and the custody battles, my body just shut off. I lost most of my hair, I got alopecia, my hair fell out and people thought I was having treatment for cancer and all sorts."*
F15 - *"I just turned to all the drink…I done exactly the same when Ryan left…And that was it; I went downhill. You know, and the girls missed him, 'cause when they came home and they said "Where's Ryan?" and I just turned round and said "It didn't work out." I couldn't go into detail and tell the girls exactly what happened, 'cause I didn't want to. It weren't fair on Ryan, it wasn't fair on me and not on the kids…The main one, who's gone without is Susie…in the future she's the one that will suffer."*
Even leading to consequences such as children being put into care (see also F5 and F15 below):
F14 - *"My mum and my step dad split up, my mum had a complete meltdown. She just went back to being some sort of kid…When we were younger…the three younger boys' dad…he kept us all together; he kept my mum….She drunk a bit, you know, but she was never, you know. But then, as soon as they split and he left… probably about six months before the boys went into care. It just went all completely downhill."*

Domestic abuse:
A mother describes her own childhood and the impact of family breakdown and domestic abuse on housing, and being put into care:
"She divorced when I was 13 or 14 from my step-dad and she lost her house in Abergele, couldn't afford the mortgage on her own. So we moved…which was like the end of the world to me because I'd been dragged away from all my friends…Didn't get on with my mum and haven't for years….When I was 10… put me in care for a year; she couldn't cope with me basically, my step-dad used to beat her and he cheated on her….then he told my mum he was leaving her so my mum had post-natal depression. She reckons that's why she did what she did with me because she couldn't cope."
Her childhood experience influenced her decision to remain in an abusive relationship:
"I was 17 at the time. Basically he was abusive as well, so I jumped out of the frying pan into the fire as it were. …I was with him for two and a half years in total; I stayed with him as long as I did because I didn't want my children to grow up without a dad because I knew what that felt like so I just really tried to make the relationship work, but there was just no way it was ever going to work." (F5)

A mother describes the effects of domestic abuse on her children, having lived in various refuges:
"It's been hard on them but they are getting used to it, I don't think they'll ever get over what he did to them…Shouting, swearing, calling each other names, calling Rebecca names, because the way she is; I keep trying to explain she can't help the way she is [has a disability]..." (F31)

Similarly, a mother talks about the impact of an abusive relationship on her child's behaviour*:*
"He's naughty in school as well, the teachers stop me every time he comes out of class, 'he's been naughty today, he's been hitting today, he's been squeezing someone today…'. … I don't teach him things like that. I don't let him see that… Because of his dad… mentally abused me when I was with him…and that's why I think he's like that, because he's seen his dad do it, even though it was a young age…they remember stuff.". (F23)

A mother describes the events that led up to her children being taken into care, and the effects on her children of choosing bad relationships:
"There's things her dad done to her when she was young, I wouldn't be surprised the way she turned out. I tried me best…I tried to be her mum and her dad, and you can't do it, it's pretty impossible… You've got one of them hitting you with doors in the kidney, and punching me and everything. Any wonder why, you know, her behaviour is all through her dad." (F15)

(See also "trigger/turning points", and "parents' childhood experiences" in the concepts section of the report.)

4.1.7 Poverty, money and benefits

The vast majority of families taking part in the study spoke about money and finances, the general theme being that they didn't have enough to provide fully for their families for various reasons and in various contexts. The majority of the families were in receipt of some kind of benefits, although this does not necessarily reflect the number of parents who were in employment (for example, parents may be in paid work but still receive disability living allowance).

Impact of poverty on families - the study provides some insight into the impact of lack of money on families in Conwy:

A mother describes the impact of poverty on her health:
"I was struggling because they had put me in a flat…it started off at £70 a week. And then they raised it…Ended up being just under £600 a month. I can't afford that…I went down to 8st 3lb…I've got photos. I look horrible, I look like a skeleton, but living off noodles, what do you expect?...And very, very cheap energy drinks 'cause I needed it for all the work I was doing, which…wasn't good for my health, either. And by then…I ended up…passing out and having fits, 'cause my body couldn't handle it.." (F9)

This family has experienced a complex set of circumstances surrounding financial difficulties. This quote illustrates their experiences of fuel poverty:
"The heating here, it's terrible. It doesn't keep my children warm, they're freezing…they're purple. The storage heaters go on…they're stone cold by six o clock at night…there's no gas up here….My mum had got me an oil filter, and we were all staying in one bedroom in winter…I was putting in between forty and fifty pound a week in the winter months for the storage heaters and I couldn't afford it….I've never had a stairs and a landing carpet here, I can't afford one. 'Cause even with working, I still had rent to pay, I've still got bills to pay, council tax to pay…" (F10)

A single mother describes her struggles with employment and debt:
"...I took out a loan with a local bank [to buy a car in order to travel to work]… it turned out I wasn't covered when I lost my job…so I couldn't keep up the payments. And …I ended up in quite a bit of debt then. It became like double the amount of what I borrowed. And then an accumulation of utility bills as well just crept up on top of me. I couldn't keep up with the high rates of electricity charges and gas charges…. I cannot stand debt ironically... But it all just crept up on me…and I didn't have the cash available to keep on top of it… So I did end up in thousands of debt, I'm afraid…" (F6)

A mother describes the stigma associated with being on benefits, and the frustration of feeling unable to improve her situation:
"Been on benefits for nearly three years and I hate it…the way people describe you. We're not 'bums', some of us do actually want to get a job. There are people out there who have kid after kid after kid and don't want to get a job, just want to live off the benefits. I don't. I'm hating every minute of it. Being stuck at home, not being able to do anything, just cleaning all the time, looking after my son, Now don't get me wrong, I love looking after him, but it's time I get off my bum and had a job or gone to college." (F23)

Systems for support - A number of the families shared their experiences of the systems that are in place to support them financially.

Information and advice are seen as key:
A mother describes her positive experience of receiving financial help and advice, and how more information would have relieved their situation sooner:

"I didn't even have a clue…because I've never done benefits before. Either me or my husband have always worked, and we've never needed to….I went to Citizen's Advice…for Tim…having Cerebral Palsy….We rent at the moment…struggling with the rent…and she was like "Oh, you need to claim disability living allowance"…And she did all the forms for me, absolutely fab…A couple of months ago somebody said that "Oh, because you're on disability living allowance, you might be entitled to housing benefit"…and some council tax benefit… So I've been paying all this money out for my rent for the last two years and then I find out that I'm entitled to about half my rent paid for." (F2)

A mother who has given up employment to look after her daughter with mental health issues describes her struggle with finding out about the financial support available to her:

"I think information about DLA should be more readily available and just benefits in general. A lot of young people just don't know what they're entitled to…I thought that was for disabled people, I didn't realise mental health people could get it. The psychiatrist was the only one who told me… When I went to the job centre they didn't tell me that...I've missed out on a bit of money there." (F5)

Similarly, another family described the isolation and confusion caused by lack of information about the benefits system and their entitlements (F7). However, this mother describes the positive effect of receiving good information and support with regard to money and benefits:

"My husband left me…I didn't know where to start with forms. I had to quit work because obviously I had to stay at home to look after the children…and …my rent was coming behind…one of my friends told me about a building…I could go and see some ladies about some benefit forms and stuff… And they said "right let's get these forms filled in"… she got all these forms out…housing benefit… income support forms and they all got sent off….otherwise I wouldn't have known where to start." (F8)

Problems with the "**system**" are described:

The lack of understanding shown towards parents with regard to disability living allowance:

"I think…employers and the benefits system understanding that it's not that we can't work…not that we don't want to work, it's that we can't work nine to five….It's an impossible task….If one of us did nights and one of us did days we'd never see each other...I understand there's a lot of people out there that cheat the system and…I know they want to get people back in work and everything else…But they don't understand. I think everyone should be means tested on what their situation is." (F33)

A family support worker describes the logistical difficulties caused by the benefits system:

"Kevin has been on benefits and then working, and on and off benefits. There's been problems with free school meals entitlement, going backwards and forwards between mum and dad ...because free school meals are linked up to housing benefit now, it's very difficult for us to intervene. In the past we could just have sorted that out…But now it's all linked up to Housing it's quite difficult." (F19)

A mother of a child with cerebral palsy describes the lack of incentive to seek employment:

"I've decided to pick up a job, it's unpaid, because I can't get paid with all the benefits and you can't work with Lucy's appointments…" (F28)

A mother describes the lack of support to improve the family situation through qualifications and employment:

"They don't do funding for those classes because they're part time. I think they do a ten week taster course which is something like £64.00…and the other courses are like between 400 and 500 pound. They said you can pay standing order. I've got a family though, and you can see we still haven't got fitted carpets….We're still at that stage where we're trying to get the home sorted and Christmas is round the corner, and you just think, I can't afford it." (F4)

(See the section on disability for more specific challenges around disability, money, direct payments and benefits.)

4.1.8 Employment

Closely linked to money and finances, the theme of employment also featured in the vast majority of the family interviews. In particular, families provided an interesting insight into the influencing factors on their employment, whether chosen or involuntary.

Parents' employment

A number of factors influence this mother's unemployment, having left school without qualifications, and a lack of affordable training to improve her prospects. Her lack of **confidence**, having been in an abusive relationship is also an important factor:
"I'd claim income support and I'd go in and I'd say "is there any way you can do…", and I just got "no, no". You weren't encouraged to go back to college, you weren't encouraged to do anything, it was all "you got yourself in this mess you sort yourself out" …I did look into it [getting work], but I wasted myself really…I certainly don't have the brains I had. But I really want to achieve something; I really want to go back to college… It's like that "what do you want to do when you grow up?" and I still don't know. I've obviously not grown up yet." (F4)

A mother describes her long struggle with **alcohol dependency**, and how this has impacted on her employment:
"I had to give up work… they found out I was drinking… I was handling it but it started to get out of control… they had to let me go….they said they had a reputation to keep. I understood all that, as upset as I was, and they were lovely…they felt awful kicking me when I was already down…. But I understood where they were coming from…they had their clients to protect…I loved my job…I wanted to go back [to] working with old people and I thought they're probably not going to take me back…I was honest; I told them the whole story…if you don't want me, that's fair enough…I have got a criminal record." (F3)

Finding a job in the first place is an influencing factor for families (parents as well as young people):
"And found it really difficult with the finances…at least I had a job…I look at it that way. It's just been difficult struggling on £5.93 an hour, with part time mainly as well…I do work when I can…For example, a seasonal job that's only lasted for so long. Been working recently again. You see, I'll take anything, even if it's temporary, seasonal, whatever, I'll do it. And then I'm back on benefits, then I find another little part time job, then back on benefits if it's stopped. That's how it's been going." (F6)

This family's struggle for employment relates to the challenges of **rurality and access:**
"Living in Llanrwst limits me slightly, especially with jobs, plus the language barrier…To be honest, really thinking of moving away, just to be able to have that opportunity to be able to work and get the job I want. Because you don't get a lot of money working in rural areas… and the buses… I can't drive; that's another problem…It's always in the back of my mind that when they [children] are older I can do it, but I keep putting it off and putting it off…" (F24)

This mother describes a complex and **difficult situation at home** and her duty towards her children, despite her desire to work:
"Over the years I did various college courses to better myself…I didn't want to be another single mother, you know living on a council estate and doing nothing else…I had to give my job up last October…when Jessica took an overdose I went off sick for three months and in that time my employers were horrendous with me…They knew what I was going through because I was having to go to court to get injunctions for my daughter to keep him [father] away… They also knew I'd worked there for three years and I was a bloody good worker….I want to go to work now but I can't 'til she's better." (F5)

A mother describes her **choice** to spend more time with her daughter despite the stigma attached to not being in paid employment:

"And money is a bit of a tight one, but I'd rather, this is going to sound bad as well, it's not meant to be. I'd rather have more time with my daughter… and be on a little less money, than be on loads of money and have a daughter that I don't know….it's a hard thing to explain, but I know my daughter a lot better now that I'm not working than when I was." (F9)

A mother describes her difficulty in accessing employment with lack of transport and **children at home**:
"I'm just hoping the workplace will be a bit more flexible…I have to go and look for a job…I don't mind travelling…but they're talking about ages away…a couple of bus rides… I've got children at home. I can't expect my eldest daughter to take full responsibility….you know to have babysitting duties from 6 o'clock onwards because I can't get home until 9…I've always had a job…but now it's a bit harder because you go into [a] job interview…you can see their face change straight away as soon as you mention kids, it's like "oooh, liability"." (F8)

A single mother describes **flexibility in the work place** as an influencing factor in her ability to remain in employment:
"I still continued to work, I managed; I had to change my shifts at work. I went to see the manager and I said "I can't do evenings anymore, because obviously he's [father of children] left." And I've obviously got Cara and Harry and Jenny, so I need to find a nursery that will take care of them, but day shifts. And my boss was absolutely amazing, 'cause I'd been there five years, and she was brilliant. She gave me nine thirty 'til two thirty shifts, four days a week." (F10)

This example of **lack of appropriate childcare** (in this case for a child with disability) reflects a number of other families' experiences:
"It's just always ongoing it's a fight, fight, fight…now I have to attend this 'focus' thing for income support, it's a joke….you find me somebody that will look after my child in the holidays, a disabled child; I'll go to work. I'll go to work full time, I will pay my rent, I will pay my council tax, I've done it for years, I've done it all my life….I phoned every single one, and there is not one that will supply a one to one support without a government grant to pay for it and they won't do it." (F10) See also F33 in the children with disabilities section)
Other families expressed the lack of and cost of childcare as a disincentive for parents to return to work (F7; F22).

The following examples provide an insight into further issues and challenges faced by parents of children with **disabilities** (or being disabled as a parent) regarding employment:
F2 - *"I can't go to work because he doesn't sleep, so I don't get much sleep. And sometimes if he refuses to go to school… If it wasn't for Damon, I'd seriously be considering [returning to work] now. My youngest is 10 and goes to high school next year, but… he's got so many medical appointments and all the rest of it, I'd rather just concentrate my time on looking after him at the moment… he's never going to get out of it, but he's going to get older, and he's going to be able to deal with his condition a lot better [than] what he can now."*
F32 - *"I'm an accountant...Huge problem with a child with health problems, or just disabilities…I've never experienced an employer who's had a problem with it. I have a problem with it, because of a duty to my work and my work colleagues… The number of times I've been called out of work for, especially in the summer holidays…it's the stress and the tension of it, actually just getting out of the house in the morning. And switching off and switching on…because there's always the health issue in the background, and then there's the behavioural stuff, and the practical stuff…We've had to make it work for us, but it's been to the detriment of things like career progression and pensions and stuff like that….I cut off at a certain level because I could only really ever be the person that actually had to leave at twenty five past three…there was no point in me having a job that I…couldn't do properly."*
F1 - *"I'm not working at the moment due to a disability of my own...I've had three lots of back surgery…I do still feel very isolated at home… My life has totally changed…just don't know which path to take in life anymore**…**I've trained in a lot of holistic and beauty therapies but I*

can't use them…I can't stand up…I'd have to be retrained in something, but then it's sort of getting in there…"

Young people's employment:

A mother describes the importance of **parents' influence** on their children's attitude to employment:
"It would still be nice to have something for me, for my children to be proud of me. I don't want to be the mum that didn't work… I find that if parents don't tend to work, then the children follow in suit." (F24)

A sibling describes her brother's **motivation** to improve his situation despite a complex and difficult background, and having been in care:
"You know, but he's always been one of these…that wants to do better than everyone else. He doesn't want to be a stoner sat on the dole, you know. That's not a very nice way to put it, but it's the only way I can think of." (F14)

This example demonstrates the importance of **confidence and encouragement** for young people:
"He's had careers come in, and he wants to go into the army, but they told him he's a liability [because of disability] and it's not the best thing they could have said to him….So he came out of that and said… "My life might as well be over…because if I can't do the army then I can't do nothing else"." (F30)

A mother and father discuss their concerns for their son with autism and his **employment prospects**:
"It's difficult with Keith because he did get a job… we just couldn't get him to go; he was making any excuse. He'd go anxious about it… We physically had to make him but you can't do that, you can't make someone go. We couldn't get him motivated to go… That's a big thing: confidence. People were saying… "is he a bid odd?" 'Cause he never speaks and he won't speak until he gets to know somebody. He started to feel really uncomfortable with that and that's why he wouldn't go." (F12)

4.1.9 Drugs and alcohol

Misuse of drugs and alcohol were discussed by some of the families taking part in the study. Most of these described the trigger or circumstances surrounding the issue. For example, drink as a way of blocking out difficult circumstances such as a partner leaving, and children being put into care (F21, F15 and F14); drug dependency following a bereavement, and partner being sent to prison (F16); peer influence and getting into the wrong crowd (F9, F12 and F13); and boredom and lack of provision for young people (F12).

Case study - one mother shared an in-depth story of her experiences of alcohol dependency. The following extracts illustrate in particular how this affected her children and family (F3):

“I was in denial, and I know I’d hide my bottles and pretend I hadn’t had a drink when I had…A lot of the nights I spent my time alone in this house…I got done for drink driving when my grandson was christened and I couldn’t go… “I can’t believe I’ve missed my own grandson’s christening because I chose drink” and I flipped over the edge then I wanted more drink….The kids were talking to me and I couldn’t go and all I did was drink…I didn’t phone anybody, wouldn’t answer the door, I just locked all the doors and I hid and just drank myself to a stupor.

…And then the kids would call and see I’d had a drink so they wouldn’t stay. Other times I’d promise myself and text and say I wouldn’t drink as much today and make them tea... Some days I’d keep to my promise other times I didn’t, but they never actually found me in the ‘diggers’, I’d always be drunk and cuddly and over the top and they wouldn’t like it. So the days they didn’t call, “oh no Mum we're not coming to you for tea, we're coming straight home to dad”, that will be the breaking point for me…crying and thinking “what have I done to myself what have I done to the family?” And then the bitterness would come and the anger and I’d think “…I hate everybody, why have I ended up like this?”...

…It was just like I’d lost the plot or something, even after I left Gareth [children’s father] and I’d drink heavy I didn’t even want to know my friends, the drink was my friend and that’s all I need….

At first the kids were like “oh go on then but you can only have one or two”, but eventually it was like “if you touch a drink, mum, we won’t want to know”. But to me I was still very lonely, I was still on my own. The kids still wouldn’t come back properly so it was still my rock if you like....

…When I was sober or hadn’t had too much to drink I was okay, still the loving mum, but never angry or horrible with them. Sometimes I turned on Katie because she is the oldest…. So I used to say to her “you’d be better off leaving me alone if I’m drunk somewhere get somebody else to come get me…” because it would wind her up seeing me like that and because she’d be aggressive I’d get aggressive…

…And in between it was all the heartache of the kids seeing me like that, hearing stories about me. I wish it could have been different, Katie was very angry… the two youngest were hearing all this…they must be thinking deep down “but it’s my mother, I love her”…It’s the same with those abuse books… they still love that mother, they still love their father even though it was them that did it to them and was cruel to them.

…I don’t know why I even did…I can’t really answer that properly, only that I wouldn’t wish it on anybody and I’d never want to go down that road again, and that’s why I chose never to touch a drink….

…It would have been probably a hell of a lot worse if I had nobody….If Gareth said “you can sod off after what you have done to me”, I don’t know where I’d be today...I’d be dead and buried by now. Or still be drinking, in a gutter and homeless probably.

…In my heart now… it’s probably safer not to touch it and for my family’s sake, my kids’ sake, I think they’d be absolutely heartbroken if I picked up a drink now.”

4.1.10 Communication and information

A recurring theme throughout the study has been the lack of information provided/available to families, and the lack of communication between services and agencies.

Phrases such as "*I've just had to work that out for myself*" (F31); "*you're having to try and figure it all out for yourself*" (F22); or "*if you look into it, you can find it*" (F33) were often used by parents.

Parents described how they acquired information through friends, family, and neighbours, rather than through professionals for example:
F10 - *"There were so many things that I found out through other people, that I did not know….It's as if the information's not out there and you're not told how to get help. I've looked myself…. it should come from professionals."*
F33 - "*The problem you've got is there's nobody out there tells you what's out there, it's only when you talk to somebody else and they go "Oh do you know about so and so" and you go "no" and then it goes on from there."*

Some parents received information through professionals, but more by accident than by design. They felt that there should be a better system in place for where information comes from:
"*The DLA thing, I knew about that, but I thought that was for disabled people. I didn't realise mental health people could get it. The psychiatrist was the only one who told me that, nobody else did. When I went to the job centre they didn't tell me that. I mean they should have, shouldn't they?"* (F5)

"But obviously you know if there's a parenting course going again for the over 11's I'll go, but I have to be referred… I felt a bit out of place asking to be referred…maybe the school should know. I mean obviously they've got people that work for the council, that come into the school…or you should be able to…phone like… somebody…in the council…and say "do you run a parenting course? If so, when's your next one starting?" " (F8)

Families also expressed frustration with the timeliness of information:
F27 - *"Everything we've had, we've had to find out ourselves and its notorious…. People have been very supportive once I've found the right people….We've found the social worker…she's been great and excellent, but it's finding out the right people straight away and being able to get things straight away."*
F32 - *"I think the worst, the most difficult thing about having a disabled child is, if I was starting out now, I would be absolutely brilliant at it, but it's taken me sixteen, nearly seventeen years, to get a handle on things and…when I needed to know, I didn't know….. And I suppose the earlier, the younger the child, the sooner you're made aware of… where to go or what there is, the better."*

Generally, parents felt that there should be one clear source of information available to them, although views differed on how this should be provided.
"We'll chat, perhaps some of the parents and we'll mention something and somebody will say "I've never heard about that." …It's because…provision is coming from different agencies, or different sources, so there needs to be…a central sort of font of information. Whether it's for benefits, you know, recreational stuff, whatever…A sort of a handbook…I mean, we do get information from different places…it's sometimes difficult to sift through it all…I suppose really the best person to… dispense the information would be a social worker. But that is if you've got one, and if she has all the information." (F32)

"*Sometimes when you have a child with a disability, you don't know where to turn, and maybe you do rely on other people to tell you. But, wouldn't it be great; problem child, got a problem, phone this line. …I would have given my right arm for something like that."* (F10)

"Having a directory with everything together, or maybe a brochure that you get given when you have a special need…This is what you may be entitled to with regards to benefits, speech, language or occupational therapy or health…have you thought about this, have you applied for this, what other things might be available…" (F27)

Communication and cooperation between services and agencies

A mother describes her views on how services could work better together:
"It's tricky sometimes because you feel like that [social worker] would be the best person to know everything and guide you with everything. It's a shame really that the social and the education and health are kind of not all together, if you know what I mean. Sometimes they have to refer you to other people and to other people…" (F27)

A mother expresses her frustration with an inefficient communication system between a housing association (to gain adaptations) and services for children with disabilities:
"He [disabled son] had four head injuries in the space of less than a year….I phoned up [housing association], I said "Could you come" because they had concreted the wall that much that the stones were sticking up. They said "no" - I had to contact Social Services and his doctors and they had to all write a letter …And they wanted a hospital letter, as if I was lying." (F10)

Where agencies do work together, this mother describes the approach as overwhelming:
"Everybody we've had contact with has been absolutely marvellous….I did get to the point where I wanted to be left alone with my baby, he's just a baby he didn't need anything…Now is when you need the involvement as things are developing…. There were an awful lot of professionals from various disciplines involved and I really did feel it was just too much….It was very well organised…the multi disciplinary meetings were just too much, every six months... Why, they all work together, they all knew what the other was doing anyway…it just felt like a complete waste of their time and money." (F25)

This mother describes a positive outcome from a multi-agency meeting about her daughter:
"She held an emergency meeting …where the police were invited and lots of other agencies were invited for me to say I was basically feeling let down by the whole system….And the result of that meeting was to have a child protection meeting…all the different agencies said what they thought, the school - what they were going to do to help her, what I thought she needed, what the social worker thought etc so there's a care plan now..." (F5)

A mother and father describe the need for better cooperation between services with accessing suitable equipment for their disabled child, for use in the home and the school:
"There's no communication between services, the schools, nobody talks to each other…There's politics going on about his wheelchair… I haven't got a clue, I keep trying to ask these people, they say…"not me, ask her"… We try and keep informed about everything that's going on but we're not getting it back…Just basic communication….Said to the [Occupational Therapist] "look can we all get together and have a meeting?" and he said "No, I'm here for you at home, I'm not here for the school"." (F30)

These parents describe the importance of understanding professional people's various roles in a multi-agency situation:
"When you're… being told your child is not well and they start telling you about physiotherapists and occupational therapists and all these people…it's understanding what their roles are…having a little booklet…a bit like a dictionary of professionals…who can do what, and what their service entails…But when we we're accessing everybody, you know speech and language, all that sort of thing, it's great to know…like a job description…you can go "Ok, that's what their role is, that's what they're coming for, ok, I can cope with that." And it's having that forward knowledge..." (F33)

4.1.11 Children with Disabilities

A high proportion of families who took part in the study had children with disabilities. Some of these families were targeted to take part in the study (through Social Services) because of the strong emphasis in the Families First project, but some of those who volunteered to take part in the study through an invitation also had children with disabilities. The sample represents children with physical disabilities and learning disabilities, and families from various socio-economic backgrounds.

Despite the wide range of circumstances described by these families, there were some clear common themes between them.

(Further themes relating to children with disabilities have been referenced in other parts of the report; for example, housing adaptations under the housing section, mental and emotional health, benefits, communication and information, employment, and education and learning. There is a vast amount of material and data on children with disabilities available in this study, with potential for further analysis, and further research into specific themes.)

General experiences from diagnosis through to provision for children with disabilities

A mother describes the lack of support and information during the process of diagnosis:
"Started to notice a change when he was about eighteen months…It was like taking him out of his own little bubble…as soon as I started taking him to the nursery, he was kicking off…screaming all the time. He refused to eat…I had an inkling that it was autism, but it was too early to diagnose…Didn't have a social worker, that didn't come in until a lot later… I didn't know what to do…Eighteen months later…I got official diagnosis of autism, and I was very pleased, because in which time [we'd had] no support whatsoever...nobody told me what to do…to look on website; take this leaflet; have you considered this; nobody called me. I did it all myself…I got it all off the internet." (F10)

A mother describes a positive experience of support and information during diagnosis and beyond:
"He's got four diagnoses. He's got ADHD, conduct disorder, anxiety disorder, and he's got problems with cognitive behaviour….He's been with CAMHS for 9 months…absolutely brilliant, they are fantastic…They've done every assessment going on him, they know exactly what's wrong with him, you know, he sees him once a week, which is brilliant..." (F2)

A family with three sons describe the differences in their experiences of diagnosis (improvement):
"[Older son, at 20 years old] went to see people…off his own back…he got so bad he was talking about suicide a lot…they said that they thought he has Aspergers….We don't know where to turn with it…If you have three boys in the household with the same thing, and each thing manifests differently…how can you pick at…which is the…supposedly normal behaviour…[Younger son had a] sessional worker…to do with the way he was behaving in school…who picked up the Aspergers….he said "well, what do you think about smoking?", then she said to him, "look, we'll cross that bridge when we come to it", and then he goes…"where is the smoking bridge?"... She picked that right up, and that's when it started." (F12)

A mother describes their proactive approach to searching out information and various therapies, and how the information provided at the stage of diagnosis could be improved:
"I think when they're first diagnosed a bit more help would be nice…I know you can't say your child's going to get better…but it would be nice to look more on the positive and say "you

know you can do this, you can do that", just different things that might be available that we could pursue…They could do with the information being together….When you are first diagnosed it's enough just to cope with the diagnosis then you've got to think about what's going to happen after…" (F27)

A mother describes being overwhelmed at the point of diagnosis and that emotional support would have been beneficial:
"I just think support for the parents… you have the diagnosis and then all of a sudden you have physios, you have an occupational therapist, you have speech therapists, you have social workers and all these things are thrown at you. Maybe it was available for me but because you don't think at that time, some kind of grievance counselling to help parents understand." (F28)

A mother expresses her disappointment with accessing consistent support (for example, emotional support, young carers support for siblings, information, and access to specialist equipment) – this quote illustrates one aspect described:
"Wanted me to attend the development centre by myself…Harry will not go on a bus…he will just scream and scream… He won't go in his push chair."…He missed quite a few sessions and I was angry…they were trying to blame me…They wanted him there at nine thirty… "Well, Cara doesn't go to school until nine o clock", which I have to walk up a massive hill, I have to carry Harry up, because he wouldn't go in his push chair…I wouldn't get there until quarter past, half past ten…. it was very complicated." (F10)

A parent describes her frustration with an inefficient system for providing specialist equipment:
"*One of the most difficult things as a parent to understand is when someone says " your child needs a piece of equipment…Social Services and Health are going to provide it…the rep will be out in six weeks…that's the earliest they can come"…We trial this piece of equipment…it's got to go to panel… "just missed the panel for this month, you've got to wait another month"….Then got to go to finance, and then it's got to be ordered, and then it's taken six months….By the time that's elapsed, your child has grown so they're only in it for six months…If that could be made quicker and easier."* (F33)

A mother expresses her frustration with the gaps in provision:
"But there are so many different things out there to deal with disabled children and sometimes, certain groups get short changed because there are so many different categories. You know, she's never been considered for the Hope House stuff because she's not terminal. And yet she's never going to get better, she's never going to be independent, so she falls through. That's frustrating." (F26)

The issue of transition from child to adult services is expressed as a concern:
"We are coming to a very difficult period…everything stops at age eighteen, but school doesn't. So we are going to have…an eighteen/nineteen year old schoolboy with nothing…He becomes an adult and so all the children's services are closed to him at midnight the day before his eighteenth birthday… They're the same young people that they were the day before…We're in transition…He hasn't been allocated a new social worker…there should be a handover period…That's almost impossible to explain to young people with learning difficulties, why…something stops; it's meaningless to them." (F32)

Respite was mentioned by most families with children with disabilities, with the following themes emerging.

A mother describes her frustration with the lack of respite, and the difference it would make to the family:
"Respite…has been mentioned over and over…it never materialised…It's the holidays, when I've got all the children at home. And I've got Jenny, who wants to go clothes shopping, she's a teenager, she wants to go out with her mum… she wants to go to the pictures... I've

got Cara "I want to go to the park"; "I can't go to the park…because of Harry"…I've got no one to take her" (F10)

A mother describes the positive effect of respite on the entire family:
"Our son has a place at the fantastic respite facility…The positive effect that it had is like an enormous boulder going into a pond that ripples out, it has affected every member of our family indirectly…because it's enabled us to do things. It's recharged our batteries; it's been the most wonderful experience for our son…you just can't really put a value on that, especially because we don't have a great deal of family here… It's been fabulous." (F32)

This family describes their choice to use direct payments for getting one-to-one help for their autistic child at home, and how this is more suited to their situation than respite:
"Direct Payments is by far the best use…She gets used to one person, she gets quality time, she gets time at home, but we can actually rest or we can do other things knowing she's safe…It's far better than respite care because she's so poorly I have to give her medicines, I have to keep an eye on her, and she pines when she's away from me…It means we get a break knowing that somebody's with her but we're not away from her and I don't get worried…Daniel [partner] and I can talk to each other, do stuff with Juliet [younger daughter] and give her more of a normal childhood." (F27)

Some of the families described logistical problems with direct payments and respite; for example,
F28 - *"I have no immediate family support. We were offered three hours through the direct payments which my auntie did. Then my auntie retired, she was a Nurse in St David's hospice and I advertised; and you have to tax and national insure these three hours, so who would then be employed for three hours a week, as a second job, only to receive half of the money. So we jacked all that in, not worth it."*
F30 – *"He is meant to have respite…He absolutely hates it, as soon as he goes…it is a really good thing that they do…it's such a nice place…[But] there's no point taking him out of his routine to get him upset there….They say to us "if you don't go you won't get offered it". We feel we have to go….I'm on absolute edge when he goes every time…It works for some people and it doesn't for others."*
F26 *– "The direct payments enabled us to find somebody…that would mean that we could do things with Camilla [other daughter]. That worked fine for about four or five years…she loved it, and they were super. That's finished now because the lady's had to find a different job and hours. Once Rhian went for full time, she lost her hours for direct payment, and the lady who helped her, couldn't afford to lose so many hours, and was in the middle of juggling jobs and had to basically step down this year*."

Impact on money, finances and employment

A father describes his decision to halt his career progression as a school deputy head in order to care more effectively for his disabled daughter:
"I went to my head…said "I'm not doing as good a job as I want to do…I'm going to have to step down… the one thing that is going to be the constant is the fact that I've got a disabled child…It was nice to think you can climb the ladder, but it was too hard for us to balance all that…wasn't worth the pressure on my family…my children are the most important thing in my life…more important than my career…Everyone can go to work and worry about their kids, that's life. But if you are a carer…" (F26)

A mother explains the need for flexibility, including home schooling:
"It's more cost effective for us to be at home for her…we can be more flexible with her, she can have a rest if she needs it, and we can concentrate when she's well because her pattern of pain is so erratic. She was good for three hours yesterday so meant you could take her on a boat trip…go and spot the birds, do some exercises…But if she was in a school setting you have to fit in with their times." (F27)

Parents describe the impact of having a child with a disability on their finances and employment:
"It just came to a point that the day nursery couldn't cope…because of her epilepsy and feeding issues. I had to make the choice to give up work…I lost £1000 a month. And you're still having to pay your mortgage and go to all these appointments…and live and survive...In some ways physically we can work; mentally we're elsewhere because you're thinking of the medication she needs…you've been up half the night with her….You've got all those things that are going to impact on the next day…If you've got a job that's quite stressful as well…we've got enough stress at home, you don't need that." (F33)

(See the section on Employment for further examples.)

Impact on siblings was described by a number of families:

A mother describes the isolation experienced by her children because of their siblings' disability:
"She became very isolated…she grew up very quickly. She started to do things for herself, because I always had the babies….I have other children, they're all on the back burner. These poor kids…all her friends are going out to parties; she couldn't have no friends here…no sleepovers… she's a very quiet girl…I'm so glad, now she's twelve, she can start going out herself; she's had no support…" (F10)

A mother describes the impact on her older children, including embarrassment by their sibling's behaviour in public, disturbance when trying to study for their GCSE's and A Levels, and that they have never had a family holiday. Despite this, she describes how they have responded:
"It's a completely forgotten group; the brothers and sisters…The elder two…have got a huge capacity for understanding, patience, waiting their turn, not getting stressed out. They have to learn things…it stands them in good stead, but it's a kind of hard lesson to learn when they are younger." (F32)

This family describes the difficult decision to have a second child:
"It took us a long time to decide whether to have her sister…they've got a lovely relationship together… but it's been a struggle…Juliet has had to grow up a lot quicker than she should have done, but it's also meant she's… sensible, she's only four and a half but she does act like the older sister…It's not a bad thing for her to have to see people struggle….Things will get trickier as she gets older…because she can't do something or have friends to sleep over…" (F27)

Some families described the frictions caused between siblings because of the perception of favouritism and being pushed out, for example:
"I just want them to get on….Polly is picking on Rebecca, she doesn't get the way she is….I can't help her, I can't say it's not her fault and it's not my fault either, you know. She keeps saying Rebecca is my favourite, but none of them are my favourite, I treat you all the same, that's what I try to do." (F31)

(The section on Respite includes examples of the positive impact of respite on siblings)

Parents' fears – many of the families discussed aspects causing them fear and anxiety.

A mother of an autistic child describes her fears for her children's **safety**, as well as fears for an unpredictable future:
"He might be one of these children who's not going to improve. Nobody knows…He might be like this for many, many years, and I'm prepared for that…He'll always have this condition… but if he doesn't improve, my fear is going to be when he gets bigger…the

violence, and then I'm going to be scared for the girls, 'cause he attacks them now…how am I going to deal with that?" (F10)

A mother describes her fears around **making decisions** for her disabled child:
"The first big, big decision that you have to make…is what school do they go to when they're five;…We got it terribly wrong… I'm facing this same problem…and we are at the same point with further education, and I am worried in case we make the wrong decision." (F32)

A mother describes her **fear of letting go**:
"…Even though she's older and she's still stuck in baby mode…I was treating her like a baby, but she's twelve. I can't keep wrapping her up in cotton wool and she's got to get away from me a bit, because it's not healthy for either of us…And the main worry about her is basically if she gets any illness or what's going to happen to her when I get old?" (F29)

Representative of other families taking part in the study, this father describes his fear for his disabled child **when the parents are no longer there** to care for them:
"The elephant in the room, the unspoken thing…my nightmare, is "What's going to happen when I'm not here?"….There is going to be a point where I'm too old to help her physically…she will never be independent...And as a dad…the wee small hours if you wake up, that's the thing that is in your head is; 'One day, I'm not going to be here, and how will she cope with that?' and 'Is it fair for me to lay the responsibility on her sister?', which we've never done, we've never actually made her sister be a carer….No one is going to care for her as much as we do…no one is going to love her as much as I do.
…We don't want to waste anything…give her as much and enjoy as much…I'm hoping that she develops her life skills…You just realise how frail your life is." (F26)

On the other side, this mother and father describe their fears about **losing their child**:
"As she gets older, not only is it going to get harder, but she's going to get poorlier…She's never going to get well because of her condition…We know we haven't got her forever and that's hard, but we are going to keep her as well as we can for as long as we can. But it's still the emotional side, nobody wants to lose their child and you don't need the extra stress of people, through…lack of understanding and training [saying] "well you can do this"; "no, I can't, my daughter needs me and I want to spend as much time as I can with her while I can"." (F33)

Fears about the **unknown** also affect parents of children with disabilities:
"But it is frightening when anybody get's a diagnosis like that [autism]…You wonder "what the hell am I going to do?"…and how it's going to affect your life…I don't know what's going to happen for her, post 16…maybe thinking of something to do for her life. But those things are far away from us at the moment and I only tend to think of today because things change so fast… you have to be hopeful for your child …You know she's never going to get better but I think she needs to be the best she can be." (F27)

A seven year old with cerebral palsy joined the interview with her mother, and describes her fears about her **future in secondary school**:
Mother: [Operation] is not going to help her walk…but it's to help her be more independent. Every child is entitled to be independent as possible and when they go on about costs and stuff…I just said to him "she's seven now, she's in nappies, give her this operation and she can make herself go to the toilet"…when she's fourteen in secondary school, still in nappies, it's just not fair on her when there's something that can be done

Daughter: When I'm in second school I will be a baby

Mother: No, you're not a baby now

Daughter: But I will still be in nappies, won't I? (F28)

Stigma associated with disability - most of the families of children with disabilities taking part in the study spoke about stigma in one form or another, whether this was associated with their own reactions, perceptions, and attitudes, or relating to the response that they have had from others.

Internal responses:
A mother describes her first reaction to finding out that her child had a disability:
"The one thing that I wish would have been there more is the support when I found out that Lucy was disabled because I went off…I was shouting at random people in the street, I was grieving, I'd lost my healthy child and up until two years ago I wasn't able to do anything on Mother's Day because it was always the day I lost the child I should have had… it was a really sad day for me" (F28)

Parents describe their perceptions of disability:
"It's not 'til you have a child with a disability, that you start seeing this, because we all want the perfect family; the 2:4 children and when it doesn't happen, not only is it a slap in the face but you think 'What do I do with them?'" (F33)

A father describes his aversion to needing help:
"People who work with [families of children with disabilities] need to know the emotions involved. That most people don't want to be in that situation, nobody wants a disabled child, nobody wants really to ask for help in situations, and most people don't really want you to give them stuff. Well, I don't, but I suppose some people do. We don't want handouts from anybody" (F26)

A mother describes the process of accepting the situation, and her perception of receiving help from Social Services:
"There probably was help there I just didn't ask for it a lot of the time in case people thought I was weak and I am a bit stubborn…After a while you try and accept the disability, but it takes years to see that she's not going to be like everyone else…When the social workers got in touch I was a bit dubious, I didn't want to talk to anyone…I was thinking if I showed that I'm weak… they'd want to take her off me but it was the complete opposite really." (F29)

A mother contrasts her own attitude towards seeking and accepting help:
"I still would still like support…I feel like I'm crying out, I feel like I'm screaming at my lungs "Please." …Some of these people that say "I don't want Social Services"; I want them…I want the phone calls, I want the knock at my door; "Hello, how are, how's your son? What's going on? Do you need help?" …Because I've never had it. I haven't had it from one six months to the next six months…" (F10)

These parents made a conscious decision not to be defined by the fact that they had a child with a disability:
F33 – *"As well as being a mum, you're an adult, you're a wife; whatever, and it's having my own personality. For a long time, I sort of lost that, and especially with having a poorly child, you are just a mum. You are not a person, you are just someone there who goes to the appointments and answers questions and follows guidelines from these people, you know, and it's very difficult."*
F28 – *"I didn't want to become one of those mothers who just have friends with disabled children"*
F32 – *"I tried very hard not to define myself in terms of him and his difficulties, because I think you can turn into quite a miserable person with a single theme. So, I suppose one of my coping mechanisms has been in public, when I, to the outside world, I will tend to describe the funny side of life, rather than the sort of difficulties."*
F26 – "*I've always tried never to use my daughter or her condition as an excuse…Jade will not tell people that she has a disabled daughter…she will not show that weakness, whereas a lot of people use it as the biggest excuse they've got…we have not involved ourselves too*

much in being crusaders for stuff….she's not a bargaining tool…We're not going to open our arms to the whole world of disability, we have to focus on our job…"

External responses:

Parents describe their frustration at society's ignorance around disability, and the need to raise awareness:

F33 - *"People…don't see them as people or children; they're someone to stare at…You get a mixture of looks, …this is the 21st century…we're all equal, why shouldn't I take my daughter for a walk round town without you gawping at her like she's a freak show?…There is still a definite lack of understanding about…disabilities out there…Until it happens to you, you don't realise…I think because there's nothing out there that we can access, people aren't taking their children out, so people aren't used to seeing these children out for it to become a part of society…So it's that vicious circle that needs to be broken…"*

F32 - *"A lot could be done to make other young people…normal children…aware. The younger children come into contact with children with disabilities, the easier it is…for them to form friendships and understanding which will stand them in very good stead in later life….If somebody's 13 before they have somebody in their class who's different, then that is just ripe for bullying and misunderstanding …Younger kids; they've got huge capacity for understanding, and they don't see it as odd or strange."*

F30 - *"He doesn't like to stand out…he knows that he stands out…he could walk into school and there could be loads of kids looking at him…and he'll smile and put his head down and walk….I used to get cross people staring at him, so I used to hold his arm or hand next to me"*

Parents describe their struggle with feeling judged by others:

F20 - *"Taken him to Tesco's or something and he's playing up…you get people looking at you, and I think "I shouldn't justify myself to you" but you feel as though you want to say "Sorry, but my child's got behavioural problems"."*

F10 - *"He tried to call me an irresponsible parent for not keeping a better eye on him…I am not an irresponsible parent…He's a grown boy…am I meant to chain him to the floor, so he doesn't move, like a dog?... You've made me feel like I've got this awful child that can't go anywhere…"*

F26 - *"People make assumptions about her and make assumptions about us. Things like the motability car…we've got one because she can't get anywhere…we just have an estate car. And it can get a wheelchair in if we needed it…we don't abuse the system. It annoys me that you can be tarred by somebody because they have abused the system….But, we would like that little bit of respect back, the respect that you've been here, you've been doing this for seventeen years. You know, you haven't turned to drink and drugs, you know that level of respect."*

Parents describe the labelling that happens in society, and how this affects attitudes towards disability:

F10 - *"Nobody round here…know of his condition…they used to just think I was rude, they didn't actually understand the fact of the matter that I had a son with behavioural, very bad difficulties….They didn't come and knock my door "We don't see you, is everything all right?"…They do now, and that's only because since Harry goes to this special school with a special badge that they realise "Oh, yeh she's got a boy that has autism and other difficulties." So, they must have thought I was a bad parent."*

F26 - *"We had one run in with [county] because they blanketed the children under this 'children at risk'… Our daughter isn't at risk…But more than that, she wasn't really a child in need, she was a disabled child. I'm not too hung up on PC stuff, you know, my child is disabled. It's not her fault, but she is. She's got a visual impairment, well; she's blind. Sometimes, you have to be blunt to get the message across."*

4.2 Concepts: families' reasoning about their experiences

A number of interesting concepts have arisen from the study, which don't necessarily fit into one service area. These are overarching concepts which provide some useful insights into questions such as "why" and "how".

4.2.1 Crisis or turning points / triggers (and intervention/prevention)

The language that families use to describe their situation or a course of events can be extremely revealing. A number of families taking part in this study have identified or reflected upon a turning or trigger point in their circumstances which has either changed things for the worse or for the better. Phrases such as "it all went downhill from there" or, "that was the turning point for us", "that's when the cracks started to appear", "since then…" were used frequently and often unconsciously by families as they told their stories. This provides a useful insight into the role and importance of intervention and prevention.

The following examples demonstrate the various points of crisis or turning points. Some families, as they describe, reflect upon what was useful, or what might have been useful at the time of crisis (or previously) to prevent their situation, or as an intervention to help them through it. These reflections are included in the examples.

Family breakdown:
F9 - *"Within a month or so they managed to get me into [secondary school]. I was there for about six months, but I ended up having lots and lots of panic attacks and wasn't in there much because of them. I think that's probably down to the pressure of my parents breaking up and everything, 'cause I took it quite hard. And then I decided I didn't like that either, and refused to go back there."*
F8 - *"It was when my daughter was… only 2 months old, my husband left me, and that was a real struggle, because, I didn't know where to start with forms, I had to quit work because obviously I had to stay at home to look after the children, and I thought "…what am I going to do?"…My rent was coming behind and everything… Somebody… told me about a building…I could go and see some ladies about some benefit forms and stuff, so I just went in there and said "my husband's left me", I said "I've…had to quit work and I don't know what to do"."*
F15 - *"When Ryan left, that's it, I went downhill. And the girls missed him because when they came home and said "where's Ryan?" I just turned round and said "it didn't work out". The main one who's gone without is Susie. Three and a half years in the future, she's the one who will suffer. Since Ryan's come back I weren't drinking but he's come back and everything's changed."*

Bereavement:
F3 - *"A lot of my friends say because of the abuse… and you know settling down too young and rushing in to marriage and falling pregnant quick, then losing a baby; and maybe it's just built in my head over the years of trying to keep it secret and not having counselling for the baby, trying to deal with it and thinking 'what did I do wrong?'… Until one day it just exploded and I went off the rails so to speak. [Leading to alcohol dependency]*
F14 - *"My sister died when she was about six months old… so my mum struggled to deal with that through the years. I think my mum could have done with a lot of grief counselling, because even now – anniversaries, birthdays… she's more down than normal… I think my mum has sort of been on this downward destruction button since Claire died. Through the years it's just got worse and worse."*
F19 – *"suddenly her mum died. Right and when her mum died, she went to pieces, you know because it all, it started surfacing then about her dad [abused her as a child]… I knew*

*where her head was going and you know, I know what the grieving process is... But I wasn't expecting her to like p** off to Scotland in the middle of the night …and leave the kids in the house"*

F16: *"And then I fell pregnant with my second boy who I lost in 1998, cot death and that was just the start of a lot of problems then….That's when I started hitting heavy drugs…I was grieving in my own way, wrapping myself in cotton wool…I still haven't had no counselling to this day for it. But my ex partner had been sent to prison at the time when I was pregnant as well, so my head was all over the place. I was using a lot of heavy drugs…I wasn't answering the door to the social workers, wasn't going to no antenatal appointments. I just locked myself in the house…In the end I did open the door and I opened up to them all and said "Listen, I need help". Showed them my arms and they got me help."*

Domestic abuse:

F4 - *"I just fell into an abusive relationship…. just ended up in a snowball really…I was at that stage where I was forced to be helped… there's a sort of trigger point in an abusive relationship…where something clicks and you think "I don't have to live this". I think when that trigger point comes…I don't know if there was one dedicated support team just for people in that situation where in a drop of a hat they're there, I mean that's just asking too much, but unfortunately when you're in that relationship that is what you need…because situations when you come out of a violent relationship they change - you're on a knife edge."*

F4 - *"Then since then she's had lots of mental health issues been a right nightmare the past eighteen months…. As the weeks went on…the way he behaved the way he did the worse, she… wasn't going to school. She was a straight 'A' student before all this happened, never had a phone call off the teachers about her behaviour before any of this - no complaints about her…She was up all night crying…since last year she's taken five overdoses, she cut herself numerous times, she's been missing from home at least twenty times, I've reported it to the police."*

F16 – *"He [partner] started drinking and then…the violence started...me being stupid, wouldn't tell nobody…had to cover up for him, as women do, don't they…a lot of it started going pear shaped...I don't know why I went back in drugs…our whole lifestyle just went totally downhill from there…I've done well the last twelve months, there's been a major turnaround in myself…how motivated I am… I wasn't getting helped towards the end; once the kids had been removed from me, it was like all that support just went "whoomph", out the window."*

Becoming a teenage mother:

F9 - *"I could have seen myself being a proper mess. If I hadn't fallen pregnant with Abby in the first place, I don't know where I'd be now, because I was heading down a bad road…I was hanging around with the wrong people, I was doing all the things you shouldn't be doing at that age…During the pregnancy everything changed. I stopped being rebellious…Put me on a training course… and I went on a Skill Build course, because I didn't have any GCSE's or anything….I stopped drinking all the time… 'You have got to change; you are going to be a parent. You are going to be responsible for someone else; you've got to bring that child up.' And, it is literally, like a big kick up the behind…I wish it didn't take so long for me to get - not to get pregnant - but to get the reality check I got."*

Losing a job / lack of employment:

F6 - *"But when it came to it, it turned out I wasn't covered when I lost my job… so I couldn't keep up the payments. And I ended up… in quite a bit of debt then. It became like double the amount of what I borrowed. And then an accumulation of utility bills as well just crept up on top of me. I couldn't keep up with the high rates of electricity charges and gas charges and I fell behind there as well….So I did end up in thousands of debt, I'm afraid, it accumulated to thousands."*

F13 – *"He always wanted to join the army but he got told last year that he can't because of his autism and he's gone much worse, downhill since being told that, because it's all he really thought he wanted to do, and, but he mixes with you know, people who are as old as 19, 20 and they're getting into all kinds of bother…"*

Lack of suitable school place:
F13 – "*Everything collapses without those…Everything, just you know goes downhill because, without school properly, he's got nothing to do, he's got days with nothing, I can't do anything because I have to stay in with him… and if he could have had a secondary school that was adequate, and settled, it could have been really different, you know, its too late now really but, it could have been really different."*
F14 – *"I think something should have been done school wise. When he was six he was permanently expelled from school. They should have maybe looked into boarding school and stuff then, instead of leaving [it] until he was like twelve or thirteen."*

Losing accommodation:
F19 (support worker) - *"That's impacted on them, losing the house… [when the family moved in with their Grandmother] I thought that things might improve… but actually it deteriorated and that's when I heard within the school that Neil was truanting with other kids"*
F4 – *"There was just no help, there was no one there that I felt I could turn to and say "what the heck do I do, can you help me to find somewhere suitable?" I mean I was basically sharing a house with a load of men, I was a 16 year old girl. I look back on it now and I just think… "anything could have happened"; I mean they were weird men."*

Lack of early diagnosis:
F18 - *"If we knew what were wrong with Patrick in the first place, if the health visitor would have listened to us from day one, we wouldn't have gone down the road where we let ourselves go because we were all too scared to leave Patrick in here on his own when he were being sick, and jumping. We were scared of him choking on his sick… we were that worried about him because we didn't know what were wrong with him."*
F14 - "*Also with Mick you know you could see – I know ADHD has not been diagnosed long [recognised] but Mick was only diagnosed with it when he was twelve and my mum's been dealing with this since he was… two/three. You know a lot more could have been done to help her with Mick when he was younger. My mum's obviously then sort of 8 or 9 years of hell with him, you know. I think Social Services could have gave her a little bit more of a, I don't know, a break from him, if you like"*

Lack of early intervention and prevention:
The following examples illustrate some parents' frustration with the criteria for gaining support, and a system which is geared towards intervention at the point of crisis, rather than earlier intervention and prevention:
"What can I do? I do what I can, I phone them up; I tell them. I never hear from them back. What have I got to do, have a breakdown? Have I got to start turning to the booze, be a druggie? Do something, hurt my kids…to get any kind of support, because they are the people that seem to be getting the support. And us ones who just get on with it, and just fight every day, we get nothing. We're lucky if we get once every few months phone call; "Oh, hello. Are you all right? Is everything ok? Must catch up with you sometime and have a discussion."…"What the same discussion we had six months ago, twelve months ago, 'cause nothing's changed"…It makes me very angry…" (F10)

"Well the waiting lists would be better if they were shorter for CAMHS and also the parental input should be taken more seriously… you know your own kids, you know when they're ill or not ill, mentally ill or physically ill…I pestered the hell out of them. It took her to have two overdoses in which to do anything and in my view it was too…late then….I feel she should have had the help and support she needed before all that." (F5)

"In the two years that he's gone [following family breakdown], I've had trouble with the eldest. The school offer the kids the support but they don't offer the parents any support, you know, I mean I have actually phoned social services again about my daughter, my eldest to see whether there was anything I could do, or they could offer me some support, and they said

'well there's nothing really we can do unless there's been an incident or something like that' and I went 'well that's not really good is it'." (F8)

"All the courses…I mean the self confidence courses and that sort of stuff…I think they'd be good for kids to actually do. Because if you think about it, when they leave school they go on and do their own thing, and then things go bad, and they end up like me. So, if they, if I had all that, all what I've had over the last couple of years, while I was in school to prevent the crap happening, then I would have gone further. You know, things …would have been different 'cause I would have had…what I need." (F21)

4.2.2 Coping strategies

The way that the families told their stories and the language that they used gives an interesting insight into their attitudes, and their coping strategies or mechanisms. Using some discourse analysis, the following examples provide a brief look at how different families see their situations, how they cope with them, and the varying levels of resilience.

Independence and dealing with a situation – a number of interviewees used phrases and language such as "I don't like to rely on anyone else…I put myself in the circumstance, I will deal with it" (F9); "I can do it myself" (F31); "taken it on the chin - we've always been a self contained unit, as in we've always done everything ourselves...we got on with it, we managed" (F26); "I managed…try and sort something else out" (F10); "he's just sort of got on with it…we just muddled on as we were" (F25).

Willingness to ask for help – "I've never been afraid to ask for help when I was desperate" (F32); "I'm gonna deal with this myself now… I thought I could, but I openly admitted to them that I'd relapsed and needed help again" (F16).

Acceptance – "it's the past isn't it now and I've gotta move forward and I said the kids are happy, that's the main thing" (F16); "I'm not worried about it, and I'm not going to worry about it…You can't force an autistic child to eat what they don't want to eat, end of" (F10); "Gives you a bit of a hard skin…you both lose layers of skin, you become more vulnerable, but you also get a hard shell….It means you get the extremes…I can fill up watching a stupid film, and I can also be a harder faced person because I've had to deal with stuff that nobody else has to deal with… We are working to give our kids the best quality of life that we can, it's a bit like a game of cards, you use the hand you're dealt with…we're supposed to cope" (F26); "I've learnt to deal with it now...I'm quite a negative person…quite a realist really. I'd rather be expecting the worst then something good happen and vice versa, come crashing down…but nobody's life is perfect, everyone has their own things." (F5).

Remain positive – "we try and be as positive as we can" (F26); "she's never going to get better but I think she needs to be the best she can be" (F27).

Take one step at a time - "there are so many potential problems for her that we can't even think about them all, we just take as they come, one at a time" (F26); "set goals…I am getting there you know…it's little, little steps…breaking down the big steps into more manageable ones and then getting to the next and just climbing the ladder" (F21); "just going to take it one day at a time" (F31).

Gratitude – "we're trying more and more not to think of the 'what if's' and just to get on with celebrating what we've got, you know" (F26); "I bore with it, decorated as best I could and it turned in to home; my damp hovel…you know, it was home" (F24); "when it's getting on top of me I'm like hold on I nearly didn't have her and that's what helps you to not to fall to bit sometimes" (F29); "so that is one good thing about not having much, you do appreciate things more, definitely" (F5).

Identity – "that's not who we are…I don't want to be defined by having a disabled daughter…I just happen to have a disabled daughter" (F26); "I tried very hard not to define myself in terms of him and his difficulties, because I think you can turn into quite a miserable person with a single theme"; "adapt your whole self and your whole family to it" (F27)**.**

Reflection and hindsight – "I just think 'oh I can't cope with this'. Even though I can cope with it; it just never feels like that at that time does it?" (F5); "we've always forgotten how it was in the early days; we just did it, we got on with it. But we managed, and it's made us kind of stronger people… we have lurched and swung and fallen, and you know, safety netted our way through the last seventeen years" (F26).

Humour - *"One of my coping mechanisms has been in public…to the outside world…describe the funny side of life, rather than the tragedy…It helps if you see and concentrate on some of the absolutely positive things that can happen. So I tried very deliberately to become that kind of person and not bitter or unhappy by it all…I was completely overwhelmed by the difficult side of things, I wasn't strong enough to deal with the practical things and I didn't know what I know now. I would be much wiser…I actually have had very good support, and I've never been afraid to ask for help when I was desperate… I tend to be a coper, but I have been at nearly breaking point a couple of times."* (F32)

Fight / battle - one family with a child with a disability uses the metaphor of a battle to describe their experiences:
"Mine's nothing in particular, there's not one thing to focus on, it's just life in general with a disabled child, because I won't sit back and not do anything for Lucy. I want to fight so she can have an independent life when she's older. So it's one constant battle…When we left Gobowen on Thursday the surgeon just dismissed this SDR after fighting for two years for it, I was upset and I won't let her see me upset and I never let her see me get angry. I don't bring her up in a hostile environment where she's led to believe it's because of her that I do all the fighting…I'm not one that craves attention and I don't feel the need to have someone with me at all times, I'm fiercely independent and I don't like to put my problems on other people either. I'm not one of those that are like "oh I need help and support for me"…" (F28)

Case study (F27) – the language and metaphors used by a mother to describe their experience of caring for a child with a disability reveals a lot about her attitude and coping mechanisms. These include: realism, taking one step at a time, empowerment that comes from being informed, being an activist, a positivist, and the importance of hope and being grateful.

"So it's been a long road really but at least we know what's up with her now, so we can now start to tackle that, and when we've tackled that we can do loads with the autism …Things will get trickier as she gets older; they're bound to because… she can't do something or have friends to sleep over and things like this and you know there will be things that we have to work out. You can't think of those in advance, have to work them when you get to them…
…I think, well we knew it was serious straight away. My husband and I we are fairly resourced we've been in education a long time, both teachers then. And we weren't frightened by it in that sense we just knew we had to read around and find out what we could do for her.
…And really there is a lot you can do, we found loads you can do….therapies that can help, I mean it's never going to be cured ever, I mean she may never speak even, it's better to give people some kind of hope and say look you can do this, you can do that, there are plenty of options available. It would have been nice to know what options were available.…I think when they're first diagnosed a bit more help would be nice.

I know you can't say your child's going to get better, and you can't do that for most with disabilities and illnesses but it would be nice to look more on the positive and say, "you know you can do this you can do that"… just different things that might be available that we could pursue, or things for the future…

…But I mean I don't know what's going to happen for Bella, post 16… I'm hoping maybe go to Gogarth by then and maybe thinking of something to do for her life. But those things are far away from us at the moment and I only tend to think of today because things change so fast. I have no idea if she will be speaking by then. You've got to look on the hopeful side because it's not worth looking on the bleak side. I mean I'm probably an optimist but you have to be hopeful for your child because you want better for her. And if you don't; well you know she's never going to get better but I think she needs to be the best she can be. If I can get her that much better in another five years maybe I could get her to do something. Even if it's like painting or drawing, you know, it's something for her life, it's something she can do you know but you have to look on the positive side. You can't look too far ahead because you just don't know what's going to happen.

…All we spend our money on is food for the children and things for the children, I don't have any spare but we've managed, and we've managed to run a car, not a great car but a car. …and as Juliet [sibling] gets older she'll obviously want more but we'll have to cross bridges when we come to them.

…A disabled child, it really is a steep learning curve. It's very very hard and you have to adapt your whole self to it and your whole family to it. But you can get a lot of joy because she is a lovely child…. But I think it is so very hard. I mean we've done things that we would have never expected to do. You know we went to America with her to do the sunrise programme with her. We raised thousands in our old house to build a therapy room because we didn't have one, we've done things that we wouldn't have ever done and you have to try and make them positive, you know you have to try and make it positive for her and for us."

4.2.3 Parents' childhood experiences

Parents taking part in the study often referred to their own childhood experiences, and how this has contributed to or influenced their situation in some way. This provides an interesting insight into the importance of breaking unhelpful cycles and patterns within families from one generation to another. The following examples illustrate:

Domestic abuse
A mother describes growing up within a household of domestic abuse, getting into an abusive relationship herself, and the impact this has had on her own daughter:
"Didn't get on with my mum and haven't for years… When I was 10, she put me in care for a year; she couldn't cope with me…my step dad used to beat her and he cheated on her…She reckons that's why she did what she did with me because she couldn't cope….
…Got a flat with my boyfriend at the time, that's the father of both my children, I was 17 at the time. Basically he was abusive as well, so I jumped out of the frying pan into the fire as it were.
…But as a young person myself…must have still been 22 when I did it [attempted suicide]… I was mixed up about my mum. I still get upset about it now… but I've learnt to deal with it now. But Jessica [daughter] needs to get to that point where she's like "right well that's just the way my dad is and that's the way he's always going to be and I have to learn to deal with that"….Since then she's had lots of mental health issues…the way he behaved the way he did the worst, she… wasn't going to school." (F5)

Other examples of domestic abuse include a mother whose childhood experiences of being sexually abused by her brother contributed to her alcohol dependency as an adult (F3); a mother who fell into an abusive relationship at a very young age, left home and school prematurely, with subsequent problems with her own children (F4); a social worker's description of how being seriously neglected as a child has impacted on their client's "*own parenting capacity*", and getting into abusive relationships (F17); and a father who describes how both his and his ex-wife's experiences of childhood domestic abuse affected their parenting and caused family breakdown (F19):
"But because of like how I was brought up, what I went through with my dad…that's my weakness with him [own son]…When he was a kid…I raised my hand to him like once, and because he cowered, it just brought something back. It was like my head had just gone… And that's my only weakness with him…Don't get me wrong, I discipline him, but he just gets away with murder, I'm too soft with him….And I suppose…that's a bit of my downside…do you know with the school and that … 'cause of what my dad did to me, I've never been able to handle authority."
[Describing his ex-wife's situation]… "*My missus, I found out later on that …her dad had been messing about with her when she was a kid….She was just bottling it all up, so I knew where it was leading to, and it was making her ill…it all points back to him, because if he hadn't have done what he did to my wife when she was a kid, she wouldn't have reacted the way she did…When her mum died she was angry at her mum…That's why her head went …and that's why she ran away…"*

Being in care
A mother describes the cycle of her childhood experiences of being in care, the impact on her own parenting capacity, and the consequences of her own children going into care:
"We were all in a home…that's how I don't want my girls to be…I was in foster care…then back in the home, and then fostered out again….put in a boarding school…All I ever done was just kick off and smash things and then drink….But if we'd have had decent social workers when we were younger, we'd have been all right. When the twins got taken away…it was exactly the same [as] us getting taken away from me mum…it was horrible…I couldn't discipline the girls, because I didn't know how to …How can you know what discipline is

when you've been [in a] home for most of your life?... One member of staff would discipline you, and another one would come on duty and they'll tell you to do something else…There's about eight of them, every day telling you different things to do…it's confusing…Because that's how I used to speak to my kids, 'cause basically that's how I was brought up…" (F15)

Unstable / complex family circumstances
Some families described a very complicated family set-up when they were growing up, which is reflected in their current situation. This family is one example:
"She were calling Zoe step mum…and I thought there's nothing wrong with that…and then when they explained it properly to me, we'd stopped that…But she'd start calling her mum, but she knew that Idris was her mum…And social services said "no that's wrong"…I said "when I were younger, I used to call my sister my mum because she looked after me all the time, but I knew she was my sister when my dad explained to me"…I knew that my two parents were my mum and my dad… because they brought me into the world, I knew who my two parents were…My children are calling granddad "father" because we all call him "father", my children's picked that up, and they said "that's wrong, the children shouldn't be calling him 'father', you're the dad, he's not" and I said "well, I don't see nothing wrong"…" (F18)

A young mother describes a difficult childhood of behavioural and educational issues, partly attributed to her parent's break-up. Her fear for her daughter is that the pattern will be repeated:
"That's the one thing that worries me with my daughter; I don't want her to be, if she becomes sixteen and pregnant, then she becomes sixteen and pregnant. I would be the supportive mum, like my mum was supportive to me. But I don't want it for her because you do miss out on the kind of things that, during between sixteen and …twenty one, all the kind of things all the other people my age are doing. You do miss out on it, and you have to grow up fast; you have to, there isn't a choice." (F9)

4.2.4 Evaluation of who or what is responsible for a situation

Whilst telling their stories, many of the families would try to make sense of why a situation has occurred, where to attribute blame, and evaluate who or what is responsible for a problem. While some families blamed external factors, others could see their own contribution and mistakes. Some families would take it upon themselves to solve a problem, even if it hadn't necessarily been of their own making, whilst others would feel that the responsibility lies completely with the services working with them. The following examples illustrate these points:

Assigning responsibility:

A mother blames the influence of her ex-husband on her son's attitude and criminal behaviour:
"It's the normal path of…a teenage boy in the wrong environment…it started off with petty theft… He had another fight…I think the violence has come through from his dad. He just has no respect for women at all….I mean he is a lovely lad. He's sociable, he's funny and he's popular. But he's just so easily led… One of these lads that just thinks the whole world owes him a debt for being around basically. He's got that from his dad….He wants what other people have got. If they've worked for 10-15 years for it, he wants it now because he deserves it - that's his mentality which is awful." (F4)

Parents, whose son is receiving support from the Youth Justice Service for alcohol related problems, assign some blame to the fact that there isn't enough for young people to do:
"Sometimes with the drinking it's just because the boredom, they've got nothing else to do… they're just hanging around in batches…getting drunk every night. They seem to be walking

the streets at 2 in the morning drinking…There's nowhere for them to go and nothing for them to do, it's just…dead end… There's a youth club…twice a week, but there's nothing locally…that I know of…Wherever they go, if they're in groups, they get moved on because they're being anti-social or what have you." (F12)

Parents describe the cost of activities as a contributory factor to their son's boredom and behaviour:
"*More sports, taking them or doing activities and stuff like that…Because there's nothing really anywhere for them to do is there, and if they do go anywhere it's like expensive isn't it really for them to go places. [Wouldn't attend the youth club] because there's always trouble."* (F11)

A mother assigns boredom, peer influence, and lack of suitable placement at school as the major contributory factors to how her autistic son got involved in offending behaviour:
"Ended up getting into the wrong crowd because he had too much time on his hands being off school…[He had] confrontations with bus drivers, because he felt that they were relying on him doing something wrong…It's inevitable he's going to get into trouble… I think it's given the education authority an opportunity to not place him in schools with proper support because they say he's got certain needs and they can't support them, so they don't do anything.…If he could have had a secondary school that was adequate, and settled, it could have been really different, you know, its too late now really"
The worker linked with the family expresses concerns that his reputation has influenced his behaviour:
"…Another factor has been his social defences.…He gets quite easily led by peer groups.…There have also been a lot of rumours that have pursued him throughout education, and I'm…concerned that he's becoming a self-fulfilling prophecy…He was allegedly carrying weapons and dealing substances, and now it's starting to look like he might actually be getting into those sort of behaviours." (F13)

A mother identifies the patterns established within families in terms of their lifestyle choices:
"Same with smoking, same with anything. You usually find you know, if there's a family of smokers the children tend to pick up. I was one of those children; I hated smoking…but my mum and dad smoked, then my sister smoked…my brother smokes, and now I do…big factor." (F24)

Appreciating the difficulty faced by services with heavy case loads, this family expresses that it shouldn't always be left with the family to take the initiative to ask for support:
"People won't come here unless you phone them to tell them there's a problem…its case loads I suppose… they deal with the ones that are on the phone all the time…we're not one of the [those]. So I suppose we get forgotten. Even if it's only a quick phone call to say "Six months since I last spoke to you, are you ok?"… And if I need something or if I've got a question to ask I will phone the relevant person. But I'm also the sort of person to deal with it myself, which then means that I take on too much, which adds to my stress level, which adds to the families' stress level." (F33)

A mother describes a situation where support is pulled away from her daughter because of lack of engagement on her daughter's part; she feels services are responsible for continuing support:
"She needs help…I pestered the hell out of them! It took her to have two overdoses in which to do anything…It was too late… When she hasn't engaged they've just closed the case…Anyway she held an emergency meeting…lots of agencies were invited for me to say I was basically feeling let down by the whole system. Because if she doesn't engage they just close the case and that's not helping at all, so then she thinks they've given up on her, so in fact that makes her feel worse" (F5)

A mother and father express their frustration as they feel they haven't been given the opportunity to prove themselves and take responsibility as parents:

"That to me is wrong…we haven't been given a chance to prove that we're decent parents… we were asking to go on these parenting skills…still waiting…And it's just messing us all up, because we're trying to work with them, and they seem to go the opposite way all the time …All we want to do is be good parents…But they don't listen to us, they don't have it…They could have done something more to help us…. We're trying to move forward. But none of that's been mentioned. It's just the bad things that have been mentioned. None of the good things that we've done… where we've improved." (F18)

A very small number of families were unwilling to take any responsibility for their own situation, and had high expectations of the services supporting them. This mother and father were keen to receive a break from looking after their children:
"More time for ourselves and that, that will do, more space…The kids are hanging round 24/7 because there isn't anything for them to do…She can't work if she's got 5 kids to look after." (F11)

(See the sections on "parents' childhood experiences" and "engagement with services" for different examples of where families assign blame or responsibility for their circumstances.)

Taking responsibility

A sibling describes a complex situation where her brothers were taken into care. She often repeats phrases such as "*a lot more could have been done*…" and "*could have been helped with a lot more…*". But she also acknowledges her mother's role in asking for help:
"It's just everything, through the years…she must have got to the point where she was thinking "what did I do to deserve this?" …She's not had it easy when we've been growing up…but she could have dealt with it better, you know, I think. She could have asked for help, you know, with the counselling and stuff." (F14)

A mother describes how she should have taken responsibility for her situation by asking for help, and the fears associated with this:
"It's my own fault probably because I didn't ask for the help. I didn't realise and at the time I was thinking if I showed that I'm weak I'd be thinking they'd want to take her off me, but it was the complete opposite really." (F29)

A mother describes being trapped in a vicious cycle in terms of her lifestyle, and being able to take responsibility for obtaining the support that's available for her:
"I mean it's my fault as well though, 'cause I haven't been able to get to the doctors to sort it all out either….But I can't get to there… It's a vicious circle really with me. But…we're trying to get it sorted…At the [names provision], they didn't really do anything. I had one appointment, I went there once after hospital and that was it. But it's probably my own fault, 'cause I missed the appointment." (F21)

A mother recognises that the difficult situation at home was responsible for her son's behaviour, and that support was available to her if she had been willing to accept it:
"He was a child with a lot of problems, you know, behaviour…Looking back now, it's… probably everything that was going on in the house was the cause of it all because where he is now on placement he's brilliant, he's like a different child…I just wish I had done a lot more with the others, because then maybe things would have been a lot different, but, it's the past isn't it now and I've got to move forward.
…I can't look back and say "Well, they didn't do this for me, they didn't do that for me" because they did….anything I need, they used to get…they did put on a heavy support package. I just sort of, took the mickey sometimes, didn't I?" (F16)

A young mother describes her determination to take responsibility for her own situation:
"So I was also sixteen when I gave birth…As soon as I fell pregnant, everything changed, because I don't believe in getting rid of children; if you fall pregnant, it's your

responsibility…you deal with it… I'm the kind of person who, I don't like to rely on everyone else; I'm very independent…. I'll deal with the circumstances, I put myself in that circumstance…I used to get angry if someone used to try and take my independence away…I'd be like "I will do it my way - it's my life"." (F9)

A mother describes her frustration with a system that doesn't encourage families to take responsibility for their own situation, feeling that she misses out on the support that she needs:

*"There's people that I know that do drive but they still rely on special transport to take their child to school; why? Take your own child, you've got a car…These people drain the funds, and it makes it c**p for people like me… Mum said to me it's because I don't do anything about it… I do what I can...What have I got to do, have a breakdown? Have I got to start turning to the booze, be a druggie?...Hurt my kids? To get any kind of support, because they are the people that seem to be getting the support. And us ones who just get on with it, and just fight every day, we get nothing."* (F10)

A mother with alcohol dependency did not expect to receive help because of her perceived responsibility for her own situation:

"I was at the…doctors… because I thought it's self inflicted I won't get any sympathy off these…and he was absolutely brilliant with me…People try to say it's an illness and you can't help it, but maybe deep down they just wanted to say "oh you're an alki" or whatever…People ask why do you drink, has it become a problem? I just didn't know how to answer it whether I had a breakdown and that was my rock, I don't know. I can't really answer that properly, only that I wouldn't wish it on anybody" (F3)

In contrast, this mother felt judged for her contribution to her situation (remaining in an abusive relationship):

"He'd then wear me down so much…I was in fear of what he was going to do and I dropped the charges and that's when the police changed. I can see now where they're coming from, how frustrating it is. But the worst thing that an abused woman needs is to feel that the police are there and don't turn against her because she is doing everything to keep her children safe…They went from been very sympathetic to treating me like a piece of dirt…It's an awful situation but other than that the police were brilliant…they feel powerless, don't they? There's not an awful lot they can do." (F4)

4.2.5 Engagement with services

A common concept emerging from the study, “engagement with services” gives an important insight into the success or failure of interventions and provisions. Families often described their own, or their children’s attitude towards services, positive or negative, and how this impacted on their situation.

Establishing a **good relationship with professionals** was often seen as a key factor in terms of engaging effectively with a service or intervention, as illustrated by these cases:

These families describe the value of a positive role model and mentor outside the family situation:
F13 - *“I suppose that’s the best thing about [youth worker], is…when Rupert says he’s got an issue, he just confronts it, and it’s better for him…I suppose he’s a bit of a mentor really, he’s not just a youth worker…Rupert thinks he’s quite cool…he’s got somebody to look up at… Even though maybe he doesn’t think that Rupert engages as much as he could, but if you knew Rupert, he doesn’t engage with anyone, so it’s massive that he does.”*
F12 - *“Having someone that he can get on with, like a mentor…I think the first thing I found with any of them, Keith, Callum, any of them, their impressions is this, if they click with the person that comes, that’s it then, they’re fine, they get comfortable with them…and will do virtually anything for them… If somebody else from outside is talking to them they’ll listen, they’ll respect, you know.”*
F9 - *“Allocated us a worker [housing support officer]…she was absolutely lovely….I gave her this big hug and I didn’t want to let her go; I still don’t want to let her go…she’s fantastic and she’s a helping hand that anyone could be, she would help anyone in anything.”*

These examples describe the importance of co-operation and mutual respect between families and professionals:
F25 - *“I do have a good relationship [with social worker]. I did find her difficult to connect with to begin with and I don’t find her terribly approachable, she has a way about her, but… that’s not how she really is, that’s just how I perceived her when I first met her, and I still get that feeling I just know that’s my perception not how she really is. She’s been great…”*
F32 - *“If I was giving advice to somebody who was, who had a very young child with any kind of difficulties… you’ve got to have a social worker and you’ve got to have a good relationship with a good social worker. [They] are the key to everything…and if you have got sort of a nice kind of stable relationship…then you’re half way to getting it cracked….I’ve had a good relationship, but that’s because I’ve wanted to have a good relationship with the social worker….I’ve had the right attitude to make sure that it works. So I’ve helped, I’ve done what I could, I’ve been open with them.”*
F18 - *“She [health visitor] worked with us and we worked with her, and she were fantastic.”*
F33 - *“We have always got on really well with everyone [various professionals] because I just feel that they are all trying to do their job, so there’s no point in shouting and screaming because you don’t get anywhere….They are all trying to do their best. And I think because they can see that we’re trying to do our best for Gayle, and that we appreciate that they’re trying to do their best for Gayle that, rather than clashing, we are going nicely side by side...”*
F26 - *“I think we are on social worker number ten….but the fact is that we didn’t really want a …social worker. You don’t really want some people coming in your house, stripping you down, but we are used to it now, we are used to telling it [again]…because they’ve not read the notes…because they haven’t done their homework…You judge people on how they will interact…You can get the best specialists in the world, and if they’re not good at the listening and talking, they’re not good for you…People who treat you with respect, talk to you quietly, are patient, empathise with you, are worth more… Some people want their social workers to be their friends and we just want them to do…a good job…. Once you build up a rapport or a relationship with somebody, you respond to them and you want to keep it.”*

The importance of consistency in terms of relationships with professionals is described by these families:
F3 - *"I really took to her [key worker during detox]… I opened up to so much and there was so much I wanted to talk about and the next thing she turns around and says "I won't be here"….She said this is my last session with you today, somebody else will be with you tomorrow….I was so gutted… "what do you mean, I've opened my heart out to you"…let my barriers down….I was ready to sign myself out…Even to this day I wish I stopped drinking when she was helping me because she deserved the credit because she helped me so much."*
F30 - *"She's [occupational therapist] an enigma…She's a strange one …You just can't get hold of her… She doesn't see our son and yet she seems to think [she knows] what's best for him never mind what mum thinks; it's so frustrating…We get told by other parents that their OT is more than willing to offer help….We just get told it's who you have, who you're allocated to, who you're lucky to get. Some of them will bend over backwards, some of them won't."*
F15 - *"I can't remember my first social worker, I had quite a few [as a child]. It was like being in a children's home with everyone coming in and out. So, you get used to one person, and then another one comes along. You get used to that one, and then another one comes along, and you get used to another one… I don't know how many social workers I've had, that's probably why I'm so bloomin' confused."*

Other factors concerning effective engagement with services and interventions include the following examples:

A mother describes her son's reluctance to engage because he **doesn't want to receive help**:
"He was part of the Youth Offending Team…he used to have to go to these meetings once a week, and I'd ask "do you think they're helping?" and he'd say "no not really". I'd ask if they offer any support, but you just can't get anything from him, so I never know. I did phone the guy at one point…you can tell they're feeling just as frustrated as I was…. He's in that category that doesn't really want to be helped. He does while it looks good on paper for the courts, if he didn't have to he would rather not, thank you very much." (F4)

Parents describe their struggle to engage with services and their perception of '**interference**':
"Half of my social workers, well to me in my head, were interfering too much….Even when I had me girls, they were around every day….having a look at the house, sniggering… Oh, she didn't half moan, and that was it, then, me house just went down, I thought "Can't be bothered no more'…What I like about [current social worker] is [she's] straightforward…Even if it upsets me, I don't care; you tell me, and be honest with me and tell me what you think, then I'll be happy. And I can correct it… I'll do anything and everything they ask me. And, if that means I'll get me girls back, well…." (F15)

A family worker identifies a reluctance to engage with a service because of **suspicion**:
"That's the difficulty that you have with parents that are quite resistant to taking up support, and committing to support….They are quite suspicious of agencies….We do have an okay working relationship with [father]…when they were evicted, he did ring out of concern for Neil….But I think there is that suspicion…don't want people looking in too closely and finding out what's going on." (F19)

A mother feels that **lack of flexibility and understanding** from service providers prevents her from engaging with it:
"Maybe if none of us want…to do anything, I don't want the attitude of "Well, you don't want the respite for your son, well don't think you're going to be offered it again then." Where does that all come from?...They're meant to be there to help and support, but because, either the child doesn't feel like it, or the parent, there might be something else going on, they're

saying "Well, if you don't attend, you're not going to get it." So that worries me, I'd like it, but I don't want it…" (F10)

A family describes their **confusion** about what is expected of them, and how this prevents effective engagement:
"So we can't do right from doing wrong at social services. Its like I keep saying to them, we're trying to work with you, but you keep on not working with us…And it's just messing us all up, because we're trying to work with them, and they seem to go the opposite way all the time…And I can't see how we can move forward when they keep on going back to the past and changing stuff all the time…" (F18)

A mother acknowledges her **fear of accepting help**, and her reluctance at first to engage with the services available:
"There probably was help there, I just didn't ask for it a lot of the time in case people thought I was weak and I am a bit stubborn, but it does get to you in the end….I thought…I'd have to deal with it on my own, I didn't realise there was so much help and there was people there, but I was like "who are these people, why are they helping me?" But you have to let them in so far… over the years I've gradually got used to them." (F29)

Chaotic lifestyle and not being ready to accept help are given as reasons for this mother's lack of engagement with services at first:
"I can't say I wasn't getting support and things like that. But my ex partner had been sent to prison at the time when I was pregnant as well, so my head was all over the place. I was using a lot of heavy drugs, I was injecting them. I wasn't answering the door to the social workers, wasn't going to no antenatal appointments. I just locked myself in the house…In the end I did open the door and I opened up to them all and said "Listen, I need help". Showed them my arms and they got me the help." (F16)

A social worker tries to make sense of a young person's lack of engagement with the support offered:
"They've not always accepted what we've offered them, and it's difficult, certainly in Sean's case, to work out why that is. He's got a major change shortly when he turns eighteen…. I think he will feel the difference in the level of support that we will be able to offer him, especially if he remains the way he is, and will not engage in education or training…All we will be able to offer him is information and advice. And he's not got a very good history of accepting that, or acting upon it… As well, he's probably smoking quite a bit of cannabis…A similar situation the other week, where he asked me to get him an appointment with CAIS…even thought there's been six appointments set up for him, he has failed to attend each one." (F14)

4.2.6 Support networks

The majority of the families taking part in the study referred to their support networks (or lack of). Often families would say as an aside, whilst describing their problems, that they didn't have family close enough (geographically or emotionally) to help them. References to support networks included family and friends, as well as support from services, community groups, or informal groups. These were seen in the context of their ability to cope with their situation, as seen in the examples below. Many described the loneliness and isolation they felt because of their circumstances and the lack of support networks available to them.

A common theme within the study, these examples illustrate the difference made by having a **supportive network of family and friends**:

F9 - *"[When I got pregnant at 16] my mum was very, very, very supportive; I could ask her anything, I could go to her for support with anything…My mum was like a guidance book; reassurance…[Without mum] I could have seen myself being a proper mess…. I had my friends supporting me as well. Two in particular, though you do lose a lot of your friends…the ones that stay with you are your proper friends."*
F3 - *"I didn't even want to know my friends, the drink was my friend and that's all I need….I promised myself no more drink…I said "I can't do it on my own"… If Gareth [ex partner] said "you can sod off after what you have done to me", I don't know where I'd be today. Because my friends had their own families and their own lives… they worked, couldn't be with me 24/7…. If he hadn't turned around and said "…I'll help you", I'd be dead and buried by now. Or still be drinking, in a gutter and homeless probably."*
F10 - *"My mum, I can't ask to; its not that I don't trust my mum, it's nothing to do with it. My mum has been a God send to me, absolute. Where would I be without her, because she's done a lot of what, of support that I should have had from other sources that I haven't had"*
F27 - *"When you've got a special need child it takes up all your time dealing with the child, try and keep the family together; again it's better if you have a mum and dad…and it was hard to think "I have to settle and find new friends in the community". But we're doing it slowly…. We've got to start to learn Welsh now…to be a part of the community."*
F32 - *"You just can't really put a value on that [good services], especially because we don't have a great deal of family here. We have my husband's very, very elderly parents, but I don't have any sort of, close family in this area, so it's been fabulous…"*
F26 – "*It's been hard because it really has been just us; our extended families don't live round here… We've always been…a 'self contained unit', we've always done everything ourselves….We managed, and it's made us kind of stronger people, but we've never had the support network that some families have… we've lost family links because they can't cope."*
F5 - *"It would have been good to have more support [coming out of an abusive relationship]. If you haven't got your family's support, and it is good to have friends' support but… they've got their own families to think about and at the end of the day I don't think I'd even ask friends….My dad put us up for six weeks last year because we were desperate but I'd never ask my friend that. I'm quite an independent person as well…I didn't even ask my dad, he offered… but I felt awful the whole time."*

A number of families described the feeling of being 'cut off', **isolated and lonely**, either through lack of family, friends and community, or through lack of support from services:
F26 - *"Once we got her back from hospital, we were almost cut off and cut loose on our own. There was no support. I remember asking a midwife for help and her saying "Well, you don't get support with multiple births unless you've had quads." And we were saying "Well, we've got one healthy baby and one baby who has got extreme needs, and how are we supposed to do it?""*
F10 - *"You worry about taking your child to somebody else's house, 'cause he's going to break this…he's going to be jumping up and down, running over the furniture, running around like a loony….If a mother came here with her autistic son, it wouldn't bother me because I have one….it's a shame that I've not been able to come across mothers like that because I bet they've been in the same boat as me, they've been prisoners; they've been alone…I didn't have no support; none…nobody would phone me up and ask me was I ok…In the holidays, I'm trapped…This house, seven weeks…you become a prisoner in your own home…"*
F33 - *"As soon as she hit school age, all that stopped….I was having people…coming and going in the house…from your OT's to your physios…and then suddenly at the age of three a lot of it would happen in school…And when you're used to people coming and going in the house…it's a link…for me to be with another adult, rather than just being with my child all day and so, you sort of lose that contact, and it's you're being an individual….But there's still nowhere to go [with suitable facilities]…so parents end up staying at home and being more isolated because they can't get out."*
F24 - *"Started speaking to other mums, started going to more groups…A lot of the mums that I see around town, they look very alone, there's a lot of mums like that, that are*

struggling….We all have those days, but you know, just to be able to have a chat with somebody and you know, vent off. Or, have a coffee and a cry or anything, just to have somewhere to go." (F24)

Different from most of the families taking part in the study, this mother expressed her independence, and didn't want interference or support from family, community or services:
"I was offered with the young carers groups…they tried to get me involved with stuff there but it just wasn't for me, I just didn't like mixing much. It was like a little clique round here; everyone knows everyone and I don't tell anybody anything and they think I'm snooty or stuck up or something. The only time they do talk to you is when they want to find out something so I don't tell them anything or they'll just have a good nosey." (F29)

5 Conclusion

This qualitative study has provided a wealth of data on a number of themes, service areas, and conceptual ideas. Please see the Executive Summary at the beginning of this report for a summary of conclusions concerning each of these areas.

Next steps

The data from this research, and the other related research will be used for the following things:

- To inform and develop Conwy's Families First Action Plan
- To provide themes to focus project development
- To inform Families First funded projects including development of Team Around the Family
- To provide themes of focus for further research (including more specific research with families through qualitative interviewing, mapping current services through service profiling, and literature reviews)
- To inform other services
- As an ongoing resource for the Children and Young People's Partnership, and partners

The methodology developed for this study will be used for future qualitative research work.

6 Feedback

Families who have taken part in the research will receive feedback through a visit, and an opportunity to see the executive summary of this report (or the full version if requested). If they choose to be involved further, they can also have the opportunity to give their opinions on the developments planned as a result of the research.

Annexe 1: Qualitative Research and Interviewing

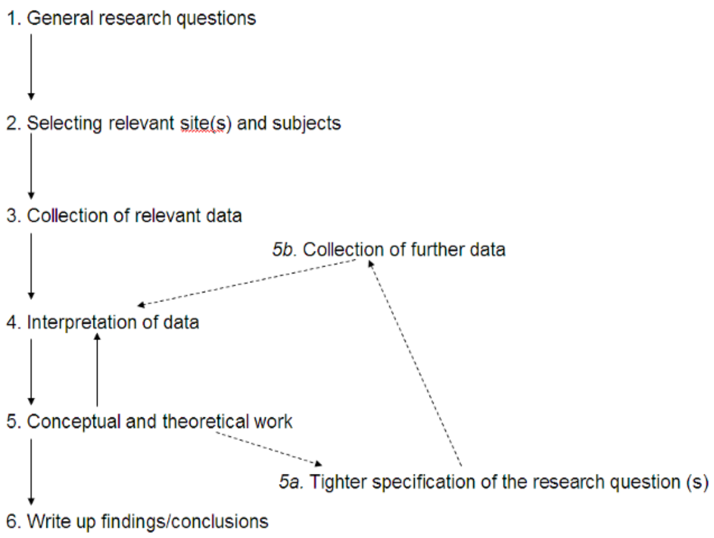
Qualitative research “aims to study things in their natural setting, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them” (Denzin and Lincoln, 1994).

This study is not about proving an existing hypothesis, but rather listening to families’ stories and generating theories alongside families: to understand how they see things and their perceptions of what they need and what has happened. The study is intended to complement (triangulate with) the data collection and quantitative research being undertaken, to provide a fuller and more rounded picture of the experiences of vulnerable families in Conwy.

Characteristics of qualitative research:
- seeing through the eyes of the people being studied
- emphasis on process: how events and patterns unfold over time - “how did you get to the point you are now?”
- Covers the unquantifiable dimensions of experience - the why, how, contexts and experience (not concerned with factual definitions, but with a lived experience)
- Concepts and theory grounded in data - a ‘bottom up’ rather than ‘top down’ approach by asking what the data is telling us.

Why interviewing as opposed to other qualitative research approaches?
Other qualitative research approaches have been ruled out for the following reasons:
- focus groups would be difficult to manage and get people engaged given the vulnerable nature of the families we want to work with
- Ethnographic approach (ie observation over a period of time) is not practical with individual families, and will take too long

Interviewing provides flexibility. We will be able to use various approaches and techniques within the interviews, beginning an interview with a completely unstructured approach, for example - “tell me about your experiences of…” (*minimalist passive interviewing*), then moving to a more semi-structured approach, asking questions and probing about some of the things that they have said. Using this approach provides a balance between:
- not putting words into people’s mouths, and listening to their stories as they see them
- getting information about specific experiences and points so that meaningful comparisons can be drawn between interviews, and interpretations can be made
- able to use a rolling hypothesis approach, following up emerging themes in later interviews:



An outline of the main steps of qualitative research

(Bryman, Alan – Social Research Methods, 2001)

The purpose of interviewing:
“To find out what is on someone’s mind…We interview people to find out from them those things we cannot directly observe…We want the respondents’ own perspective to emerge, explore the ways in which people working together share common understandings, get insight into particular experiences, find out motives behind decisions, get a view of informal procedures, consider apparent contradictions between attitudes and behaviours, and allow respondents time to provide their answers.”

Patton, M (1990) Qualitative Evaluation and Research Methods

Strengths and limitations of qualitative interviewing

Strengths	Limitations
• Interviews offer access to respondents’ own definitions of their experiences and practice (more ‘authentic’) • Allow respondents to tell it like it is • Avoid pitfalls of imposing research assumptions on respondents • Allow respondents to identify what is important	• Interview is a social interaction • Opportunity for constructing ‘self’ - people don’t have to be honest in interviews • Public accounts versus private accounts • So we shouldn’t claim that interviews allow us to identify what the respondents *really* think • Concerned with accounts, not of ‘facts’ (analysis can therefore be more challenging) • Interviewer ‘neutrality’ • Interviewer has the monopoly on interpretation

Quality – the following things have been put in to place in order to ensure research quality:

- Triangulation
  The information gathered during a single interview will not be the only source of data used to inform the analysis. Interviews will take place with professionals as well as families. This research will also be used in conjunction with quantitative data and data gathered through service profiling. This will add to the overall picture and the validity of the research.
- Fieldwork diary
  The interviewer has kept a fieldwork diary and made notes directly after the interview, which has provided the opportunity to
  - reflect on what worked well and what didn’t work, to learn from this, and adapt the interview guide etc.
  - make notes about any initial thoughts about theories and concepts for analysis, or issues to explore further
- Interview guide and schedule
  A lot of time has been given to ensuring that appropriate interviewing methods are used. Practice runs and a pilot as also used.
- Recording the information
  Typed transcripts of the interviews have been checked against the recordings by the original interviewer to make sure that words have been heard correctly.
- Using software for analysis (Nvivo9)
  Nvivo is a specialist software for qualitative research, which supports a researcher to manage the data gathered, allowing them to create codes, and pull out all of the content relating to a certain theme or concept. It also allows the researcher to return to the original transcript and understand the overarching context of the comment being made in order to avoid misinterpretation.

Ethics – the following ethical considerations have been made:

- An information sharing protocol has been written for the Families First project (based on WASPI template)
- Information sheet (see Annexe 2) - information provided to participants beforehand, clearly showing the purpose of the interview, and how it will work. This allows participants to make an informed decision about whether or not they want to take part. A pre-visit was also offered, with the possibility of a worker already familiar to the family.
- Informed consent and permission to record - the information sheet includes clear information about consent. Consent isn't a one-off event and it was made clear that participants could change their minds and withdraw their permission at any stage in the process.
- Checking transcripts – we gave participants the opportunity to look over the transcript from the interview, and take anything out that they were unhappy with being used (giving a signature).
- Confidentiality
    - pseudo names were used
    - limits of confidentiality were made clear - e.g. child protection issues
- Working with vulnerable families and children – we gave the option of having a familiar worker or advocate present during the interview, and gave a choice of venue.
- Power balance – one challenge was striking the right balance between making a participant feel comfortable, and retaining professionalism. The relationship between the interviewer and participant was defined beforehand and remained as neutral as possible.

Analysis

Analysis took place in a two stage process, which were interlinked.

- Data management (reading and scrutinising transcripts, organising data to identify key themes, and creating a coding structure for the data)
- Interpretation – finding the 'story' in the data and categorising themes.

Various forms of analysis were used. The main form was thematic analysis (focus on what is said), with some discourse analysis (focus on how things are said).

Annexe 2 - Information sheet and Consent Form

Partneriaeth Plant a Phobl Ifanc Conwy
Conwy Children & Young People's Partnership

INFORMATION SHEET

FOR TAKING PART IN AN INTERVIEW - LOOKING AT THE EXPERIENCES OF FAMILIES IN CONWY

Hello
My name is Pat Williams. I work for Conwy Children and Young People's Partnership (which is part of the Council) - you may have seen our logo before. My job is to help people have their say in Conwy. I am asking you to take part in an interview so that we can gain your views (consultation). Before you decide if you want to take part or not, I want to tell you why we're consulting, and what you can expect if you take part. Please think about this information carefully and talk about it with other people if you wish. You're welcome to get in touch and ask me any questions. Please take as much time as you like to decide. This research is being done to help us find out how to improve how we help families in Conwy. Thanks for reading this.

What is the purpose of the consultation?
Our aim is to find out about your experiences as a family living in Conwy and using our services. We want to know about this in order to help us provide services that will help you more, and make a difference to families in Conwy.

How will it work?
We would like to meet with you, and ask you to share your experiences with us. We will ask you some questions to help with this. You can

- choose where you would want to meet us (at home, or somewhere else)
- request that someone else sits in with you, like a worker, a member of the family or a friend
- choose to ask us to come and meet you beforehand to get to know each other a little and talk through the process

In order to help us listen to you effectively and record what you're telling us properly, we would like to use a Dictaphone, and type up what has been said. You can choose to ask us not to use a Dictaphone, and we will ask someone else to come and take notes instead.

How will we protect your privacy and what will happen with the information?
We will provide you with a copy of the typed up interview before we do anything else with it, so that you can take out or change anything that you're not happy with being used. You can also ask us to take out any references to names so that things can be kept secret or hide your identity.
You will be asked to sign a form 'Further use of my interview', which will give us permission to use what you have told us to help us with our work. You will be given a copy of this form to keep.

If you decide to allow your interview to be used, it would be used along with interviews from about 30 other people. The information will be pulled together in a report, which will be used by the "Families First Project Board" to help decide how to improve services for families in Conwy. All data use is strictly within the terms of the Data Protection Act (DPA 1998).

Why have I been chosen?
Your main worker has contacted you because I want to interview people who have had experience of using different services in Conwy. I will be interviewing a range of people who have had such experiences.

Do I have to take part?
It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign a 'consent form'. If you decide to take part, you are still free to stop at any time without giving a reason. Deciding whether or not to take part will not affect the services that you receive.

What will the interview be like?
The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all. While people sometimes find it helpful to talk about their story to researchers this is not the same thing as counselling.

Contact for further information

I hope that this information sheet has told you what you need to know before deciding whether or not to take part.
If you have any questions at all please telephone Pat Williams on 01492 57****.

CONSULTATION - LOOKING AT THE EXPERIENCES OF FAMILIES IN CONWY - CONSENT FORM

Please complete this form to give your consent to take part in our consultation.

There are different options that you can give your consent for - please read this carefully, put a circle around your answers, and fill in the relevant parts before signing the form.

You can change your mind and withdraw your consent at any time during the consultation process.

Before the interview:		
I would like to take part in the consultation (interview).	Yes	No
I have read the information sheet, and I'm happy that I understand what it's about.	Yes	No
I would like to meet with Pat beforehand to go through things.	Yes	No
During the interview:		
I would like the interview to take place	At home	Somewhere else (suggest somewhere here):
I would like someone else to be with me during the interview	Yes (if yes, who? ____________ ________________________)	No
I am happy for a Dictaphone to be used to help Pat listen to what I'm saying, and record it accurately.	Yes	No
After the interview		
I give my consent for the information in my interview to be used in a report. (The report will help people make decisions about improving services for families in Conwy.)	Yes	No
I would like to disguise any names used in the interview so that it will hide my/my family's identity.	Yes	No

Name (PRINTED): Signature: Date: