

MIDDLESBROUGH COUNCIL

AGENDA ITEM 5

HEALTH SCRUTINY PANEL

23 MAY 2013

DRAFT FINAL REPORT CHILDREN WITH COMPLEX NEEDS

PURPOSE OF THE REPORT

1. To present the Health Scrutiny Panel's DRAFT final report into Children with Complex Needs.

Terms of reference

2. The following terms of reference were established to guide the Panel
 - 2.1 To investigate the key indicators of child health in Middlesbrough and specifically, what they say about child health in Middlesbrough
 - 2.2 To investigate the prevalence of complex needs amongst children in Middlesbrough
 - 2.3 To investigate the current range of services available for children with complex needs in Middlesbrough
 - 2.4 To investigate whether there are any gaps in service provision for children with complex needs
 - 2.5 To explore the future challenges for services for children with complex needs
 - 2.6 To investigate the extent to which the local health and social care economy co-ordinates its efforts, in the provision of service to children with complex needs and their families.

Introduction

3. The subject of children with complex needs and how their needs are met is an emotive one and also a significant one for local health and social care systems. Medical advances mean that children survive for longer with conditions that, historically speaking, they would not have been able to. In addition, children are born with conditions that,

historically speaking, they would not have survived childbirth as a result of. All of this is a hugely impressive achievement for medical science and is to be warmly welcomed.

4. All of this, however, does mean that the public purse placed under greater pressure from an area of medical and social care practice, which can be very expensive to support.
5. As a result of this, the Panel felt it was an opportune time to investigate and establish the current picture relating to Children with Complex Needs in Middlesbrough. The Panel decided that this should focus on causes, treatment, availability of services and the future for children with complex needs, and the services they access, in Middlesbrough.

What is a Child with a Complex Need?

6. The definition of a 'child in need' under the Children Act 1989 is as follows:

'For the purposes of this Part, a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability'

Facts and figures relating to Children with Complex Needs

7. According to Contact a Family:
 - 7.1 1 child in twenty in the UK a born with a disability. This means that there are currently around 770,000 children in the UK affected.
 - 7.2 99.1% of disabled children live at home and are supported by their families.
 - 7.3 52% of families with disabled child are at risk of experiencing poverty
 - 7.4 income of families with disabled children averages £15,270, which is 23.5% below the UK average income, and 21.8% have incomes that are less than half the UK mean.
 - 7.5 Only 16% of mothers with disabled children work, compared with 61% of other mothers.
 - 7.6 It costs up to three times as much to raise a disabled child, as a child without disabilities.
 - 7.7. One in 13 receive regular support service of any sort from their local authority.

Support for Parents

8. The Panel was interested to gather some preliminary information about the rights of those with children with complex needs and the support they are entitled to.
9. Parents have the right to ask for their child's needs to be assessed by the relevant social services department. They also have the right to ask for an assessment for themselves. An assessment could lead to services for a disabled child being provided, or services to help the carer.
10. Local authorities have a duty to provide certain services to disabled children. The kind of services that may be offered include:
 - 10.1 practical assistance in the home
 - 10.2 provision of, or support in acquiring, a radio, television, accessing a library, or similar recreational facilities
 - 10.3 recreational facilities outside the home and help to use educational facilities
 - 10.4 travel and other assistance
 - 10.5 home adaptations and facilities
 - 10.6 holidays
 - 10.7 meals
 - 10.8 telephone and other related equipment.
 - 10.9 Other services may be provided by the local authority such as advice and guidance, laundry services and financial help in exceptional circumstances.

Evidence from the Health Scrutiny Panel meeting on 23 October 2012

11. Having identified a strong interest in the topic of Children with Complex Needs, the panel felt it would be useful to hold an initial discussion with a number of key representatives of the local health and social care economy. The purpose of the discussion would be to consider Middlesbrough Council & NHS Tees representatives' initial thoughts on the topic, and to consider which issues would be most important to tackle in an investigation into Children with Complex Needs.
12. From the outset, The Panel heard that there were different interpretations of what constituted 'children with complex needs'. The

definition provided by the Department of Education was reported as

'such children have a number of discrete needs that require additional support from more than one agency. Their needs are often chronic and may be lifelong. Different needs tend to interact, exacerbating their impact on the child's development and wellbeing.'

13. It was confirmed that NHS Tees does not have a definition as such, although considered a child with complex need to be one that had a ongoing healthcare need, requiring an intervention. Whilst it was considered that this may be a strength, as having too rigid a definition may then exclude some from assistance, it concerned the Panel that NHS Tees and the local authority did not have a shared understanding of what a child with complex needs was.
14. In order to assist deliberations a series of questions had been prepared as outlined in the report and circulated to the representatives prior to the meeting. Those questions were
 - 14.1 *What definition does the Local Authority/NHS Tees use for Children with Complex Needs?*
 - 14.2 *How many children are there, in Middlesbrough, with complex needs?*
 - 14.3 *Does the Local Authority/NHS Tees know how many are born each year?*
 - 14.4 *Does the Local Authority/NHS Tees know what its current spending is on Children with Complex Needs?*
 - 14.5 *From a Local Authority/NHS Tees perspective, what are the areas of concern/future attention regarding Children with complex needs?*
 - 14.6 *What, in the Local Authority /NHS Tees view, is good about service provision for Children with Complex Needs in Middlesbrough? What could be improved?*
15. The Panel heard from senior officers, who gave an indication of the legislative background and wider interpretations of what constituted 'children with complex needs', with reference to National Assistance Act and Children Act.
16. In terms of determining the approximate number of children with complex needs in Middlesbrough it was pointed out that this was a difficult exercise given the different professions involved and various definitions. It was said, however that at the time of the meeting, there were 274 disabled children in Middlesbrough that were known to the local authority, in the sense of constituting a caseload. The Panel heard that national research would indicate that 1.2% of the population would have a disability, which would suggest that there were around

370 or so disabled children in Middlesbrough, so there are potentially around 100 disabled children not engaged with the local authority.

17. The Panel heard that physical disabilities were easier for services to quantify and classify, it is more difficult for children on the Autism Spectrum to be classified and for their service needs to be accurately understood. It was confirmed that Middlesbrough Council's children's disability service currently costs in the region of £2m per annum.
18. As far as NHS Tees was concerned, the Panel enquired as to how much it would spend on children with complex needs in 2012/13. It was reported that as the NHS Tees paediatric contract was a block contract, it would be very difficult to disaggregate what was spent on disabled and non-disabled children. It was noted, however, that it was almost certain that spending on disabled children would increase markedly in future years.
19. The Panel was keen to gather the views of those present on future challenges, in relation to the caring for children with complex needs. A range of issues were highlighted which included the following:
 - 19.1 Reduced budgets and uncertainty around health funding;
 - 19.2 Meeting appropriate housing needs;
 - 19.3 Increasing number of children with complex needs, at an earlier age
 - 19.4 together with higher level complexities often requiring 24 hour care;
 - 19.5 Advances in medical science;
 - 19.6 Low take-up of immunisations
 - 19.7 Increasing number of babies born weighing less than 5lbs;
 - 19.8 Higher than average local figures for autism
 - 19.9 Foetal Alcohol addiction
 - 19.10 More complex disability in Children

Evidence from Health Scrutiny Panel meeting on 5 December 2012

20. In an earlier meeting, the Panel heard that low birth weight and/or pre term delivery are risk factors in children developing complex needs.
21. The Panel was keen to explore this point in more detail and so received a briefing from Public Health professionals on low birth weight (LBW) in Middlesbrough.
22. The Panel heard that LBW is an enduring aspect of childhood illness, a major factor in infant mortality and has serious consequences for child health both in early years and later life. It was confirmed to the Panel that it is caused by either a short gestation period, or intrauterine growth restriction (IUGR) (or a combination of both).
23. The Panel was keen to ascertain what LBW is defined as. The Panel was advised that LBW is defined as births under 2,500g (Krammer 1987). It was confirmed that there are further sub classifications for birth weight which includes:

- 23.1 Extreme Low Birth Weight (ELBW) less than 1,000g
- 23.2 Very Low Birth Weight (VLBW) less than 1,500g

- 24. The Panel was interested to learn if any groups were at greater risk of having LBW babies. It was confirmed that LBW babies are more common in the following circumstances:
 - 24.1 Babies born to mothers under the age of 20 and over the age of 40
 - 24.2 Babies born to mothers living in deprived areas or mothers with low socio-economic status
 - 24.3 Babies born to lone mothers
 - 24.4 Babies born to mothers born outside the UK – especially in some black and minority ethnic groups

- 25. The Panel was advised that LBW babies can be born full or pre-term and have varying degrees of health, well-being and psycho-social outcomes, with LBW being associated with a broad spectrum of growth, health, and developmental outcomes. It was reported that whilst the vast majority of LBW children have normal outcomes, as a group they generally have higher rates of subnormal growth, illnesses, and neuro-developmental problems. It was confirmed that these problems increase as the child's birth weight decreases.

- 26. It was confirmed that as LBW is a leading cause of infant mortality, preventing it is highly important to public health and evidence of effective interventions is urgently needed, to contribute to the delivery of these targets.

- 27. The Panel was advised that international comparisons suggest that factors beyond genetic constraints are responsible for differences in birth weight within populations and that birth weight distributions can potentially be altered by public health interventions (Paneth, 1995). It was emphasised that a key message from the Marmot Review highlight's that health inequalities results from social inequalities, and in order to facilitate that every child has the best possible start in life, action on health inequalities requires action across all the social determinants of health (Marmot 2010).

Preventable environmental factors for low birth weight

- 28. It was confirmed to the Panel that smoking during pregnancy is the major modifiable risk factor contributing to LBW and preterm delivery, with greater risk associated with heavier smoking. Babies born to women who smoke weighed on average 200g less than babies born to non-smokers; so the incidence of LBW is twice as high among smokers (Messecar 2001).

- 29. It was highlighted to the Panel that NICE guidance (Bull et al 2003) highlights that women who smoke in pregnancy are more likely to

experience lower socio economic status, low education, lower income and employment status.

30. It was confirmed to the Panel that whilst cigarette smoking appears to be the most important mediating factor for LBW, other factors such as low gestational weight gain and short stature also play an important role. For pre-term births there are significant social gradients associated with smoking and bacterial vaginosis, this social gradient may also explain some of the socio-economic disparities reflected in the data on pre-term births. (Bull et al 2003)
31. The Panel was interested to note the table below, which illustrates the association between increased social and economic disadvantage and higher levels of smoking amongst women with young children.

Social disadvantages and cigarette smoking among women with young children, UK 2001 – 2002 (n=13,573)

All mothers	28%
Mothers with childhood disadvantage (based upon father's occupation)	33%
+ Left school \leq 16 years	44%
+ A mother < 20 years	63%
+ Adult disadvantage (Annual household income \leq £11,000)	69%
+ Lone mother	72%
Mothers experiencing none of above	12%

(Graham 2010)

Factors that contribute to low birth weight

Risk Factor	Prevalence
Substance misuse	More common in low SES women
Work/physical Prolonged standing and activity strenuous work	
Bacterial vaginosis	
Psycho-social factors More stressful life events, more chronic stressors	
Depression and low levels of social support	
Micronutrients Low dietary intake	
Cigarette smoking	Higher prevalence and heavier smoking among low SES women
Anthropometry/ nutritional status	Short stature, low pre-pregnancy body mass index (BMI), low gestational weight gain more common in low SES women
Prenatal care	Lower uptake among low SES women
Multiple birth	Less common among lower SES groups

(Bull et al 2003)

Local picture

32. The Panel heard that Middlesbrough's proportion of LBW children (9.5%) is approximately 1% above the Tees Valley average and 2% above the national average (2010). Current performance indicators (2012) for Middlesbrough show that the number of LBW babies continues to rise (10.1%).

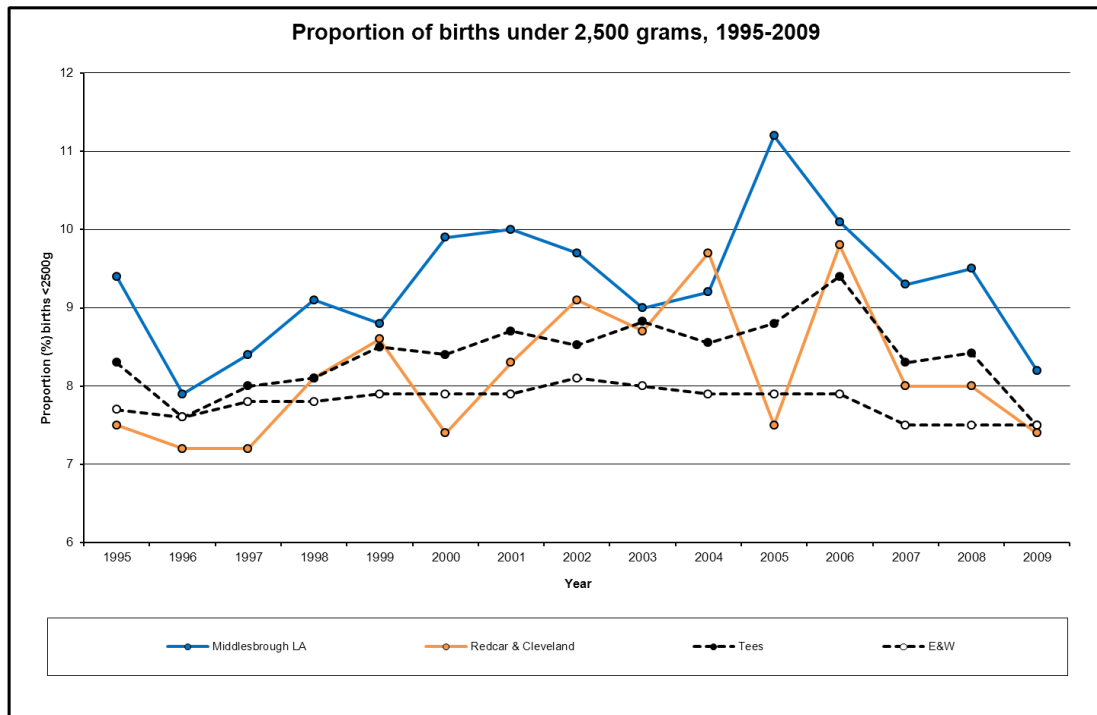
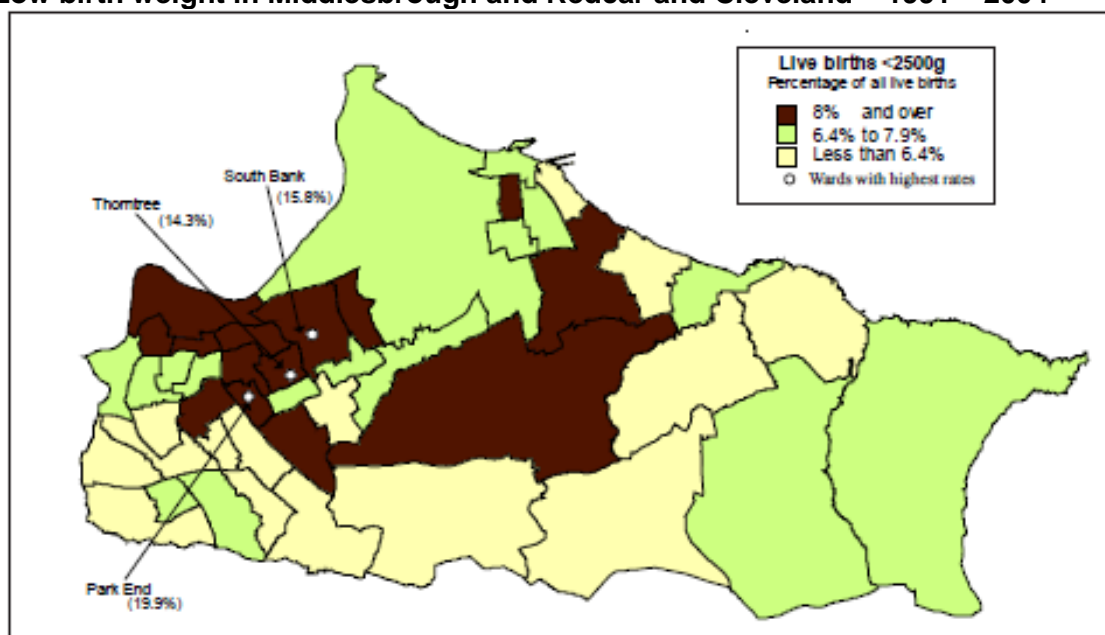


Figure 1: (Aszkenasy et al 2007)

33. The Panel was particularly interested in understanding how LBW incidence figures varied within Middlesbrough. The Panel was surprised to learn that in Middlesbrough (1991 – 2004) the average rates for LBW children ranged from a low 2.4% (Nunthorpe) to 19.9% (Park End). There is an associated distribution of LBW and SES. There is a higher distribution of LBW children in poorer areas (figure 1 below).

Low birth weight in Middlesbrough and Redcar and Cleveland – 1991 – 2004

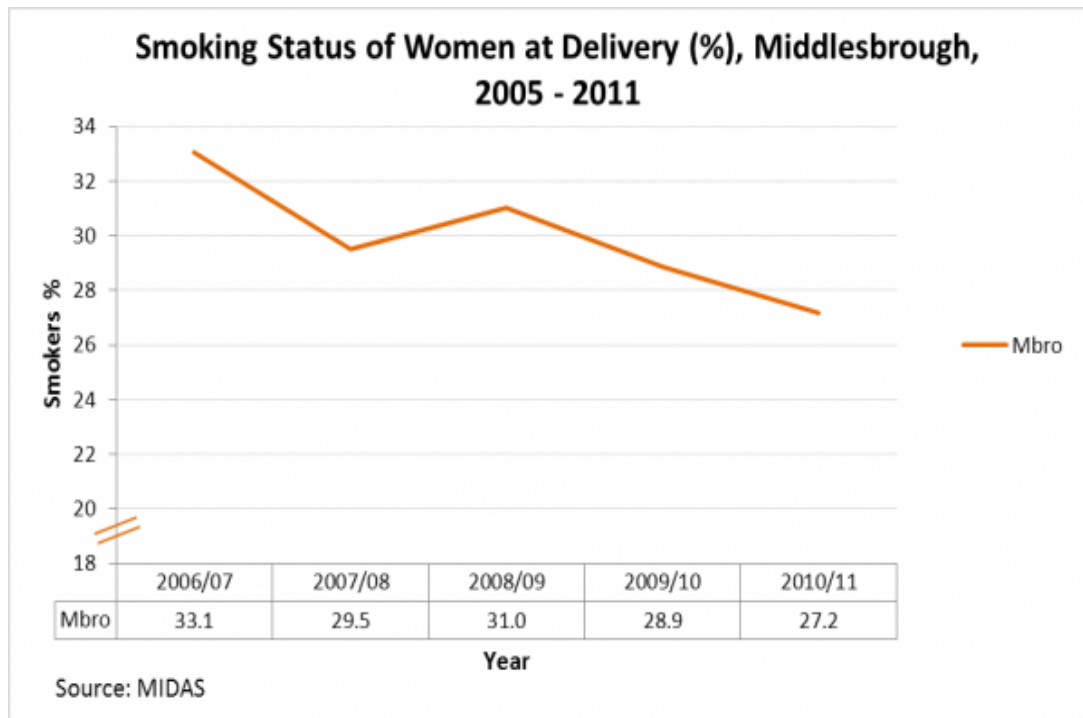


(Aszkenasy et al 2007)

Smoking in pregnancy in Middlesbrough

34. The Panel heard that a recent analysis of the pregnant smoking population in Middlesbrough using Mosaic¹ confirms that this profile is replicated in Middlesbrough maternal smoking population.
35. It was reported that Middlesbrough has consistently had poor outcomes in relation to smoking in pregnancy. Middlesbrough Smoking and Tobacco Control JSNA 2012 identify that 31% of women aged 20-24 smokes. The Panel heard that the prevalence of smoking in pregnancy in Middlesbrough is 27.2%; this is double the national average in England of 13.5%, and significantly higher than the regional average, which is 21.1%.

¹ Mosaic Public Sector is the UK's only classification designed specifically for use by the public sector and focuses on the needs of citizens. It provides a detailed and accurate understanding of each citizen's location, their demographics, lifestyles and behaviours. Please see <http://www.experian.co.uk/business-strategies/mosaic-public-sector.html>



Middlesbrough JSNA Tobacco (2011)

36. The Panel was advised that the distribution of smoking prevalence in Middlesbrough, mirrors the patterns of deprivation with the deprived wards having higher percentage of smokers compared to affluent wards. In an analysis of the maternal smoking population in Middlesbrough (2011) using Mosaic, 80% of the maternal smoking population is distributed across 6/69 public sector types.

Public Sector Type	%	Preferences	Non-receptive	Service Channels
Families in low rise social housing with high levels of benefit need (public sector group)				
Vulnerable young parents needing substantial state support	40%	SMS Text Face to Face National Papers Local Papers	Internet Telephone Mobile Phone Post	Face to Face
Older Tenants on low rise social housing estates where jobs are scarce	15%	Face to Face Local Papers	Internet Telephone Mobile Phone Post	Face to Face
Lower income workers in urban terraces in often diverse areas (public sector group)				
Older Town centres terraces with transient, single populations	9%	Face to Face Local Papers SMS Text Interactive	Internet Telephone Magazines Post	Face to Face
South Asian communities experiencing social deprivation	6.5%	SMS Text National Papers	Internet Telephone Face to Face	None-significant

Lower income families occupying poor quality older terraces	3.5%	SMS Text Face to Face Interactive TV	Magazines Post	Mobile Phone
Residents with sufficient incomes in right to buy social housing (public sector group)				
Older families in low value housing in industrial areas	6%	Face to Face Local Papers	Internet Telephone Mobile Phone Post	Face to Face
Total Maternal Smoking Population				80%

Table 3 (Mosaic Data on Maternal Smoking in Middlesbrough 2010 – 2011)

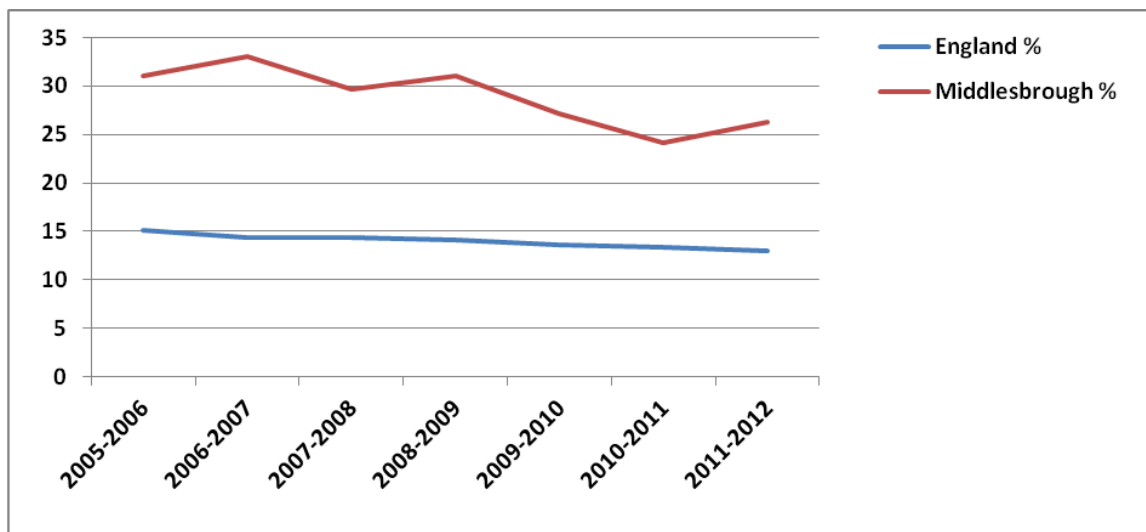
37. On the subject of tobacco use in pregnancy, the Panel was keen to gather more detail about the current picture in Middlesbrough and how services can assist expectant mothers in stopping.
38. The Panel was supplied with an evidential paper from the Public Health Directorate, which was considered whilst the Panel was preparing its final report. It was confirmed that the data period used for this report runs from January 1st 2012 – 31st December 2012. The national comparative data is for the period April-September 2012.
39. The Panel was advised that quitting smoking in pregnancy is challenging. It was reported that women that commence pregnancy as a smoker perceive smoking as central to their lives and identity. Smoking is a dependency that is particularly hard to break in times of stress, with pregnant women viewing smoking as an enjoyable and relaxing activity.
40. The Panel was advised that research indicates that social networks and relationships are entwined and the smoking status of a partner/family, is an important factor in the likelihood of successfully quitting smoking. Pregnant women report that guilt, stigma and social disapproval trigger intense feelings, whilst managing to stop smoking alleviates this guilt. It was reported that working to address this contradiction between pleasure and guilt is highly complex.

Smoking in Pregnancy at Time of Delivery in Middlesbrough 2012

41. It was reported to the Panel that 564 women were identified as smoking (based upon smoking at time of delivery). This is a smoking in pregnancy rate of 26.6% and represents an increase of 0.5% for the same period (2011).

Access to Stop Smoking Services In Middlesbrough

42. The Panel heard that in 2012, 128 pregnant women set a 'quit' date. In comparison to 2011, this is a 27% reduction in the number of pregnant women accessing the SSS.



Smoking in Pregnancy Rates 2005-2012

43. It was reported to the Panel that in 2012, 49 women (38.3%) successfully quit at 4 weeks and 38 women (29.7%) were lost to follow up. In comparison to 2011, this represents an increase of 6.2% of pregnant women successfully quitting at 4 weeks.

44. In summary, the Panel heard that the Stop Smoking Service worked with less pregnant women, however were more successful in the quit rates at 4 weeks.

Performance in Relation to National Rates

45. The Panel was advised that the following data is based upon the time period April 2012 – September 2012 as the Q3 national data set has not yet been published.

45.1 Middlesbrough has a maternal quit rate **5.1%** below the national average.

45.2 Middlesbrough has a lost-to-follow-up rate **6.7%** higher than the national average

46. In summary the Middlesbrough Stop Smoking Service has below average 4-week quit rates and loses above average rates of pregnant women during treatment.

Performance in Relation to Hartlepool

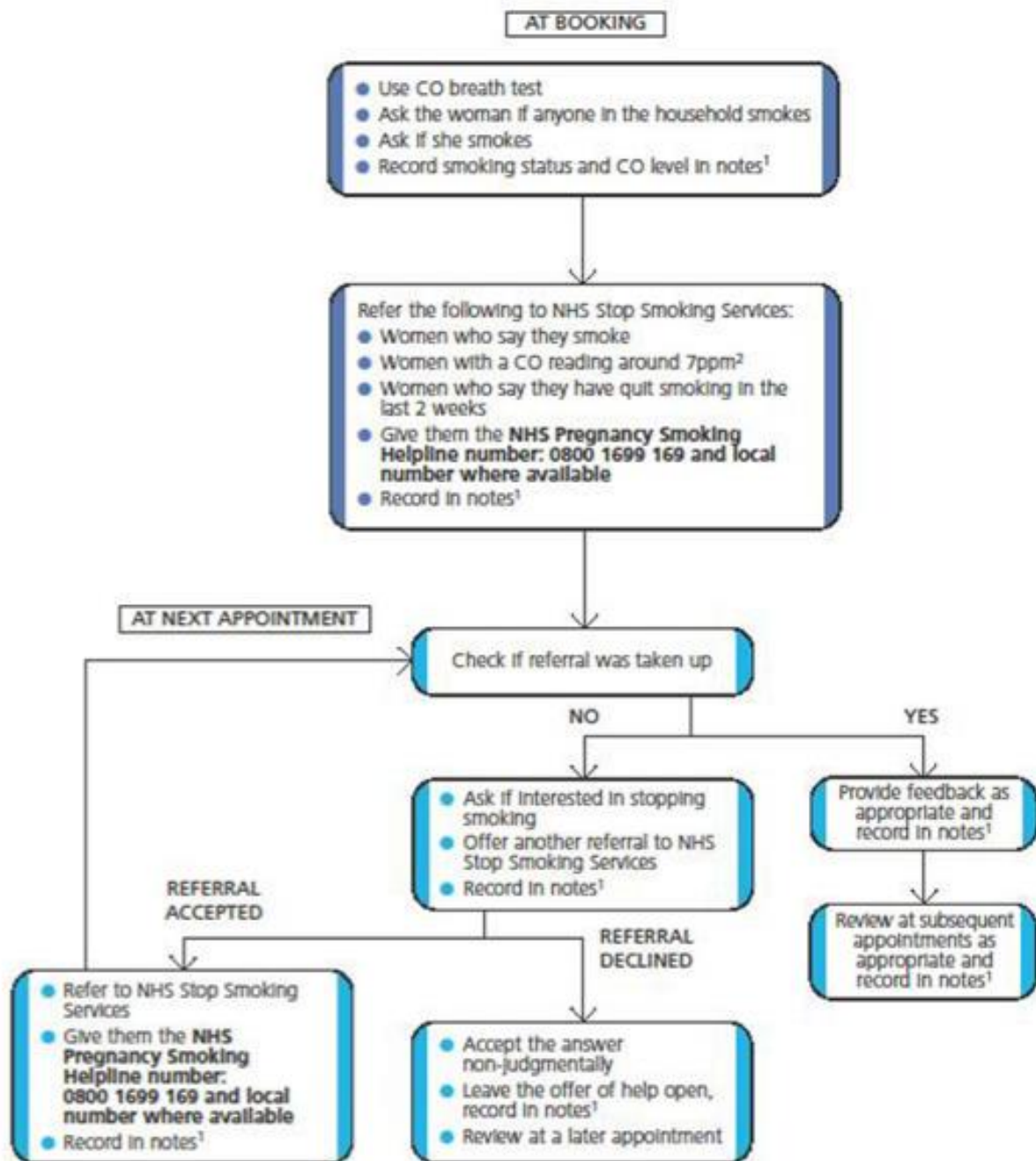
47. The Panel was interested to learn that there is a striking comparison to Hartlepool in terms of access, where 82% of pregnant smokers will access the Stop Smoking Service in Hartlepool, although the overall quit rate is similar to Middlesbrough at 38%.

48. The Panel was advised that this replicates a growing evidence base

that reports similar quit rates amongst pregnant smokers that voluntarily access Stop Smoking Services, in comparison to pregnant smokers that are automatically referred to Stop Smoking Services. This suggests that motivation to stopping smoking is an important factor contributing to successfully quitting smoking in pregnancy.

National Evidence

49. The Panel was advised that in 2010 National Institute for Health and Clinical Excellence (NICE) published national guidance for practitioners and commissioners on effective and evidence based approaches to help facilitate pregnant women to stop smoking. This guidance built upon a number of previous reviews.
50. The Panel learned that NICE reported that the evidence relating to pregnant women included; developing tailored interventions increased acceptability and access to services and that routine administration of leaflet-based interventions, demonstrated a positive effect and were cost effective.
51. The Panel was advised that NICE guidance recommends that midwives use carbon monoxide (CO) breath-test as an independent validation of smoking status and to actively refer all pregnant smokers to Stop Smoking Services and provide information to all pregnant women on the risks of smoking to the unborn child.



Barriers to Take-up of services

52. It was reported that a fear of failure and disappointing a health professional is cited as the main patient barrier. Receiving different messages is also problematic; midwives advising reduction, where as GPs and doctors advising stop smoking. The communication skills of the professional are very important as they can be perceived as nagging and preaching
53. The Panel was advised that barriers centre on the relationship between the pregnant woman, partners/families and the midwife. When the midwife is seen as health-professional, pregnant women do not share concerns about smoking, as the role of the midwife changed into

confidant/door opener, motivation to quit smoking increased. The structure of midwifery appointments and the clinical environment reinforces the role of midwife as health-professional.

54. The Panel was advised that other obstacles include; sessions being too long and available at the wrong time, both in terms of time in the day and also timing in relation to pregnancy/delivery. The Panel was interested to note that issues relating to mobility, transport and childcare were reported as barriers.
55. There are contradictory messages within current clinical protocols, relating to cut-off points for CO monitoring and whether to enforce an opt-out direct referral to SSS. The evidence suggests that the quit rates are the same for opt-out versus voluntary referrals. These mixed messages are confusing and can undermine credibility.
56. The Panel noted that practical considerations relating to the engagement of partners/family into the Stop Smoking Services pathway, will require reconfiguring a service that has solely focused on women; this presents a huge cultural shift in maternal services.
57. Rates of smoking in pregnancy/motherhood increase with low socio-economic status. The feasibility of reaching this population has challenges particularly so in Middlesbrough, which in 2010 ranked as the 8th most deprived local authority in England.

Local Developments in Middlesbrough to Increase the Access and use of Stop Smoking Services

58. Following a 2012/13 recovery review of South Tees stop smoking service provision, the 'Tees Stop Smoking and Tobacco Control Strategic Commissioning Group' reached an agreement to decommission the STHFT Specialist Stop Smoking Service contract as part of a three-year plan to increase the efficiency and effectiveness of stop smoking provision locally with a core focus on providing a wider distribution of antenatal SSS.
59. Middlesbrough maternity services are scheduled to receive the 'Baby Clear' training package (May 2013). Baby Clear training will be targeted at midwives and aims to transform the delivery of SSS in pregnancy. The training has been commissioned by the Clinical Innovations team for maternity care. Fresh will be coordinating the roll out of this training across the North East.
60. The training will be evaluated by Newcastle University and will include an analysis of cost effectiveness and acceptability of the approach amongst pregnant women.

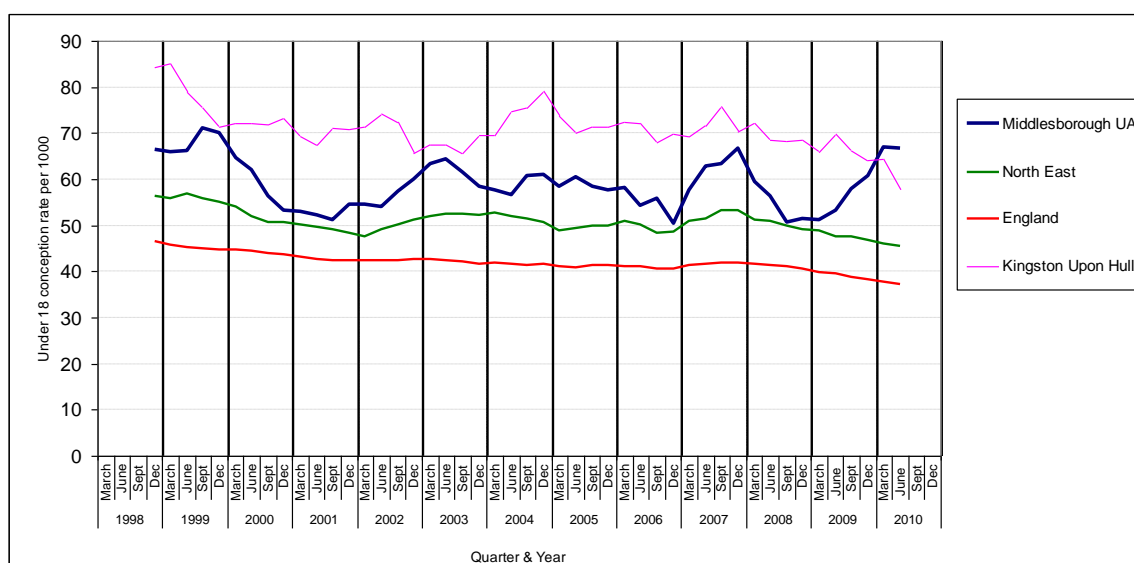
Teenage pregnancies

61. The Panel learned that births to women under 20 years is a known risk factor of increased likelihood of LBW children. It was confirmed that Middlesbrough has the 2nd highest rates of teenage conception in England. In 2010 the teenage conception rate was 64.5 per 1000 women aged 15-17 years; this was a rise of 7% on the previous year, which was 60.4 per 1000. Overall for the same period the average rate of teenage pregnancy in England has fallen by 7% (2009 – 2010). (ONS 2010).
62. The Panel heard that in Middlesbrough there is a strong correlation between teenage pregnancy and levels of deprivation. The more deprived the area, the higher the number of under-18 conceptions. Almost 48% of teenage conceptions in Middlesbrough in 2009 were in East Middlesbrough or in the adjoining wards of Clairville and Beechwood (Table 3 below)

2009	Rate per 1,000	Numbers
National Average (England)	38.2	
Regional Average (North East)	46.9	
Middlesbrough	60.4	174
East Middlesbrough	80.4	83

63. Average conception rates have fluctuated between 1998 and 2010 (Figure 4). The overall trend shows a slowly declining rate over this time period. Rates are higher than the North East, and England rates but lower than Kingston upon Hull until 2010.

Under 18 conception rate (per 1000 15-17 year olds) in Middlesbrough and comparator areas, 1998-2010



Substance misuse during pregnancy – drugs and alcohol

64. The Panel was advised that alcohol consumption of more than one unit per day during pregnancy is a risk factor for low birth weight, foetal alcohol syndrome and foetal alcohol spectrum disorders. It was reported that women who drink 1 to 2 units per day are 1.62 times more likely to have a LBW baby; women who drink 3 to 5 units per day are two times more likely to have a LBW baby (Tolo et al 1993).
65. The Panel heard that substance misuse during pregnancy is associated with a range of health problems for both the mother and the baby. This is due to a complex combination of the direct impact of drugs on the growing foetus, other health issues that may co-exist with the substance misuse during pregnancy (poor general health and health problems associated with the drug misuse) and wider social and economic factors such as poverty, crime and domestic abuse. Further, it was reported that pregnant women who misuse substances may not seek ante-natal services until very late in pregnancy.
66. It was reported to the Panel that further work is required to understand the patterns and levels of drugs and alcohol consumption during pregnancy in Middlesbrough and the current services that are in place to address these issues for pregnant women.

Dietary intake

67. The Panel heard that low dietary intake and low body mass index during pregnancy are associated with LBW and poor outcomes for the baby and the mother. Maternal nutrition plays a crucial role in influencing foetal growth and birth outcomes. The Panel was advised that it is a modifiable risk factor of public health importance in the effort to prevent adverse birth outcomes, particularly among low-income populations.
68. The Panel heard that Women with low pre-pregnancy weight for height or low BMI are at increased risk for a number of adverse pregnancy outcomes, including pre-term birth, LBW and Intrauterine Growth Restriction (IUGR). It was said that a low BMI interacts with other risk factors such as smoking and stress to increase risk of poor pregnancy outcomes.
69. The Panel was advised that further work is required to explore the local data that is captured by maternity services on maternal weight gain in pregnancy.

Antenatal care

70. The Panel heard that low uptake of prenatal care is identified as a risk factor for poor outcomes in pregnancy (Bull et al 2003). It was confirmed that there is sufficient data from repeated epidemiological studies that socio-economic deprivation is linked to both decreased access to antenatal care and increased maternal morbidity and mortality (Downe et al 2008).
71. It was reported that data on access and service usage to antenatal care in Middlesbrough will capture more detailed description of any demographical differences.

Bacterial vaginosis

72. The Panel heard that Bacterial vaginosis and other infections (commonly referred to as Strep B) during pregnancy are associated with low birth weight and small for gestational age. It was reported that there is a socio-economic gradient in the distribution of bacterial vaginosis with more women in lower socio-economic groups having the condition compared to more affluent socio-economic groups. Local data is not available on the extent and socio-economic distribution of bacterial vaginosis in Middlesbrough.

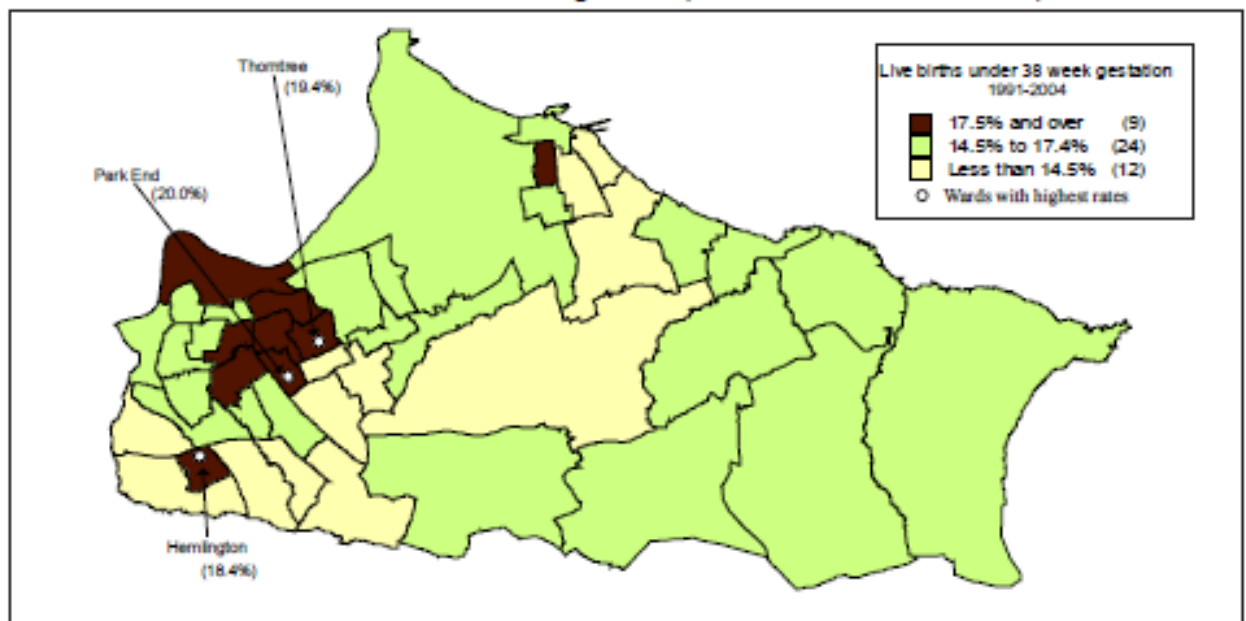
Psycho-social factors

73. The Panel was interested to learn that stressful life events, poor mental and emotional health and chronic stressors during pregnancy are associated with low birth weight and poor outcomes for babies. There is a complex interaction between psycho-social factors and other factors such as deprivation, smoking during pregnancy, alcohol and substance misuse and poor engagement with antenatal care services.
74. It was reported that domestic violence and abuse during pregnancy can have serious consequences for maternal and infant health. Evidence suggests that around 30% of domestic violence starts or worsens during pregnancy. It is estimated that one in six pregnant women will experience domestic violence at some point during pregnancy with a greater proportion of these being women from deprived areas. Domestic violence and abuse during pregnancy can also indirectly impact upon the health of a woman and her baby through poor diet, poor mental and emotional well-being, poor physical health, homelessness and restricted access to antenatal care. On this point, the Panel was interested to learn that there are established biological connections between stress hormones and the likelihood of a baby being delivered prematurely.
75. The Panel heard that further work is required to understand the scale and distribution of domestic violence during pregnancy in Middlesbrough and the effectiveness of the services that are in place to deal with this issue.

Pre-term births

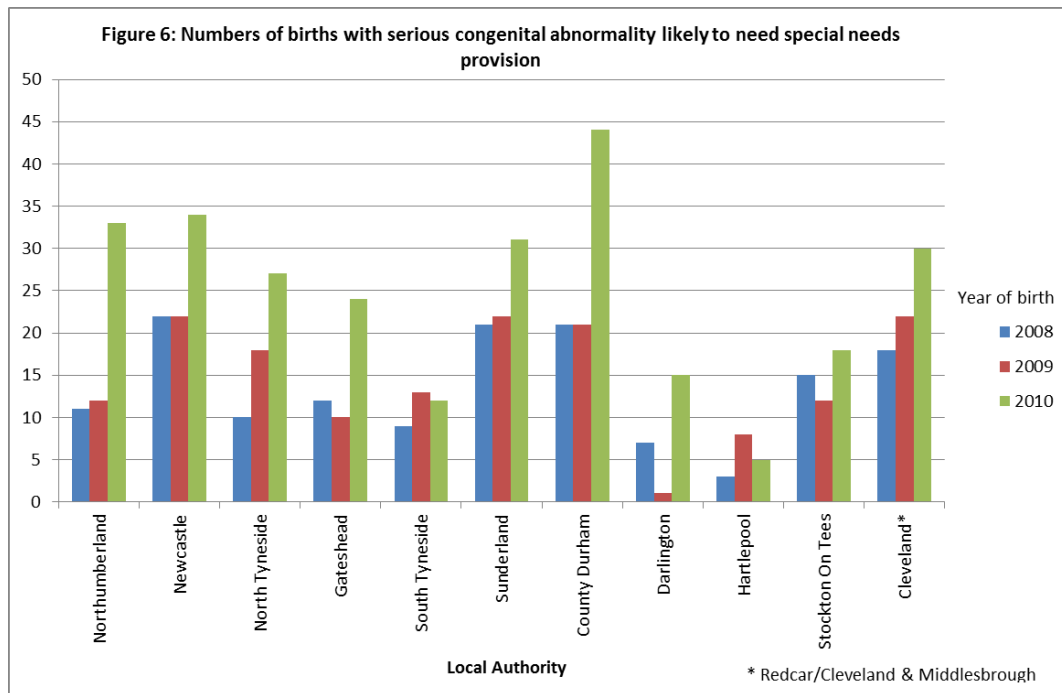
76. The Panel was interested to hear about pre-term births, its impact on health outcomes and its interplay with LBW. The Panel was advised that LBW and gestational age are inter-related, as a LBW can be as a direct consequence of a pre-term birth. It was confirmed to the Panel that there is less evidence on the causes of pre-term delivery, although it was clearly outlined to the Panel that research has shown that birth before 26 weeks gestation, is associated with a high prevalence of neurological and developmental disabilities. In Middlesbrough there are a higher percentage of pre-term births in deprived areas compared to more affluent wards.

Distribution of all live births under 38 weeks gestation, South Tees electoral wards, 1991-2004



(Aszkenasy et al 2007)

77. The Panel was advised that research has demonstrated that at 30 months of age, 24% of survivors have severe disabilities (Marlow et al 2005), with a total of 80% of survivors experiencing some form of disability (Bradford et al 2012). It was reported that the Regional Maternal Survey Office (RMSO) has undertaken a rapid data retrieval of information about children with disabilities. The Panel was interested to note the graph below, which charts the year on year increase in the number of children likely to require special needs provision, as a result of serious congenital abnormalities.



(Bradford et al 2012).

78. The Panel was advised that the RMSO has identified that increase in survival rates of preterm births have improved over the last 15 years. The Panel was interested to note that in the North East and Cumbria, survival at 24 weeks is around 60% (RMSO 2012). It was stated that further work is required to understand the outcomes of pre-term births and the impact of improved survival rates on health and well-being outcomes for the babies, current and future special needs provision.

Current work streams to address low birth weight in Middlesbrough

79. The Panel was keen to hear about the work that is currently underway in Middlesbrough to address low birth weight.
80. The Panel was advised that The Middlesbrough Joint Health and Wellbeing Strategy identifies as one of its strategic aims, the need to ensure children have the best start in life. The Health and Wellbeing Board signed off the strategy at a meeting in October 2012 and work is underway to develop the board's annual work programme, performance management framework and the delivery mechanisms for the strategy.
81. It was reported that across South of Tees, a maternal health sub-group has been proposed to provide a strategic forum for maternal health services and programmes across Middlesbrough and Redcar and Cleveland.
82. It was also reported that a SEN and disability review is being carried out through Middlesbrough Achievement Partnership, and this includes

a review of the preventative programmes delivered during pregnancy aimed at the environmental factors

83. The Panel heard that the Middlesbrough Tobacco Alliance has reviewed data on maternal smoking in Middlesbrough and is exploring ways of engaging with maternal smokers using social marketing methods.
84. The Panel was advised that the healthy child programme (HCP) is a complex, inter-related, multi-disciplinary preventive health programme that requires the involvement of statutory and voluntary sector organisations. The HCP covers the breadth of a child's health and well-being needs from 0 to 19.
85. A number of priorities were presented as:
 - 85.1 Working within the emerging commissioning structures and the NHS reforms is a key priority.
 - 85.2 Implementation of the single care plan for 0 – 25 year olds with complex care and special needs (April 2014).
 - 85.3 Working with the National Support Team's recommendations on reducing infant mortality rates in Middlesbrough.
86. The Panel was interested to hear about the regional roll out of training for midwives, to implement NICE smoking cessation in pregnancy care pathway. Midwives will be trained to support pregnant women to stop smoking. Middlesbrough is in the phase 2 roll out (March – June 2013). This programme will be evaluated by Newcastle University.

NEXT STEPS

87. Following the Panel hearing about what work was currently underway, the Panel was keen to hear about what the local health and social care economy should do next, to improve maternal and infant health.
88. It was reported to the Panel that the Middlesbrough Children and Young People's Trust/Executive Board has formed a task and finish group that will oversee the following work streams.

MATERNAL HEALTH NEEDS ASSESSMENT

89. This involves the undertaking of a full Health Needs Assessment (HNA) for maternal health and outcomes for babies and children aged under 5 years. The Panel was advised that the needs assessment will combine an analysis of routinely collected information as well as explore opportunities for carrying out bespoke data collection especially for risk factors where data collection does not currently exist. The HNA will also seek to engage service providers and stakeholders to gain an

understanding of services and programmes that are currently being delivered, interagency working and gaps in the current model.

CO-ORDINATION OF MATERNAL WORKING GROUPS

90. The Panel was advised that there are a number of work streams and groups whose work will have an impact on maternal health and outcomes for babies and infants. It was said that with the current NHS reforms, there is need to ensure co-ordinated efforts and collaborative working to avoid duplication of efforts. It was confirmed that the HNA will map the current work streams and strategic groups that can contribute to reducing numbers of LBW children and improving maternal health outcomes in Middlesbrough, whilst making recommendations for co-ordinated efforts across these groups.

LOCAL AND REGIONAL SURVEILLANCE

91. The Panel was advised that there is need for robust monitoring and local surveillance systems to capture demands placed upon special care services and the nature of the complexity of the presenting cases. This will help to evaluate any changes in the needs of the population and will assist in future projections and service planning for the life course of this population.

92. It was confirmed that local services would contribute to a bespoke regional data collection project managed by the RMSO. The RMSO have access to data on region wide basis and is able to produce a data set for Middlesbrough, which could be contextualised within a trend's analysis for the Region.

- 92.1 Numbers of babies born by gestational age alive at 1 year
- 92.2 Numbers of congenital abnormalities
- 92.3 Projection of numbers likely to require special educational needs
- 92.4 Estimations of children with mild disabilities
- 92.5 Numbers of children with complex cerebral palsy
- 92.6 Mortality data (including category e.g. sudden death syndrome)
- 92.7 Analysis of LBW and gestational age
- 92.8 Survival rates and LBW, VLBW and ELBW

SOCIAL MARKETING

93. The Panel was advised that the children's trust executive will identify how best the efforts to reduce the preventable causes of LBW and poor outcomes for babies and infants can be co-ordinated to avoid silo working and pregnant women having to access a number of different services. There is also need to increase awareness of a healthy pregnancy with the use of social marketing approaches to ensure that messages are being delivered in the best way.

Evidence from Panel meeting on 17 December 2012

94. To build on the evidence collected at its meeting with Public Health professionals on 5 December 2012, the Panel was keen to get the views of the Local Authority as a provider and Commissioner of Children's Social Care. The Panel also heard from NHS Tees, as a system leader and Commissioner of health services.
95. The Panel posed the following questions to the Directorate of Care, Wellbeing & Learning. They were initially addressed in a paper submitted by the Directorate to the Panel, which was discussed at the meeting.
96. The questions that the Panel asked were:
- 96.1 *How does the Council define 'Children with Complex Needs' in the context of children's social care?*
- 96.2 *On the basis of that definition, how many are you aware of in Middlesbrough?*
- 96.3 *How would the authority normally become aware of Children with Complex Needs?*
- 96.4 *Is there any intelligence to indicate that there are children with complex needs that are not engaging with services?*
- 96.5 *The Panel has previously heard that appropriate care placements for children with complex needs are often out of area and very expensive. Why are they so expensive?*
- 96.6 Connected to the question above - what evidence do you have that repatriating children in out of area placements, into more local ones, would save money? Wouldn't staff costs be fairly fixed, wherever a facility was located?
- 96.7 To what extent is there a market of possible local providers now? If necessary, how would the local authority go about stimulating the market to encourage possible providers to establish themselves?
- 96.8 *What progress has been made in identifying or stimulating providers of care for children with complex needs?*
- 96.9 *What framework does Children's Social Care have in place to establish the quality of outcomes for people using the service?*
- 96.10 *How does the Department ensure that the views of families & the children involved, influence services?*
- 96.11 *The Panel has heard previously that the Department has encountered difficulty in securing CHC funding from NHS sources to support clients?*

Could you provide a couple of anonymised case studies to highlight some of the issues faced?

96.12 *What intelligence does the Department have about how future demand looks for services aimed at Children with Complex Needs, from population data*

How does the Council define “Children with Complex Needs” in the context of Children’s Social Care?

97. The Panel was advised that definitions of ‘disability’ vary, but it generally means children who need significantly more support than other children, to do the things that children of their age would be able to do. It was reported that the term “children with disabilities” covers a very diverse group, ranging from children who have autism or a learning disability but who can undertake most tasks and activities with support, to children who have severe learning disabilities or severe physical disabilities and need all their care needs to be met by others. Further, some children are technology-dependent. Some have such extreme behaviour as a result of their disability that they are a risk to themselves or others if not provided with significant levels of care.

98. The Panel was advised that the Children Act 1989 defines a category of ‘children in need’ for whom children’s services should provide services; the Children Act defines a disability as:

“A child is disabled if he is blind, deaf or dumb, or suffers from mental disorder of any kind, or is substantially and permanently handicapped by illness, injury or congenital disformity or such other disability as may be prescribed.”

On the basis of that definition, how many are you aware of in Middlesbrough?

99. The Panel heard that Health, Education and Social Care services define children’s needs in different ways. On this point, the Panel heard that in the view of the Local Authority, a shared definition of ‘Children with Complex Needs’ may be useful, although it would need to be fairly loose, as the tighter a shared definition is, the more chance there is that someone could ‘fall foul’ of the definition. The Panel heard, therefore, that in some respects not having a definition could assist people in ensuring they can access the services they need. Irrespective of definition, the Panel heard very clearly that there is an agreement across services, that there is a significant rise in the number of children and young people in the region with a disability and those disabilities are increasingly complex.

100. The Panel heard that this is particularly so in Middlesbrough, where there is an increase in the number of children diagnosed with severe visual and hearing impairments; motor disorders, including cerebral

palsy; severe intellectual disability; complex language disorders; complex mental health disorders; and severe emotional and behavioural disorders.

101. It was reported that Middlesbrough also has higher than national average incidences of children with autistic spectrum disorders, which again is causing assessment and school placement pressures. The NICE guidelines, "Autism Recognition, referral and diagnosis of children and young people on the autism spectrum" (September 2011) recognise that ASD is no longer considered an uncommon disorder, but is prevalent and often associated with co-existing conditions and learning disabilities.
102. The Panel was advised that guidance issued as part of the Aim High for Disabled Children programme suggests a figure of 1.2% of the child population as a proxy measure for the number of severely disabled children in a local area. Based on ONS population estimates for mid 2009, this suggests a cohort of 376 young people aged 0-17 in Middlesbrough. The Children with Disabilities Service in Middlesbrough currently provides support to 274 children and young people. The Panel enquired as to whether efforts should be made to 'find' those that are apparently missing from services. It was stated that some families may be managing within their own resources and networks, without the need to seek help from statutory services.

How would the Authority normally become aware of children with complex needs?

103. It was reported to the Panel that Children's Services may not be immediately aware of a child being born with complex needs or a child moving into the town with complex needs. A family may make a referral themselves or there may be a referral from health staff; however, a referral can only be made with the consent of the family, unless there are safeguarding issues.

Is there any intelligence to indicate that there are children with complex needs that are not engaging with services?

104. The Panel heard that the service does not have any information relating to children and families who are not engaging with services. Some families may take time to accept a diagnosis and may not be ready to seek support at an early stage; some families manage within their own resources.

The Panel has previously heard that appropriate care placements for children with complex needs are often out of area and very expensive. Why are they so expensive?

105. The Panel was advised that following a recent review of residential commissioning, the evidence states that there are low numbers of

children/young people in independent residential placements. It was reported that the Children with Disabilities Team has developed some excellent services that allow children/young people to remain at home. At the time of the meeting, there were seven young people with complex needs in residential placements and only two are significantly further than 20 miles away from Middlesbrough; they are placed in Ripon in residential educational placements. Four young people are accommodated with a provider in Middlesbrough and the most expensive placements have been with a provider in Stockton.

106. The outcome of the children's residential homes review has highlighted a need to develop more local capacity and it is anticipated that by the end of November 2012, NHS Tees will agree to release some capital that has been held by Middlesbrough for some time and will be used to allow Gleneagles to deliver short break services for young people with complex health needs, and the remainder of the capital will be released to Middlesbrough Council to develop or commission a small home for young people with complex needs in Middlesbrough. This will mean that many out of area expensive placements are likely to be avoided in the future.

Connected to the question above – what evidence do you have that repatriating children in out of area placements into more local ones would save money? Wouldn't staff costs be fairly fixed wherever a facility was located?

107. The Panel was advised that the short break resource within Middlesbrough is fairly priced and when the potential costs of an in-house facility are analysed, it is fairly matched. The Panel heard, however, that there is a resource the Council has no alternative to use in Stockton, which is very expensive. It was reported that Middlesbrough Council has struggled to get the provider to justify their cost structure, as they have so far failed to engage. The Panel found it difficult to accept that the Council pays a significant amount to a provider, yet does not seem able to ascertain a detailed breakdown on costs.
108. Nonetheless, the Panel was advised that if local capacity could be increased and use of this resource avoided, there would be a saving of £120,000 per year, per placement.
109. The Panel was advised that there are also significant other costs that would need to be considered when looking at the benefits of children being placed closer to home. It was stated that when children are a long way from home, there is significant expenditure on social work visits and supporting contact with families.

To what extent is there a market of possible local providers now?

110. The Panel was advised that the residential market is not fully developed in the North East for every category of need and it would be accurate to suggest that the market is in need of further development. It was reported that commissioners are continually trying to work with providers in order to evidence the need and potential for developing the market, although it would seem that difficulties have been encountered in attracting providers to the region. The Panel was advised that professionals felt that the advent of Health, Social & Education Plans would probably bring about more of a market and would encourage new providers to become involved. It was noted that whilst personalisation of such services was largely to be welcomed, it was important that every effort was made to ensure that the providers that 'came 'to Middlesbrough' would be beneficial for the town and the people they sought to serve. The importance of high quality advice for children and their families was emphasised.
111. It was reported that the local provider in Middlesbrough has a good working relationship with the Council and the young people in placement are doing very well. It was reported that the provider has discussed the potential to expand the service, but to date no further work has been undertaken. In releasing the capital that is available to the Council², there could be the potential to offer the provider the opportunity to develop the service in partnership with the Council; however, this would be completed in line with formal procurement guidance.

If necessary, how would the local authority go about stimulating the market to encourage possible providers to establish themselves?

112. The Panel heard that there are a number of avenues open to the local authority in seeking to stimulate the market. Given the relatively small size of Middlesbrough Council, the Panel heard that it would always look to consult with the other Tees Valley/North East Authorities in order to identify any opportunities for joint commissioning. It was said that if such a joint venture was felt to be possible, this would potentially be more appealing to the market and provide confidence that there was a definite need to be met.

What progress has been made in identifying or stimulating providers of care for children with complex needs?

113. The Panel was advised that significant work has already taken place to encourage more providers of support services – the services used for short breaks or domiciliary care that prevent family breakdown and the need for costly placements. It was reported that the Council now has a good range of providers, but this has taken a number of years to achieve.

² The Authority has recently received some capital funding from NHS Tees

What framework does Children's Social Care have in place to establish the quality of outcomes for people using the service?

114. The Panel heard that the service relies on statutory Looked After Reviews and Ofsted Inspection Reports to monitor progress and outcomes. The Commissioning Team also monitor quality through feedback on placements.

How does the Department ensure that the views of families and the children involved influence services?

115. The Panel was advised that the service works very closely with the parents' forum, *Parents4Change*. It was reported that the group are consulted about everything the service does and are involved in the recruitment and training of staff, the giving of grants to providers and in the selection of providers. It was confirmed that there are several mechanisms in place for seeking the views of children and families, including information/consultation days and user feedback questionnaires. The Parents Forum is also represented on the Short Break Planning Group.

The Panel has heard previously that the Department has encountered difficulty in securing CHC funding from NHS sources to support clients? Could you provide a couple of anonymised case studies to highlight some of the issues faced?

116. The Panel was advised that there are distinct differences between the Children's Continuing Health Care Guidance and the Adult Continuing Health Care Guidance, which has meant that very few young people have met the criteria for funding, or where they have, the NHS already has commissioned services in place, e.g. CAMHS, and therefore funding has not been provided. On this point, the Panel also heard that the NHS Commissioners in the North of Tees area, tend to pay a higher percentage of care costs for children. The reason for this is not known, but the Panel felt it was noteworthy. This is particularly so as already stretched budgets, come under more and more stress.

117. It was confirmed to the Panel that working in collaboration with Adult Services colleagues had been very positive in terms of understanding the way the service interacts with children's providers; services have adopted similar tactics when negotiating with providers. It was reported that, in the future, the service will still need to engage with Clinical Commission Groups in order to ensure that children/young people remain a priority. There is also a need to consider requesting assessments for children/young people where the Council are providing in-house services, as there may be missed opportunities to secure funding.

What intelligence does the Department have about how future demand looks for services aimed at Children with Complex Needs from population data?

118. The Panel was advised that, as discussed earlier, the Safeguarding and Specialist Service may not be immediately aware that a child has complex needs. Whilst some are identified at birth, a number of children are diagnosed at a later stage. The Panel was interested to hear from officers that there are many factors which contribute to rising numbers of children with complex needs, including low birth weight, increased numbers surviving trauma and growing numbers from ethnic groups.
119. The Panel was advised that the number of children born with low birth weight is above average for Middlesbrough. The national average is 8%, with the South Tees Area having 10% and areas such as Park End having nearly 20%. Middlesbrough has the highest rate of pre-term deliveries in South Tees.
120. It was reported that environmental factors that influence these data include foetal alcohol syndrome, drug abuse and smoking during pregnancy, along with poor diet and nutrition. In addition, the Panel heard that an increasing number of older mothers and mothers who have received infertility treatment have led to an increase in some congenital conditions and multiple births, which also increase the risk of early birth/low birth weight.
121. It was reaffirmed to the Panel that low birth weight increases the chance of childhood illness, cognitive disorder and respiratory illness. It is likely to have serious consequences for health in later life.
122. The Panel was concerned to hear that Middlesbrough also has the lowest percentage in the North East of children immunised for Diphtheria, Tetanus, Polio and Pertussis (whooping cough) before their first birthday. This results in an increased risk of adverse health conditions.
123. The Panel was advised that James Cook University Hospital, which is based in Middlesbrough, has a highly successful neonatal early births survival rate. As a result, children survive accident and illness more frequently and live longer. Those born with severe health needs or disability survive where they would previously have died. It was reported to the Panel that some children are supported by new technology and remain technology-dependent. Some children, for example those with tracheotomies, would previously have remained in hospital, but are now supported at home and in schools.
124. The Panel heard that Middlesbrough has a growing number of children from BME groups, which is significant as research suggests that there is a higher incidence of children and young people with complex

learning disabilities and genetic disorders within minority ethnic communities. In addition, there are also increasing numbers of migrants from Eastern Europe, which include a significant number of children and young people with high or complex needs. The Panel felt it was important to report this information, as it has substantial implications for the allocation of resources in future years.

125. At the same meeting, the Panel received evidence from NHS Tees. NHS Tees was asked the following questions

What is the definition of 'Children with Complex Needs' that NHS Tees uses to guide its operation?

126. NHS Tees does not have an agreed definition. There is no agreed standard definition of complex needs in policy or across professional groups. Though NHS Tees and CCC use recommended guidance and professional tools to determine a child's on-going needs.

According to that definition, how many children with complex needs does NHS Tees pay for their on-going care? At what cost?

127. The Panel heard that calculating exact numbers and associated costs is difficult, as there is no agreed definition of complex needs. Many children will use multiple services on an on-going basis and at undetermined levels.
128. It was reported to the Panel that to examine numbers further would require setting parameters to which children would be defined as having complex needs, which may be useful in some instances such as calculating spend, but inflexible or restrictive when determining resource. The Panel heard that NHS Tees' current contract framework utilises block payments and isn't tariff based, which would further complicate the detangling of usage of multiple services and differing specialist levels.
129. It was reported, however, that determining approximate costs would not be impossible but would require further engagement with a range of healthcare professionals from across both acute and community settings and engagement with children, young people and families. Some examples were provided of services and the various ways that complex needs are defined:

Children's Continuing Care (CCC):

130. A continuing care package is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.
131. There is no agreed definition of 'Complex Needs'. As part of the assessment, CCC use the nationally recommended Decision Support

Tool, which contains ten care domains which each have up to five levels of needs. The Panel heard that children who score 3 'highs', or 1 severe, or 1 priority, will usually qualify for continuing care, however this tool outcome does not inform the decision alone. The outcome of the assessment is taken in to consideration along with professional reports and involvement from those involved with the child, e.g. physiotherapists, specialist Epilepsy Nurses, consultants and evidence from documentation e.g. incident reports etc.

132. With a continued focus on Personalisation and the announcement that from 2014 all individuals that qualify for CCC will be offered a personal budget, the Panel heard that it is critical that NHS Tees and the local Clinical Commissioning Groups (CCG's) understand the potential impact. As of December 2012, during 2012/13, CCC have supported 24 children at a cost circa £400,000.

Paediatric Therapies

133. The Panel was advised that the South Tees Hospitals Foundation Trust Community Paediatric Therapies, identify 3 groups of children with complex health needs

133.1 Children with life limiting or life threatening conditions who may be technology dependant with health funded complex packages of care

133.2 Children with multiple and profound impairments, multisensory impairment and severe and complex learning disability

133.4 Complex physical health care needs

134. It was reported that within these three categories the current caseload is A) 10 B) 343 C) 40, this is 30% of the entire caseload. The Panel heard that this serves as a good example of how determining cost would not simply equate to 30% of the total block contract, as this particular caseload due to complexity and level of usage, may place a greater demand on the service overall.

How well advanced/resilient is the local market for services aimed at Children with complex needs?

135. The Panel heard that evidence tells us in the future there will be more children with complex needs, due to an increased length of life with increased complexity in conditions. In turn, this could present risks to the current market, as demand will be greater. Whilst local services are advanced and deliver evidence based quality practice, further needs assessment are required to understand the local market's resilience, in terms of future demand. It was also pointed out that as personalisation increases, consideration will also need to be given to the quality and skills of providers outside of the NHS so as to support families to make safe choices.

Does, in the view of NHS Tees, the local market in services for children with complex needs, require further stimulation/development?

136. The Panel heard that in the future, there will be a greater demand, alongside increased focus on delivery of the Personalisation agenda, it will be essential that families who qualify for and choose to use a personal budget have access to services that meet their needs from a provider of their choice.
137. It was pointed out that NHS Tees and the CCG's would need to work with individuals and providers to ensure flexible innovative solutions are available. Locally on Teesside, there is a dominant Foundation Trust health economy.

Does, in the view of NHS Tees, NHS Tees (and the coming CCGs) have a role to play in stimulating the market?

138. NHS Tees and CCG's have a role in stimulating the market and will need to communicate with providers offering active support to recognise the opportunities personalisation provides and redesign services accordingly.

To what extent does NHS Tees commission with a focus on high quality outcomes for Children with Complex Needs?

139. NHS Tees commissions services based on high quality outcomes and is particularly guided by national policy related to children with disabilities.

How would NHS Tees describe its working relationship with the local authority, in relation to services for Children with Complex Needs?

140. NHS Tees has a positive relationship with Children's services both commissioning and operational functions. An example of this has been the recent joint commissioning of short break provision for children with a disability.
141. NHS Tees is fully engaged with Middlesbrough Children Trust arrangements. In relation to CCC NHS Tees currently works in partnership with the Enhanced Needs Panel where cases are more complex and joint commissioning may be considered.

How does NHS Tees work with the families of children with complex needs, to ensure that their feedback shape services and service design?

142. NHS Tees encourages patient experience gathering as a key quality requirement for all healthcare contracts. You're Welcome accreditation was offered as a CQUIN, an NHS contractual incentive scheme, in

12/13 and will be again within 13/14 and continues to be embedded within all new service specifications for children's services.

143. South Tees Hospitals NHS Foundation Trust strategically prioritises the involvement of Children, young people and families. Each individual service will have a process for feedback. They have a youth group that meets monthly and has been involved in a variety of participation activities.
144. CCC do not gather feedback from families in a formal manner but informally through on going contact and dialogue. This is to be developed further once an effective tool has been developed to use appropriately with both children and families.

Does NHS Tees have a view on what the future demand on such services will look like as demographics change?

145. This is difficult to model at this time as current data collection is not aligned to inform future planning though the introduction of the maternity and children's secondary uses data set will inform future planning. We do know that excellent neo natal care and continually improving medical care that allows children with a range of conditions to live longer and in better health will continue to impact on services locally to understand and plan accordingly needs further assessment. Linked to further assessment is the proposal locally to co-ordinate work related to Maternal Health with a particular focus on Low Birth Weight of which a paper was presented to Scrutiny earlier in December.
146. This will be supported by the changes related to Special Education Needs legislation. Draft legislation requires data-sharing across agencies to support early identification, intervention and integrated assessment 0-5.

**Evidence submitted from Contact a Family
15 January 2013**

147. The Panel was keen to seek the views of Contact a Family. Contact A Family is a national charity, with a North East regional office, which describes itself as "The only UK-wide charity providing advice, information and support to families pan disability from 0-25 years".
148. The Panel was advised that Contact A Family have a number of key organisational goals. They were reported as follows.
149. Families with disabled children will know how to get the right support
150. Families with disabled children will be more confident to deal with the challenges they face

151. Making sure families with disabled children are understood, valued and included as equals in their communities and society as a whole
152. Reducing the financial disadvantage that families with disabled children face
153. The Panel was interested to ascertain from Contact a Family, what sort of demand it faced for advice and related services. The Panel was advised by Contact a Family that in the last year, it supported 320,000 families with advice and support.
154. The Panel learned that in the North East region, during 2012 Contact a Family received 1149 enquiries, with over half (51%) coming directly from parent/carers.
155. The Panel was interested to learn that Contact a Family offers a quarterly newsletter, which has a circulation of over 4,000 with 2,972 going directly to North East parent/carers.
156. The Panel was interested to hear that in Contact a Family's view, against the backdrop of a public sector recession and allied to so many large scale changes to services, the demand for Contact a Family's support and advice would be greater than ever.

Common themes

157. The Panel was interested to hear from Contact A Family, as to whether there were common themes that were raised by parent/carers as areas of concern.
158. The Panel was advised that during 2012, Contact A Family asked families about the top three issues they were concerned about now, and over the next 3 to 5 years.
159. It was reported to the Panel that the top issue parents were concerned about is education for children with complex needs. Education, the Panel heard, was closely followed by concerns about access to specialist services for their children and the impact of stress and anxiety on families and their welfare.
160. The Panel heard that there are a number of other concerns felt by parents/carers, which centre on concerns over care for their children in the future and how the transition from children to adult services will be handled.
161. The Panel was interested to note that more parents than previous years were concerned about benefits and financial support. It was felt that this was clear evidence of parents awareness of the way welfare reform will affect them in future.

162. The Panel was also interested to hear from Contact a Family on whether there were any common health-related themes, that the survey picked out.
163. The Panel was interested to learn that in 2011, Contact A Family surveyed parents about their experiences of GPs which found 76% don't visit the GP about their child's disability or condition. This was a matter of concern and some surprise for the Panel. Upon asking the representatives at the meeting, it was reported that due to some conditions being so rare, general practitioners may have no experience of a particular condition. As such, parents can often feel that there is little point in approaching general practice when seeking advice or assistance about their child's condition or disability.
164. Whilst the Panel could understand why parents/carers made this pragmatic decision and sought specialist advice, it was felt somewhat concerning that a significant majority felt that such little expertise existed within General Practice, that it was not worth seeking its advice, even as a preliminary step. This is all the more concerning, given that as of April 2013, General Practice will play a leading role in the commissioning of local health services. The Panel felt that it certainly raised the questions about the level of expertise that Clinical Commissioning Groups would have available to support such patient groups.
165. It was accepted that to some extent, the lack of knowledge of such rare conditions amongst General Practice is perhaps inevitable, given that the average GP may work for years without coming across a particular condition. As such, it undoubtedly highlights the point that General Practice requires some form of assistance, or a repository of expertise, to assist it with children with complex needs, when required.
166. This is also a relevant point to consider about how children with complex needs access General Practice, regarding health matters that are not connected to their primary condition. The Panel heard that autistic children could find it difficult to cope with a busy waiting room, so parents would often seek the first or final appointment of the day, to reduce the possibility of it being so busy and stressful. It was reported that General Practice staff often did not understand this and an increased level of awareness would help parents and their children a great deal.
167. The Panel also heard that there are concerns around the following points:
- 167.1 It is felt that there is a lack of access to therapy services and child development teams.
- 167.2 The Panel heard that there could be delays in getting diagnosis and there can often not getting support in school until there is a diagnosis.

On this point, the Panel heard that it is, at times, understandable why a diagnosis can take a long time to obtain. The Panel heard that it can sometimes be technically difficult for a consultant to make an accurate diagnosis and there can be a fear of diagnosing a condition and 'labelling' someone.

167.3 It was reported to the Panel that there are issues of concern around gaining access to CAMHS.

168.4 The Panel was advised that there are issues with continence service.

169.5 The Panel was advised that support for child's health needs in a school setting.

169.6 The Panel was also advised that there are issues of concern around getting support to manage their child's sleep or behaviour.

170. Contact a Family briefed the Panel what it saw as its main areas of priority.

171. The Panel was advised that Contact A Family, in their view, give families with disabled children the skills and confidence to live the lives they want to lead by:

171.1 Providing good quality advice and information on any aspect of caring for a disabled child. (national Helpline, online, or in person)

171.2 Putting families in contact with each other through a network of parent support groups and online communities

171.3 Supporting parents to have a voice locally and nationally with government, commissioners and providers

172. In the North East CAF have an office based in Newcastle, produces a quarterly newsletter, weekly e-bulletins, provide workshops for families and work in partnership with other organisations (e.g. legal surgeries).

173. In conclusion to the presentation from Contact a Family, the Panel heard that the biggest issues facing services for children with complex needs are:

173.1 The Welfare Reform Act will impact on families unable to work due to their caring responsibilities. It was reported that there is potential for more families to be pushed into crisis and to breaking point. This could mean that services will be challenged to continue to meet the needs of families, with a limited and decreasing budget

173.2 The Panel was advised that proposals set out in *Support and Aspiration* will not be deliverable unless the structures set up by the

Health & Social Care Act in England provide clarity for child health. It was reported to the Panel that, in the view of Contact A Family, the lack of statutory duties on health services, is a significant weakness to providing joined up services for families. It will, the Panel heard, engender confusion for services and families, as to responsibilities and duties.

- 173.3 The Panel heard, with concern, that the Health & Social Care Act does not provide a platform for education providers to take part in local decision making at Health & Wellbeing Board level, which will make integrated commissioning more difficult. This was a theme that the Panel agreed to pursue further, at future meetings.
174. The Panel was interested in the view of Contact a Family on the impact of a public sector recession, on services for children with complex needs:
- 174.1 The Panel was advised by Contact a Family that evidence collected, suggests local authority budget cuts are chipping away at a range of services for disabled children. This would include including short breaks and vital specialist services such as speech & language therapy.
- 174.2 The Panel heard that, in the view of Contact A Family, unless disabled children are a priority for local authorities, with strategic planning to assess need and ensure adequate provision, more families with disabled children will hit crisis point. This would, the Panel heard, ultimately costing local authorities more in the long run.
- 174.3 The Panel was advised that, in Contact a Family's view, tightening budgets may well make partnership work more difficult. It was reported that making sure families get the right services, and working in partnership to make best use of resources, is where the work Contact a Family does, to support parent participation, comes in.
175. The Panel was advised that it is vital services continue to have an open dialogue with parents to ensure they remain an integral part of the decision making.
176. In addition to Contact a Family representatives attending the meeting, the Panel also heard from representatives of Parents 4 Change. In addition to the points outlined by Contact a Family, which were agreed with, *Parents 4 Change* wanted to make a number of additional points, which are outlined below.
177. *Parents 4 Change* were keen to emphasise the point made by Contact a Family about the lack of expertise in General Practice about Children with complex needs and how General Practice would benefit from some form of training/access to expertise, to assist in a very difficult field.

178. The Panel also heard, from *Parents 4 Change*, that there is undoubtedly concerns over how diagnosis of children are handled, or specifically the length of time it takes to obtain a definitive diagnosis. Whilst it was accepted that reaching a definitive diagnosis can be a technically difficult task, and the feeling that medical professionals may not want to 'label' a child, the Panel noted clear frustration from *Parents 4 Change* about the difficulty faced in obtaining a diagnosis. On more than one occasion, the Panel heard the phrase "passed from pillar to post" in describing parents' experiences in attempting to seek appropriate help for their child. Connected to this point, was a perception that health professionals can be a little too swift to dismiss parental concern over health or behaviour as excessive anxiety, whilst parents would argue quite strong that they know their child best, and tend to know when there is something wrong.
179. The Panel was keen to hear the views of *Parents 4 Change* as to whether they felt sufficiently involved in the development of Children's Services and whether they were sufficiently consulted on what constituted local need.
180. *Parents 4 Change* advised the Panel that their involvement was getting much more detailed involvement with the development and design of services and having a more meaningful impact on understanding need.
181. *Parents 4 Change* emphasised the point made by Contact a Family, in that there was a great deal of concern about the welfare reforms and the impact they would have on a hugely vulnerable cohort of people i.e. children with complex needs and their parent/carers.
182. It was said that whilst a large number of those affected, won't know all they need to know about welfare reform, whether people know about it or not, they would still face a reduction in income.
183. As a final report, *Parents 4 Change* felt it important to highlight to the Panel that demand for their services, such as advice, was increasing significantly.

Implications for the families of disabled children of the Welfare Reforms?

184. By way of background, the Contact a Family conducted a national survey of 2,312 families with disabled children across the UK in 2012. The key points of that survey were:
- 184.1 1 in 6 families (17%) is going without food due to financial pressures
- 184.2 More than 1 in 5 families (21%) is going without heating

184.3 A quarter (26%) of families are going without the specialist equipment or adaptations

184.4 almost a third (29%) have taken out a loan – 39% for food and heating

184.5 a quarter of loans are from quick cash schemes or from loan sharks

184.6 1 in 5 (21%) have been threatened with court action for failing to keep up with the payments – the majority for missing utility bill payments (46%).

Concern over Benefit Changes

185. Nearly 60% think that their financial situation will get worse in the next 12 months (up from 15% in 2010) – 73% citing welfare reforms as the main reason for this.

186. Families with disabled children are most worried about the replacement of Disability Living Allowance (DLA) by Personal Independence Payment (PIP) for 16-64 years old (50%), the introduction of Universal Credit (21%) and housing benefit restriction (17%).

Stigma?

187. The research suggests that families feel an increasing sense of stigma towards them. CAF says that

“Hard working parent carers feel branded as work shy scroungers for claiming vital benefits for their disabled child”

and

“They feel an escalating climate of hostility towards those claiming disability benefits has left them feeling ashamed about getting the help they are entitled to for their child.”

188. These feelings are supported by the following direct quotes from parents, in response to Contact a Family’s work.

“As if parents of disabled children don’t have enough to worry about, having to choose between paying for heating or food each month is definitely not what we need on top, its so unfair”³

“I am fed up with people accusing me of making my son’s disability up. Some even go as far as to accuse us of having a wheelchair, not because he needs it but so I can scrounge off decent people. The negative comments and hostility have got a thousand times worse in my experience. What they don’t understand is how dependent the state is on us carers, not us on them”

³ Counting the Cost page 3

Health Scrutiny Panel 26th February

Evidence from Public Health Directorate on Childhood Immunisation

189. The Panel had previously been advised that one of the most significant issues in protecting the health and wellbeing of the town's child population is to ensure that Immunisation Programmes are sufficiently widespread and utilised. The Panel has heard that an increased perceptibility to diseases, that can cause permanent disability, can be a direct result of not being immunised.
190. As such, the Panel was keen to receive the latest data on rates of Childhood Immunisation in Middlesbrough. The Panel heard from the Directorate of Public Health, who presented data from the annual returns to the Health Protection Agency (2009 – 2011) and the most recent local data for Q1 and Q2 2012/2013 (April – September 2012).
191. The Panel was advised that immunisation is one of the most effective, safe and cost-effective public health interventions. It was reported that vaccination protects individuals and communities from the risks of infectious diseases, with community protection being achieved by high levels of immunisation coverage to create 'herd immunity'⁴.
192. The Panel was advised that herd immunity theory proposes that the whole herd or community is protected, when 'herd immunity' levels of vaccination coverage are achieved, with herd immunity acting as a forum of firebreak or firewall in the spread of infectious diseases. It was clarified that for most diseases, this is usually around 95% coverage. This level is sufficiently high to prevent any sustained circulation of infections, protecting everyone in the population whether they have been immunised or not. It was reported that vaccine coverage is the best indicator of the level of protection a population will have against vaccine preventable communicable diseases.
193. The Panel heard that the childhood immunisation programme is an integral component of the UK immunisation programme, with the aim of the immunisation programme being to eradicate, eliminate or contain disease. Children are routinely offered protection against ten infectious diseases, all of which can cause serious disease and can occasionally be fatal.

⁴ Herd immunity (or community immunity) describes a form of immunity that occurs when the vaccination of a significant portion of a population (or herd) provides a measure of protection for individuals who have not developed immunity. Herd immunity theory proposes that, in contagious diseases that are transmitted from individual to individual, chains of infection are likely to be disrupted when large numbers of a population are immune or less susceptible to the disease. The greater the proportion of individuals who are resistant, the smaller the probability that a susceptible individual will come into contact with an infectious individual. Please see http://en.wikipedia.org/wiki/Herd_immunity

194. It was reported that the World Health Organisation (WHO) recommends that, on a national basis, at least 95% of all children receive three primary doses within the first year of life to provide immunisation for, Diphtheria, Tetanus, Polio and Pertussis. In addition, the WHO recommends that over 95% of children also receive one primary dose, by their second birthday, to immunise for Measles, Mumps and Rubella.
195. The Panel was advised that national evidence shows that inequalities in immunisation uptake have been persistent, resulting in lower coverage in children and young people from disadvantaged families and communities. It was confirmed that non immunised, or only partially immunised children, are more likely to live in disadvantaged areas and are less likely to use primary care services. There are variations in uptake of childhood vaccinations across the population with lower uptake in the following groups:
- 195.1 Babies of pregnant women who are not immunised against rubella or who are carriers of hepatitis B virus.
 - 195.2 Asylum seekers.
 - 195.3 Homeless families.
 - 195.4 Looked after children/children in care.
 - 195.5 Children with physical or learning difficulties.
 - 195.6 Children of teenage or lone parents.
 - 195.7 Children not registered with a GP.
 - 195.8 Younger children from large families.
 - 195.9 Children who are hospitalised.
 - 195.10 Some ethnic groups - however the relationship between ethnicity, social class, deprivation and level of immunisation uptake is complex.
196. The Panel heard that the UK childhood immunisation programme provides the WHO recommended immunisations, in addition to immunisations as identified by the Department of Health. The overall aim of the routine childhood immunisation programme is to protect all children against the following preventable childhood infections: diphtheria, tetanus, pertussis (whooping cough), *Haemophilus influenzae* type b (Hib), polio, meningococcal serogroup C (MenC), measles, mumps, rubella and pneumococcal.
197. The table below was presented to the Panel, to provide details of the full range of immunisations provided by the UK childhood immunisation programme.

When to immunise	What vaccine is given	How it is given
Two months old	Diphtheria, tetanus, pertussis (whooping cough), polio and Hib (DTaP/IPV/Hib)	One injection
	Pneumococcal (PCV)	One injection
Three months old	Diphtheria, tetanus, pertussis (whooping cough), polio and Hib (DTaP/IPV/Hib)	One injection
	MenC	One injection
Four months old	Diphtheria, tetanus, pertussis (whooping cough), polio and Hib (DTaP/IPV/Hib)	One injection
	MenC	One injection
	PCV	One injection
Twelve months old	Hib/MenC	One injection
Around 13 months old	Measles, mumps and rubella (MMR)	One injection
	PCV	One injection
Three years four months to five years old	Diphtheria, tetanus, pertussis and polio (DTaP/IPV or dTaP/IPV)	One injection
	Measles, mumps and rubella (MMR)	One injection
Thirteen to 18 years old	Tetanus, diphtheria and polio (Td/IPV)	One injection

The Local Picture

198. The Panel was advised that childhood immunisation rates have tended to be higher in Middlesbrough than the national average (except for DTaP/IPV/Hib at 12 months), however lower than the North East average and lower than the recommended level of 95% cover necessary for herd immunity and to prevent outbreaks. The Panel considered the following table:

Vaccine Coverage Comparing Middlesbrough, Regional and National Rates 2009-2011

	12 Month	24 Month	5 years	
	Immunisations			
	DTaP/IPV/Hib	MMR (1)	DTaP/IPV	MMR (2 Doses)
Middlesbrough				
2009/2010	90.5%	84.0%	Not	87.4%
2010/2011	91.7%	86.4%	Available	88.0%
North East				

2009/2010	95.7%	91.1%	91.2%	89.1%
2010/2011	95.9%	91.4%	90.5%	88.7%
England				
2009/2010	93.6%	82.2%	84.8%	82.7%
2010/2011	94.2%	89.1%	85.9%	84.2%

199. The Panel was advised that the most recent figures show that there is an increase in uptake of immunisation in Middlesbrough, in line with the national and regional trends. It was reported that where previously Middlesbrough had achieved higher coverage rates than the national average, this gap is narrowing and for some immunisations, Middlesbrough is now below both the regional and national average. The Panel was presented with the following sets of tables present the most recent data set in more detail.
200. It was reported to the Panel that the most recent returns for 1st birthday vaccination coverage shows that Middlesbrough is below both regional and national averages for DTaP/IPV/Hib, Men C and PCV. The coverage is also below the 95% coverage recommended by WHO.

Vaccination Coverage 1st Birthday Middlesbrough PCT Q2 2012/13

Vaccination	% Middlesbrough	% North East	% England
DtaP/IPV/Hib	94.74	96.4	94.6
Men C	92.73	95.8	94.0
PCV	93.69	96.3	94.4

201. The Panel heard that Middlesbrough's immunisation cover rates achieved by 2nd birthday, are more varied with the coverage for primary diphtheria, tetanus and polio reaching the 95% WHO recommended level. It was also reported that MMR1 coverage remains below 90%. The Panel heard that this rate of immunisation is an area of particular concern, as recent data shows that there has been an outbreak of Measles in the North East⁵. As at 18 February 2013, there had been 104 confirmed cases and 93 suspected cases, since the start of September 2013. The majority of the cases being in the Tees area.

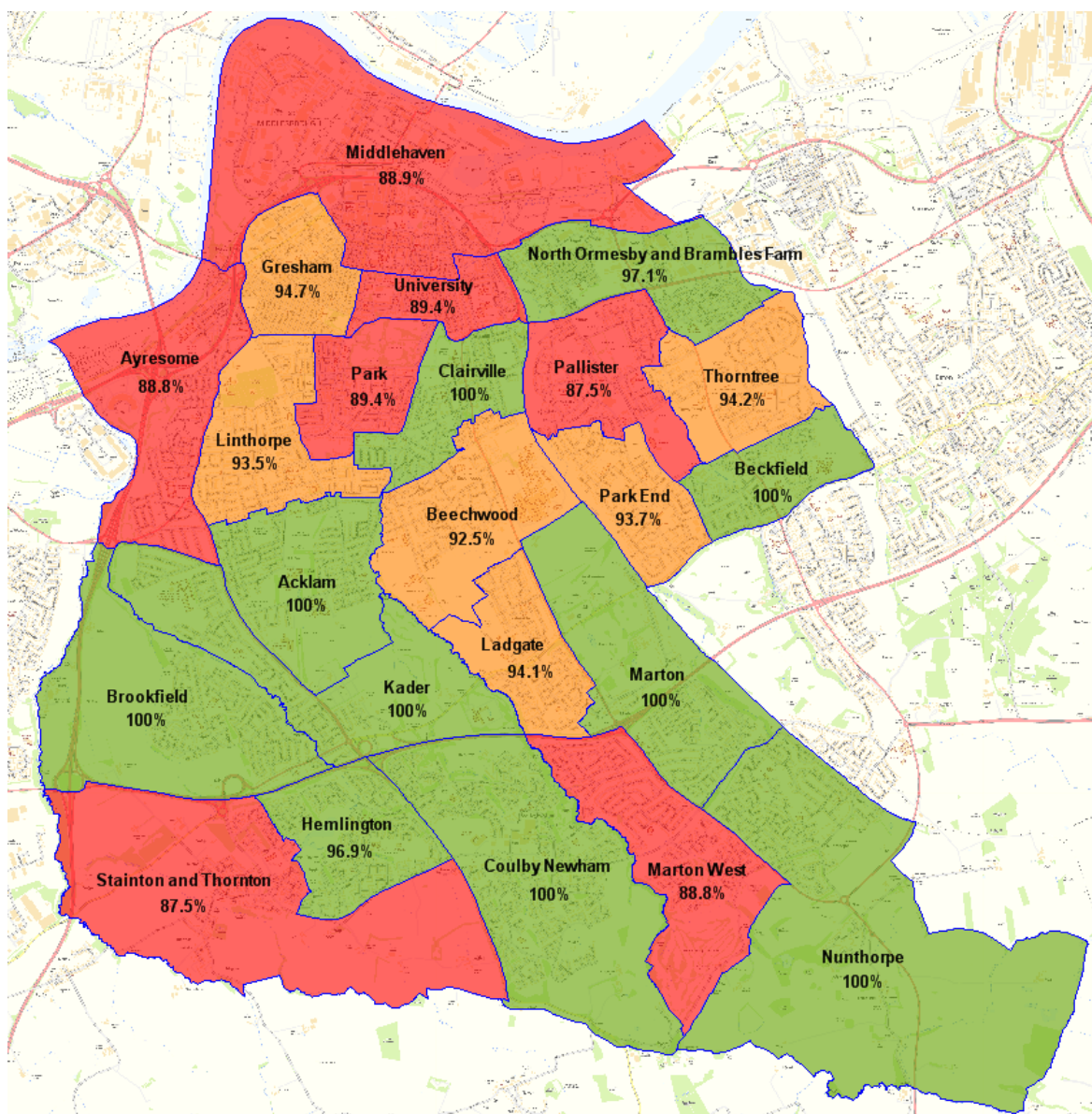
⁵

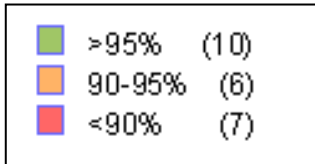
<http://www.hpa.org.uk/AboutTheHPA/WhatTheHealthProtectionAgencyDoes/LocalServices/NorthEast/NorthEastPressReleases/neast130218NorthEastmeaslesoutbreakweeklyupdate/>

Vaccination Coverage 2nd Birthday Middlesbrough PCT Q2 2012/13

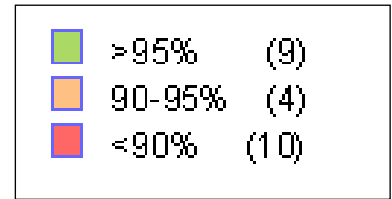
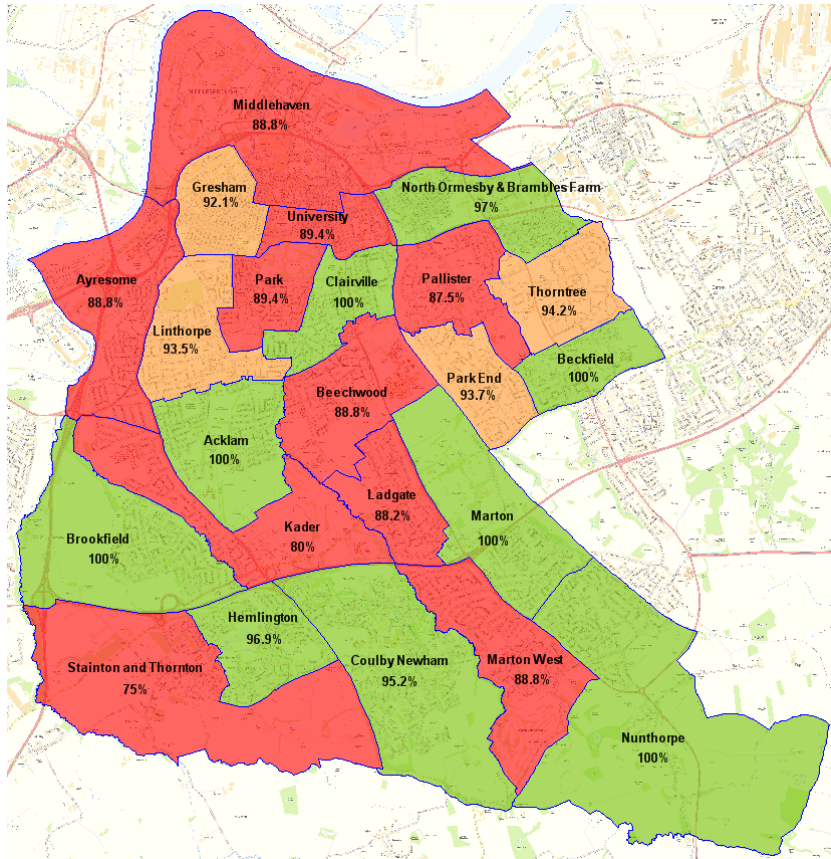
Vaccination	% Middlesbrough	% North East	% England
Primary Diphtheria	95.01	Not Available	
Primary Tetanus			
Primary Polio			
Primary Pertussis	94.83		
DtaP/IPV/Hib	94.65	97.8	96.3
Primary HiB			
MMR1	89.66	94.1	92.2
Men C	90.55	96.6	95.2
HiB/Men C	92.16	95.1	92.6
PCV Booster	90.02	94.3	92.4

Figure 1: Primary Diphtheria, Primary Pertussis, Primary Tetanus, Primary Polio & DtaP/IPV/Hib Coverage at 1st Birthday.

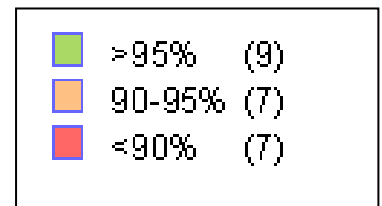
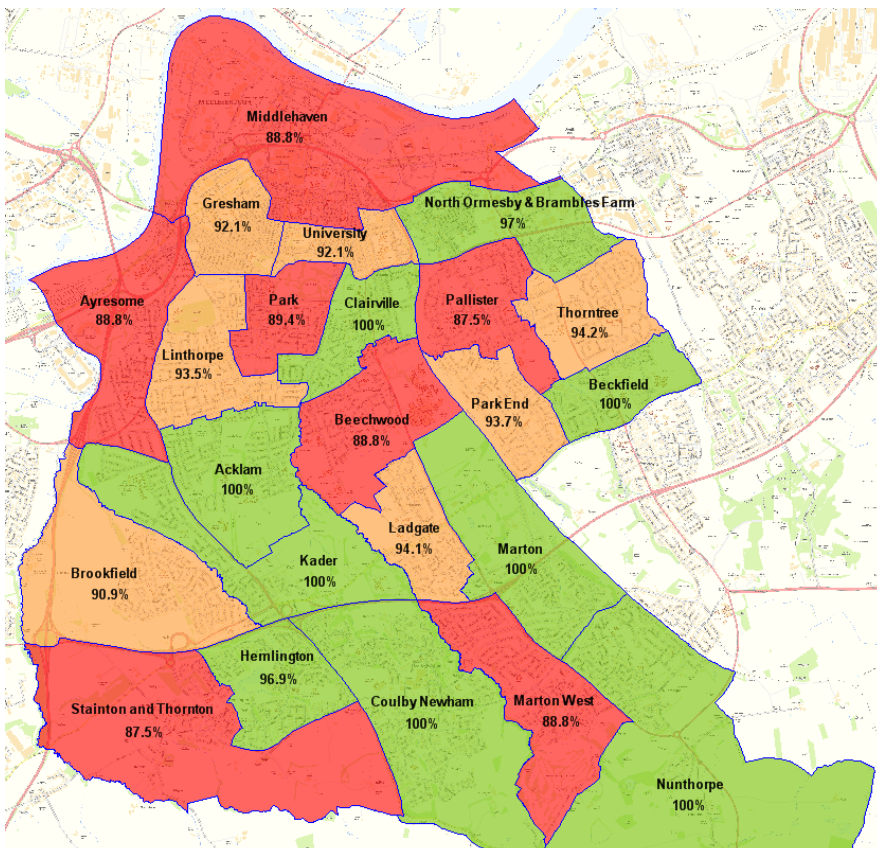




Men C Coverage at 1st Birthday



PCV Coverage at 1st Birthday



	Mar-11	Sep-12
Acklam	93.75%	100.00%
Beckfield	84.62%	100.00%
Brookfield	92.86%	100.00%
Clairville	87.50%	100.00%
Coulby Newham	94.44%	100.00%
Kader	90.91%	100.00%
Marton	85.71%	100.00%
North Ormesby and Brambles Farm	93.94%	97.06%
Nunthorpe	100.00%	100.00%
Park End	94.12%	93.75%
Gresham	81.82%	94.74%
Ladgate	90.00%	94.12%
Linthorpe	89.29%	93.55%
Thorn tree	91.67%	94.29%
Park	85.71%	89.47%

Coverage

	Increase and meeting 95%
	Increase and meeting >90% <95%
	Increase and achieving < 90%

	Mar-11	Sep-12
Hemlington	100.00%	96.97%
Ayresome	95.83%	88.89%
Beechwood	95.65%	92.59%
Middlehaven	95.45%	88.89%
Pallister	92.00%	87.50%
University	93.55%	89.47%
Marton West	100.00%	88.89%
Stainton and Thornton	100.00%	87.50%

Coverage

	Decrease and meeting 95% WHO
	Decrease and achieving < 90% Cover
	Significant Decrease < 90% Cover

Ward trend data 1st Year MenC

	Mar-11	Sep-12
Hemlington	100.00%	96.97%
Ayresome	95.83%	88.89%
Beechwood	95.65%	92.59%
Middlehaven	95.45%	88.89%
Pallister	92.00%	87.50%
University	93.55%	89.47%
Marton West	100.00%	88.89%
Stainton and Thornton	100.00%	87.50%

Coverage

	Decrease and meeting 95% WHO
	Decrease and achieving < 90%
	Significant Decrease < 90% Cover

	Mar-11	Sep-12
Hemlington	100.00%	96.97%
Ayresome	95.83%	88.89%
Beechwood	95.65%	92.59%
Middlehaven	95.45%	88.89%
Pallister	92.00%	87.50%
University	93.55%	89.47%
Marton West	100.00%	88.89%
Stainton and Thornton	100.00%	87.50%

Coverage

	Decrease and meeting 95% WHO
	Decrease and achieving < 90%
	Significant Decrease < 90% Cover

Ward trend data 1st year PCV

Ward	Mar-11	Sep-12
Acklam	93.75%	100.00%
Beckfield	84.62%	100.00%
Clairville	93.75%	100.00%
Coulby New ham	94.44%	100.00%
Kader	90.91%	100.00%
Marton	85.71%	100.00%
North Ormesby and Brambles Farm	96.97%	97.06%
Nunthorpe	100.00%	100.00%
Gresham	79.55%	92.11%
Ladgate	90.00%	94.12%
Linthorpe	89.29%	93.55%
Thorntree	91.67%	94.29%
University	83.87%	92.11%
Park	85.71%	89.47%
Coverage		
	Increase and meeting 95%	
	Increase and meeting >90% <95%	
	Increase and achieving < 90%	

Ward	Mar-11	Sep-12
Hemlington	100.00%	96.97%
Brookfield	92.86%	90.91%
Park End	94.12%	93.75%
Ayresome	95.83%	88.89%
Beechwood	95.65%	88.89%
Marton West	100.00%	88.89%
Middlehaven	95.45%	88.89%
Pallister	96.00%	87.50%
Stainton and Thornton	100.00%	87.50%

Coverage

	Decrease and meeting 95% WHO
	Decrease and achieving <95% > 90% Cover
	Significant Decrease < 90% Cover

202. Following the receipt and consideration of the above data the Panel held a discussion with the Public Health team about some of the most important issues that it raised.
203. The Panel was interested in the information submitted that indicated that on a national basis, certain groups of children were more likely to not be vaccinated than others. The Panel was particularly concerned about the idea of Children Looked After and Children in hospital being 'at risk' of not receiving the immunisations that they are due. The Panel heard that in the case of Looked After Children, it can often be a challenge to ensure that children, who can move around often, have all their immunisations.
204. Subsequent to the meeting, the Panel made enquiries about the position in Middlesbrough regarding Looked After Children. The following data has been presented to the Panel
205. The data from the Government Children in Care and Adoption Performance tables for children who have been looked after continuously for at least 12 months at the 31 March 2012, for immunisations is at 95.4%.
206. Every child has a statutory Initial health assessment with health plan identifying outstanding immunisations which are followed up and reviewed annually at the next due health reassessment whilst a child remains in care.
207. Middlesbrough as from the 31st March 2012 95%, and nationally for England as from the 31st March 2012 83.1%

Nationally broken down

4 years and under 88.4%
5-9 years 88.4%
10-15years 84.2%
16years and over 73.1%

208. To expand on this point, the Panel made enquiries as to how long term child inpatients at JCUH would be approached, to ensure they received the immunisations they were due.

208.1 The Panel asked the FT whether it has any programmes in place, to ensure that any children who are in JCUH as longer term in patients, receive their immunisations?

The Panel was advised immunisations would be given in the ward or department where children are if they are in long-term. Neonatal services would begin immunisations at 8 weeks for babies in the unit at that time.

208.2 The Panel asked the FT aware whether hospitalised children not receiving immunisations are a local problem?

The Panel was advised that the Trust is not aware that this is a significant problem.

208.3 The panel enquired as to whether the FT would even have access to a child's entire medical record, including immunisation history (or not as the case may be), to be able to influence this?

The Panel heard that the Trust would not have access to entire medical records, nor to computerised immunisation records. We rely on parents bringing in red books and on those having been completed correctly by both primary and secondary care.

209. The Panel was interested as to what would happen in the case of children in military families and contacted the Ministry of Defence to make those enquiries. The Panel heard back from Joint Forces Command, at the Headquarters of the Surgeon General. The Panel was advised that:

209.1 Children of Armed Forces families are routinely registered with an NHS GP within the UK and will be offered immunisations due as part of the UK Childhood Immunisation Schedule through civilian or Military medical Centre in the same way as any other child entitled to NHS care. In the UK, Military Medical Centres follow the same recall regime as civilian practices.

209.2 In overseas military locations such as Germany, local Medical Centres search the Defence electronic medical record system to identify children due immunisations as part of the UK Childhood Immunisation Schedule. It remains for families to decide whether to take up the immunisations.

Domestic violence section

210. In the process of considering the evidence around contributory factors for children being born with complex needs, the Panel received evidence which indicated expectant mothers experiencing domestic violence, was considered to be a risk factor. In addition, the Panel learned that actually being pregnant also increases the risk of becoming exposed to domestic violence.

211. As such, the Panel thought that it would be prudent to consider some information about Domestic Violence, which was supplied by the Local Authority's lead officer on Domestic Violence.

212. The Panel was advised that the National definition of domestic violence and abuse is

“any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or who have been intimate partners or family members regardless of gender or sexuality”

213. This can encompass but is not limited to the following types of abuse:

- psychological
- physical
- sexual
- financial
- emotional

214.1 *Controlling behaviour is:* a range of acts designed to make a person subordinate and/or dependant by isolating them from sources of support, exploiting their resources and capacities for personal gain, depriving them of the means needed for independence, resistance and escape and regulating their everyday behaviour.

214.2 *Coercive behaviour is:* an act or a pattern of acts of assault, threats, humiliation and intimidation or other abuse that is used to harm, punish or frighten their victim. This definition, which is not a legal definition, includes so called, 'honour' based violence, female genital mutilation (FGM) and forced marriage (FM), and is clear that victims are not confined to one gender or ethnic group.

215. The Panel was advised that this definition of domestic abuse was extended in September 2012, following a national consultation to be

more explicit around the area of coercive control and to be inclusive of young people between the ages of 16-18 years of age.

216. The Panel was advised that Domestic Violence impacts upon whole families and communities, it is nationally recognised as a hidden crime, with the acknowledgement that the information that agencies hold is very often an under representation of the true prevalence of the issue. The main source of prevalence data contained here is police recorded data, which provides an indication of the levels of domestic abuse that are reported to Cleveland Police. The Panel was advised that at present, it also needs to be noted that the number of reported incidents does not necessarily reflect an increase in domestic violence, as it may also be an indication in the confidence of victims in the local services that are provided. This should be considered when reviewing the incident data as well as the data presented on levels of repeat victimisation.
217. Further to this, the Panel was advised, it is important to note that the point at which a DV disclosure could take place, and the range of different agencies that may be involved at this point are varied, demonstrating the need to ensure robust data collection and sharing arrangements are in place between a wide range of agencies.
218. In acknowledgement of the cross cutting nature of the DV, and the challenge of ensuring a co-ordinated response, Middlesbrough has continued to focus upon improving its strategic approach within the last year. It was reported that in April 2010 a domestic violence strategy group (DVSG) was established, and a new Domestic Violence Strategy (2011-13) was launched which aims to co-ordinate a shared strategic vision across the town. The Panel was advised that during 2011/12, the DVSG have continued this process and have undertaken a self-assessment to identify gaps and inform our collective approach. Areas highlighted by the review such as better data collection were highlighted to the Panel here and as areas of continual development for 2013/14.

The prevalence of Domestic Abuse

219. The Panel was advised that within Middlesbrough district 29% (1147/3892) of domestic incidents were recorded as crimes between November 2011 and October 2012. Whilst the number of incidents and crimes has decreased (by 15% and 6.5% respectively) compared to the same period in the previous year, the proportion of crimes to incidents has increased. Detections however continue to decline, with a detection rate of 43.6% during the 12-month period⁶.

⁶ Performance Management Framework, Cleveland Police – October 2012

Domestic Incidents	November 2011 – October 2012			
	2012/13	2011/12	Diff	% Diff
DV Incidents	3892	4580	-688	-15.0%
Rate per 1000 pop.	28.01	32.96	-4.95	-15.0%

Crime and Detections	November 2011 – October 2012			
	2012/13	2011/12	Diff	% Diff
Recorded Crimes	1147	1227	-80	-6.5%
<i>Crime / Incident ratio</i>	29.5%	26.8%	2.7%	2.7%
Iris Detections	500	556	-56	-10.1%
<i>Detection Rate</i>	43.6%	45.3%	-1.7%	-1.7%

Figure 9.1: Domestic Incidents with Crime & Detections

220. It was reported that within Middlesbrough, 9% of overall recorded crimes were marked as domestic violence⁷. The key crime types recorded as DV over the research period are violence against the person (907) and criminal damage (200). These two crime types account for 91% of all domestic violence offences and are explored in more detail below.

Violence against the Person

221. Within this category 46% (907/2852) of overall violence offences had the domestic violence marker as “yes”, which is an increase of 16% compared to the previous period. The key offence types in this section are assault occasioning actual bodily harm and other injury (48%) which is a slight decrease compared to the previous period (50%), and common assault and battery (35%) which has remained at the same level since the previous period.

222. The key wards for violence offences remain the same as the previous period and are: Gresham, Middlehaven, North Ormesby and Brambles Farm and University.

223. Domestic related offences that were marked as ‘committed under the influence’ account for 42% (382), which is a 1% increase compared to the previous period. A further 364 (40%) were classed as unknown, which is significantly higher than the previous period (28%) and therefore the offences ‘committed under the influence’ could possibly be higher.

224. Key months for violence offences over the research period are October, December, March and June, with offences beginning to decline towards September 2012.

⁷ Domestic Violence marker = “y”

Criminal Damage

225. Within this category, the Panel heard that 8% of all damage offences had the domestic violence marker as yes, which is a slight increase of 2% compared to the previous period. The key offence types in the section are criminal damage to a dwelling (57%, previously 59%), vehicle (17% previously 19%) and other criminal damage (17%, unchanged).
226. The key wards differ for each of the offence types. Gresham and North Ormesby and Brambles Farm are the key wards for criminal damage to a dwelling. For the category criminal damage to a vehicle the key wards are Pallister and Gresham, and for criminal damage other offences; Thorntree, Park End and Beechwood are the key wards.
227. Only 8 offences list “committed under the influence” as yes, whilst 95% of offences are listed as “unknown”.
228. Key months for damage offences over the research period are October, November and March.

The affects of abuse

229. The Panel learned that the British Crime Survey (BCS) indicates that domestic violence has more repeat victims than any other crime type, with on average 35 assaults before a victim contacts police. From the way that police data is currently collected, it is not possible to state the exact numbers of individuals who may be repeat victims of DV. Data collected from Multi Agency Risk Assessment Conferences (MARAC), however, provide us with some indication of repeat victimisation levels for high risk cases.
230. The Panel was advised that MARAC is in place to ensure that information is shared in identified high-risk cases of DV, to increase the safety of the victim. On a monthly basis, the number of cases that have been live to the MARAC caseload for the previous 12 months are monitored and the number of repeat cases that have presented during this period are collated, to calculate a repeat referral rate.
231. The Panel was advised that the repeat incident figure is determined using the following definition of a repeat incident;

*“Any incident within the last 12 months of the last MARAC presentation which **if** reported to the Police would be recorded as a crime”*
232. The following table demonstrates the repeat victim rate for the previous 12 months and is worked out on a rolling 12 months period.

	Month	Calculation Period	No. Cases	No. Repeat s	Repeat Rate
Q 3	October 2011	Nov 10 – Oct 11	239	112	46.86%
	November 2011	Dec 10 – Nov 11	242	113	46.69%
	December 2011	Jan 11 – Dec 11	255	122	47.84%
Q 4	January 2012	Feb 11 – Jan 12	250	123	49.20%
	February 2012	Mar 11 – Feb 12	236	119	50.42%
	March 2012	Apr 11 – Mar 12	240	119	49.58%
Q 1	April 2012	May 11 – Apr 12	240	120	50.00%
	May 2012	Jun 11 – May 12	238	112	47.06%
	June 2012	Jul 11 – Jun 12	223	100	44.84%
Q 2	July 2012	Aug 11 – Jul 12	212	102	48.11%
	August 2012	Sep 11 – Aug 12	210	102	48.57%
	September 2012	Oct 11 – Sep 12	212	108	50.94%

Figure 9.2: Rolling 12 Month Repeat Victim Rate

233. An increase of 2.83% is demonstrated in Quarter 2 of 2012/13 and the current repeat referral rate of 50.94% is 1.36% above the year end figure for 2011/12, demonstrating a rise in repeat victimisation in MARAC cases. This figure is above the target of 44.0%.
234. The Panel was advised that analysis of MARAC cases demonstrates that there are a core group of MARAC cases, which account for a large proportion of the repeat incidents. The table below demonstrates the top 10 cases as of the 26th September 2012 which, were identified as having five or more repeat incidents during the time they have been live to MARAC.
235. The table highlights that the cases have accounted for 39 repeat presentations to MARAC during the previous 12 month period, and a total of 105 presentations during the time they have been live to MARAC.

Case No.	First Presented	No. of Repeats	Last 12 Months
294	25/02/2009	24	9
37	17/01/2007	16	2
483	12/01/2011	11	6
365	11/03/2009	11	3
449	08/09/2010	10	6
386	24/03/2010	9	2
272	17/12/2008	7	3
237	27/08/2008	6	2
374	10/02/2010	6	1
483	13/11/2010	5	5
TOTAL		105	39

Figure 9.3: Cases with 5+ MARAC presentations as of September 2012

236. A piece of work to cross-reference these cases A&E data sets demonstrated the impact on hospital admissions from this group. Both the perpetrators and victims in all 10 of the cases have been admitted to A&E with at least one admission. Male perpetrators account for a total of 46 inpatient admissions, 33 of which were alcohol related. Female victims accounted for a total of 86 in-patient admissions, 65 of which were alcohol related. (Data accurate as July 2012 search date.)
237. Victims of reported DV offences are predominantly female (82%) aged between 20-24 years old (22%) and 25-29 years old (17%). The key relationships between victim and perpetrator are spouse (21%), ex-partner (14%), boyfriend / girlfriend (8%) or acquaintance (6%). Offences are most likely to take place within the home, with dwelling (77%) and public place (14%) the key locations over the period. Police recorded repeat offences show a repeat victim rate⁸ of 47%; which is lower than that of MARAC due to taking only reported crimes into account.
238. The Panel was advised that DV can have a massive impact within households and families. An investigation of cases open to Middlesbrough Council Wellbeing, Care and Learning dept shows that on the 5th November there were 311 open cases with DV highlighted as a parental issue. An open case means that a social worker has been allocated to the family due to significant safeguarding concerns. The 311 cases equated to 48.4% of open cases on this given date with the parental issue of alcohol highlighted in 153 cases a further 23.8% of open cases. This data highlights the need to intervene earlier with

⁸ This figure takes account of the number of incidents where the victim has been the victim of another reported incident within the past 12 months – however no figure exists in terms of the number of corresponding crimes.

families affected by abuse in order to decrease risk and the need to enter the safeguarding arena.

239. The panel noted with concern that housing data shows that DV is the single largest cause of homelessness in Middlesbrough, with an average of 11 duty to house homeless cases each quarter. A *duty to house* homeless case is one, which meets the statutory definition of homelessness and where the local authority has a duty to provide accommodation. The Panel learned that although overall homelessness in Middlesbrough has reduced slightly, DV accounts for an average of 66% of all statutory homeless acceptances, which is an increase from last year, where DV accounted for 63% of all duty to house homelessness cases.
240. The Panel noted that Middlesbrough has the highest percentage of homelessness, due to DV when compared with homelessness trends for boroughs in the North East, where the average percentage is 24%, and with all boroughs in England, where the average percentage of acceptances due to DV is 12%.

Quarter	Homelessness due to DV	Overall homelessnes s	DV homelessness as a % of overall homelessness
Q2, 12/13	13	19	68.5
Q1, 12/13	10	14	71.5
Q4, 11/12	6	12	50
Q3, 11/12	13	17	76.5
Average	11	16	67%

Figure 9.4: Homelessness due to DV

241. The Panel noted that between Nov 2011 and Oct 2012, there were 247 new approaches for housing advice linked to domestic violence, accounting for 12% of all housing advice enquiries. This is consistent with the figure for approaches from existing service users, which was 869, or 13% of all current case enquiries. In the year previous to this period (Nov 10 to Oct 11), housing advice requests linked with DV accounted for 6% of approaches.
242. Between the 1st January 2012 and up to the 30th September 2012 there were a total of 108 referrals to the sanctuary scheme with a total of 64 sanctuaries fitted which in line with previous years at this stage. The table below demonstrates the number of sanctuaries fitted over previous periods. The sanctuary scheme itself is a measure design to enable victims of DV to remain within their own homes where they choose to by providing structured works to the property and a package of support to the victim to increase their levels of safety within the property.

	2010/11	2011/12	Period to 30.09.12

Referrals to scheme	194	157	108
Sanctuaries fitted	86	81	64

Figure 9.5: Sanctuary scheme referrals

243. The Panel learned that Middlesbrough Refuge has received a total of 426 referrals during the strategic assessment period (October 2011 – September 2012) a slight increase on the previous year. 93 women were accommodated during this period with occupancy levels increasing from 90% rate in 2010/11 to a 98% rate for this period. Refuge provision moved to a purpose built facility in November 2011 and increased capacity in line with national recommendations based on the population of the local community. The facility now comprises of 14 self-contained accommodation spaces. It was confirmed that 56% of the total referrals over the period were not accommodated due to a lack of space within the facility.

244. The table below provides further information on residents over the period, including additional support needs

Residents Information	2010/11	%	2011/12	%
Residents fleeing honour based violence	Unknown		14	15%
Residents with alcohol issues	7	13%	10	10%
Residents with drug issues	6	11%	6	6%
Residents with disability	6	11%	9	9%
Residents with mental health issue	14	25%	24	25%
LGBT residents	Unknown		1	1%

Figure 9.6: Middlesbrough Refuge resident's information

245. It was pointed out to the Panel that women fleeing domestic abuse, who have no recourse to public funds, has been raised as an issue by support services during this strategic assessment period. It is an issue that appears to be increasing for refuge providers who are often requested to fund placements without any financial assistance. Middlesbrough refuge accommodated 6 no recourse cases in 2012 and refused one placement due to a lack of funding options. The Panel was advised that the number of no recourse cases will be monitored and agencies have committed to developing a local protocol to ensure these cases are managed in a co-ordinated way.

246. The Panel heard that *My Sisters Place* provide a one stop shop service for victims of domestic abuse. The table below demonstrates the range of services that are accessed and the number of people accessing the provision, with approaches to the service for support continuing to be high and in line with the previous period.

Number of referrals	1243
Number of victims accessing one stop shop for support (Tel Advice not included)	608
Percentage of repeat cases	(8%)
Local Authority:	
MIDDLESBROUGH	50%
STOCKTON	23%
REDCAR	23%
HARTLEPOOL	0%
OTHER	4%
Types of support taken up:	
IDVA	553
COUNSELLING	76
SANCTUARY	182
LEGAL ADVICE	283
IDVA Data:	
MARAC	96
Criminal / SDVC	100
Number Civil Injunctions (Civil Proceedings)	102

247. The Panel heard that a community outreach service was also established by Harbour support services during 2012 and the table below shows the number of people accessing this provision since its inception.

	2011/12	2011/12	2012/13	2012/13	TOTAL
Measure	Quarter 3	Quarter 4	Quarter 1	Quarter 2	
Number of Referrals	0	15	19	35	69
Number of victims supported	0	7	18	41	66

Perpetrators of DV

248. The Panel learned that there were a total of 997 arrests for domestic related offences between November 2011 – October 2012, which is a 15% decrease compared to the previous year. There were a total of 200 convictions, which is a decline of 17% compared to the previous period⁹. Results in a conviction rate of 69.4% (i.e. of those going to court 69.4% resulted in a conviction, however the overall numbers are still low in comparison to the total number of incidents / crimes over the period). 18.4% (52) of cases were discontinued, which is an increase of

⁹ January – December 2011: Conviction data is delayed due to the CJS process

3.4% compared to 2011/12. It was suggested that this highlights a “justice gap” as incidents move through the criminal justice system.

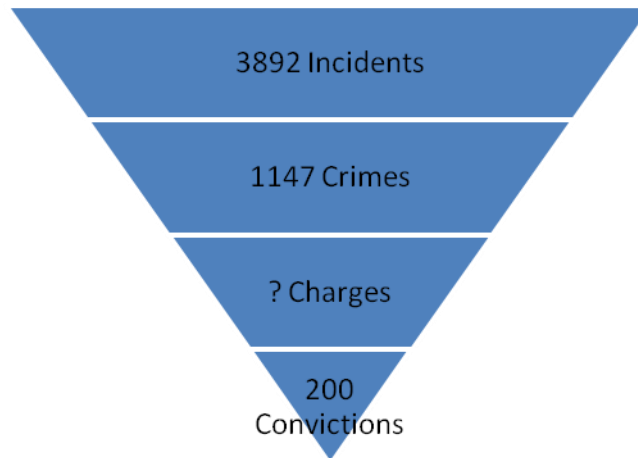


Figure 9.9: DV incidents & Progression through CJS

249. It was reported that suspects are predominantly male (88%) aged between 20-24 years old (19%) and 25-29 years old (22%). Of these 23% of offenders appear more than once, with between 2 and 14 offences classified as DV during the strategic assessment period.
250. The Panel learned that at present, there is little information locally regarding repeat offending rates of individual perpetrators; however estimations suggest that around three quarters (73%) of domestic abuse incidents are repeats¹⁰. It was confirmed that A further gap relates to the number of perpetrators moving through the criminal justice system and any correlations between the number of DV incidents and likelihood of arrest. Evidence of action taken as a preventative measure also needs to be improved.
251. The Panel was advised that in March 2012, a pilot domestic violence triage team was put in place consisting of a multi agency staff team from Cleveland Police, Durham and Tees-valley Probation, and the voluntary sector Harbour Support service. The team was asked to engage with families and to facilitate the trial of an education programme aimed at low-medium risk perpetrators. The team was based and managed within the Families Forward service, a wider multi disciplinary team who focus upon providing interventions to families with a range of complex needs.
252. It was reported that findings from the pilot have identified that the perpetrators that are in contact with services and were referred to the pilot by agencies, were being risk assessed as medium-high risk and as such, a longer-term perpetrator programme was the most appropriate intervention to put in place. In response to the lessons

¹⁰ BCS 2010/11, *ibid*

learnt through the pilot a longer-term perpetrator programme has now been commissioned for this cohort of men. Harbour Support services have further been commissioned to work alongside the Families Forward team and to provide two longer-term perpetrator programmes for men between January 2013 and March 2014.

253. It was confirmed that the DVSG will continue to develop the evidence base for initiatives that aim to educate and engage with DV perpetrators at earlier stages of identification as intervention opportunities for perpetrators remains an issue.

Summary

254. The Panel was advised that Middlesbrough has made a commitment to delivering a co-ordinated model to tackle domestic violence that requires all responsible agencies to work together at all levels, and in partnership. The Domestic Violence Strategy Group are at a mid way point of the 2011-14 strategy delivery and have undertaken a self-assessment process to determine progress against the agreed objectives.
255. The volume of reported DV incidents and DV recorded crimes has begun to decline (by 15% and 6.5% respectively); however the proportion of crimes to incidents has increased to 29.5%. Around 47% of victims were repeats within the year, and data from the MARAC shows that there has been a rise in repeat victimisation in the highest risk cases. CFL have also found that there has been an increase of 13% for referrals relating to domestic violence – many of these, involving substance misuse.
256. It was said that the appointment of an analyst within the Acute Trust may help to overcome some of the data issues that were noted in the past, for example to analyse early indicators of domestic violence and highlight commonalities.
257. 34% of DV crimes were recorded as having been committed under the influence, which is broadly in line with the finding that around 39% of all arrests were linked to alcohol. This is a reduction compared to the previous period and may be a recording issue due to the larger number of “unknowns”.
258. The Panel was advised that it is difficult to state the true number of individuals who are victims or perpetrators of domestic violence offences. At present we only have data regarding those who identified as a victim of a crime or are on the MARAC caseload. Due to the numbers of individuals accessing other services that are not in contact with the police or have not come forward at all, there is a clear gap. Where data is available we can see that repeat referrals to the MARAC are at 50.94% which is currently above target, and there are a number

of perpetrators who are not in contact with other agencies beyond the police.

259. The wider impacts of DV are highlighted with nearly half of referrals to children's social work due to parental issues of domestic abuse during the strategic assessment period. Information from housing and Middlesbrough Refuge, show the impacts DV can have on homelessness or those fleeing violent relationships.

Issues

260. It was reported to the Panel that one of the main gaps is around good information that can lead to the provision of more effective services and processes. Some of these gaps relate to information from partner organisations such as the health agencies, social care, and schools and in areas that can demonstrate the impact of abuse on families such as joint data to inform the picture around alcohol and abuse.
261. There are further gaps in the prevalence data that is collected within certain minority groups, notably within the LGBT community, the BME community, and for issues linked to the wider violence against women and girls agenda such as Female Genital Mutilation (FGM) and Forced Marriage (FM). Further due to changes at the Local Criminal Justice Board (LCJB), court data remains a notable gap in this year's assessment.
262. The repeat victimisation rate in high-risk MARAC cases remains above the 44% target that has previously been set. Despite this repeat rate being influenced by a core group of complex cases, analysis work also demonstrates that there has been a 17% decline in convictions across all reported DV cases, highlighting a 'justice gap' as incidents move through the criminal justice system including high-risk MARAC cases. Analysis of the 10 cases with 5 or more repeat incidents during a 12 month period demonstrated that these cases accounted for over 142 reported incidents with 61 crimes and 1 conviction.
263. The Panel was advised that earlier intervention in repeat cases needs to be improved, at present data is not available to state the exact numbers of people who may be domestic violence victims and repeat victim data is only available in the highest risk cases.
264. The detection rates for domestic violence have continued to fall and are currently 2% lower than the previous period at 43.6%. The number of cases being discontinued has increased and is currently at 18.4%. A further concern is that offences recorded within the Violence Against the person category have shown an increase of 16% during the assessment period
265. Ensuring that adequate provision is in place for perpetrators of violence remains a priority. Although there is a longer perpetrator programme in

place for 2013/14 this is only one approach that can be accessed by a relatively small number of individuals. Further approaches need developing in order to understand the needs of perpetrators and how both mainstream and voluntary sector services can intervene at an earlier stage.

266. Wards in the Town Centre and East Middlesbrough have the highest prevalence of domestic violence, but as yet there is no location-based approach to the issue although 77% of cases occur in the home. These are areas where crime related to alcohol misuse, are also comparatively high.
267. The Panel was advised, funding remains a priority within this area of work, whilst funding levels have been maintained for existing services in the 2012/13 financial year, due to the short term nature of funding within this sector, there will be pressures on provision again post March 2013. The self-assessment has also highlighted that spend on preventative measures needs to be identified.

Education provision for Children with Complex Needs.

268. Whilst the Health Scrutiny Panel's focus was the health of children with complex needs, it felt as though it would be missing an important aspect of the debate, should it not pay close attention to the educational provision for this cohort of Children.
269. As such, the Panel was considered a paper from the Directorate of Care, Wellbeing & Learning, outlining some initial questions that were put to the Department, by the Panel. Those questions were:
- 269.1 *Could you provide the Health Scrutiny Panel with a brief synopsis on the key points of the SEN White Paper, currently going through Parliament?*
- 269.2 *What will the major impact of the SEN White Paper be on Middlesbrough?*
- 269.3 *Could you please provide some detail on current provision for SEN in Middlesbrough? E.g. How many facilities does Middlesbrough have and what type of Special Educational Needs does each facility meet?*
- 269.4 *How would a child find their way to one of those specialist facilities? Is there a typical referral process?*
- 269.5 *In the view of Middlesbrough Council, does the capacity of SEN provision match demand?*
- 269.6 *Could you please provide some detail on the aims and aspirations of the SEN review, that has previously been referred to? Are there any early findings from that, which could be shared with the Panel?*

269.7 *Does the Dept have any views on what impact demographic changes will have on demand for future SEN provision?*

270. It was confirmed to the panel that there was very strong evidence to suggest that advances in medical technology and knowledge dictated that more children with complex needs, were being delivered successfully and living longer. As such, an important aspect to consider, the Panel was advised, was how their educational needs were being met and the nature of the educational services available to them. The Panel heard that specific attention should be given to the extent to which current services were configured, to be able to accommodate rising numbers of Children with Complex Needs.

271. Evidence submitted to the Panel outlined the key points of the current SEND legislation, which was seen as the most wide-ranging review of the area for over 30 years since the Warnock report, which set the direction for the current SEN framework. The Panel was advised that although the full impact of the proposals had yet to be determined, the local authority response has been to initiate an audit of its current provision with a view to drafting and consulting on a Strategy for Vulnerable Learners, that would guide the local implementation of the policy.

272. It was reported to the Panel that, in the view of the local authority and most policy commentators, there was a lack of clarity from the Government on future arrangements, including the funding regime, which was complex and needed to achieve a fair balance.

273. Specific reference was made to the new Education, Health and Social Care Plan (EHSCP) which replaced statements and spanned ages from 0-25. The Panel was advised that it would be required to contain commitments to resources from health and social care, as well as education and would set out learning and life outcomes, as well as needs.

274. The Panel acknowledged the need for further clarity with regard to future funding arrangements in respect of Academies. With effect from 1 April 2013 a multi-agency team including education, health and social care would undertake a massive exercise examining the overall needs and funding arrangements. It was said that there were a relatively small number of children subject to EHSCP, with the vast majority of children with needs not being eligible.

275. The Panel heard that parenting was often felt to be the key to effective early intervention, but it was said that there was concern given the increasing economic difficulties facing the region. It was reported that the impending legislation and SEN review, presented opportunities for parents to train as key workers.

276. It was also noted that funding arrangements were to be explored

including the national funding framework for specialist provision, that allowed more transparency and consistency between areas, with better alignment between pre and post 16 provision. The trial of delegated funding to schools for alternative provision for SEN pupils would be evaluated.

277. The Panel heard that as Middlesbrough has more vulnerable learners than neighbouring authorities, and that there were projections that suggested that the numbers of children with complex needs were set to rise significantly in the future, the legislation would have profound implications for service provision in Middlesbrough. This would make the need for effective early intervention and prevention all the greater.
278. The report submitted to the Panel gave an indication of the categories of vulnerability. The Panel was advised that children/young people entered Middlesbrough's settings/schools with a range of risks, of not fulfilling their potential in terms of outcomes.
279. It was reported to the Panel that many children and young people required Wave 1 / Wave 2 levels of intervention. Often, Quality First Teaching and Care, Support and Guidance enabled the majority of pupils to make appropriate, positive progress. A number of pupils, however, need more intensive or more specialist input in order to address their needs at Wave 3/ Wave 4 levels of intervention. The report submitted to the Panel outlined the categories of children/young people identified as requiring such interventions which included culture and language; attendance and mobility; not in school/at risk of exclusion; SEND; transitions; health and wellbeing; and home circumstances.
280. The Panel was advised that in order to cope with the level and complexity of need in Middlesbrough, a range of bases/units in mainstream schools complemented the special school provision in the Town.
281. The Panel heard that the imposed Government minimum floor standards to be achieved by primary schools in relation to English and Mathematics, was seen as a possible barrier when endeavouring to cope with the increasing number of children, with higher levels of need.
282. In terms of access to the variety of provision available it was reported to the Panel that there was a range of referral processes. Using the proposals for Education, Health and Care plans as a guide, the Cleveland Unit which currently had a waiting list had pioneered a simplified, multi-agency referral system which would be used as a model to review and simplify the overall system.
283. The Panel was advised that in response to the proposed legislation and funding changes, Middlesbrough had instigated a review of all its SEND provision. The Panel was advised that the initial details were

descriptive and formed the basis of the information provided in the report under the heading specialist provision for pupils in special education needs. It was confirmed that a further stage of the review had been completed providing recommendations for strategic decision-making. It was reported that the following recommendations were draft proposals which would form the basis for further consultation with special school leaders in Middlesbrough's Inclusion/Collaborative and Headteachers of schools with specialist bases/units:-

- 284.1 Audit of all vulnerable learners (0-19), to identify their locality and level of service provision to establish a reliable and accurate current baseline.
- 285.2 Rationalise existing referral panels to establish a central referral pathway and hub for early years intervention services.
- 285.3 Develop the role of the Cleveland Unit to retain a central hub for the most complex children and their families, to establish a central referral pathway, to track and monitor vulnerable learners, to establish spokes for community based provision in the localities where the need has been identified as the greatest, to support workforce development.
- 285.4 Develop greater accountability of service provision in line with the principles of best value.
- 285.5 Develop tracking and monitoring systems for vulnerable learners (i.e. virtual school, Capita One), narrowing the gap.
- 285.6 In line with the proposals of the SEN Green Paper develop a multi agency referral panel and move towards a single plan for vulnerable learners.
- 285.7 Undertake a pilot to develop a single panel for early years referrals for vulnerable learners (CU, Portage, Inclusion Support).
- 285.8 Review the CAF process to simplify systems for parents/carers and professionals to ensure simply and easy access to appropriate interventions/services for vulnerable learners and their families.
- 285.9 Develop a workforce development strategy for supporting children, young people and families for early help as part of the strategy explore new ways of supporting agencies and practitioners with best practice initiatives.
286. Given the Health Reforms, due for implementation on 1 April 2013, the Panel considered it prudent to gain a perspective from the Clinical Commissioning Group with regard to EHSCPs. It was clear that at the time of the meeting, the local authority had had very little contact with the emerging CCG on this topic, which caused some concern for the Panel.

Meeting of the Health Scrutiny Panel on 2 April 2013

Evidence from the Local Authority & Clinical Commissioning Group

287. Further to the meeting of the Panel on 26 February 2013, the Panel was keen to gather the views of senior representatives of the Local Authority and the South of Tees Clinical Commissioning Group (STCCG) on the development of Education, Health and Social Care Plans (EHSC) and in particular their introduction, use and how they will be funded.
288. In order to assist deliberations, a series of questions had previously been forwarded to the representatives are outlined below.

Questions of the South of Tees Clinical Commissioning Group (CCG)

- 288.1 *What is the CCG's current thinking about how it will approach its responsibilities in relation to funding for EHSC plans?*
- 288.2 *Does the CCG have any intelligence as to the likely necessary financial commitment related to EHSC's in Middlesbrough and the likely numbers of children involved?*
- 288.3 *Does the CCG consider there to be any potential problems with the introduction of the EHSC plan?*
- 288.4 *What does the CCG see as potential problems in the development of the EHSC plans?*
- 288.5 *How well developed is the relationship between the CCG and local authority in preparation for the requirement to discuss and progress EHSC plans?*

Questions asked of the Local Authority's Education function

- 288.6 *What, thus far, have the national Pathfinder sites told us about the development of the EHSC Plans?*
- 288.7 *What, in the view of the Dept, will be the challenges for Middlesbrough in successfully implementing the EHSC?*
- 288.8 *What does the Dept feel will be the benefits that the EHSC Plans will deliver?*
289. In beginning to address the questions, The Chair of the STCCG referred to a joint meeting recently held when a high level of agreement had been reached regarding the principles, in terms of the financial support from the respective organisations with regard to EHSC Plans.

290. NHS England representatives confirmed her experience of such matters and that there was involvement with four other CCGs. In particular, reference was made to a pilot scheme which had operated in Hartlepool and the lessons which could be learnt from such an exercise. Primarily North Of England Commissioning Support had developed expert advice and best practice, which could be applied elsewhere.
291. It was confirmed to the Panel that, from a Middlesbrough Council perspective, the prevailing legislation was still valid, but referred to legislation currently going through Parliament which provided an indicative draft Code of Practice for Special Education Needs, which was expected to be enacted in September 2013.
292. Following enquiries, the Panel was advised that the impending legislation, in general terms, it appeared to be more person centred and focussed on improving outcomes for children, young people and families in a more positive way. The Panel heard that it outlined the expectations from the different organisations from a family's perspective and assisted families from being referred from one place to another. The Code of Practice provided a definition of special educational needs and disability and also differentiated between 'MUST', which referred to a statutory requirement, and 'SHOULD' relating to guidance that was a non-statutory requirement.
293. It was confirmed that for children and young people with more complex needs, the Code provided a co-ordinated assessment of needs and a new 0 to 25 EHC plan. For the first time it gives new rights and protections to 16-25 year olds in further education and training, comparable to those in school. It was reported that approximately 735 families would be affected, although the panel heard that those children with a physical disability were not eligible for ECH plans. An assurance was given that the Code aligned with other provisions and the overall approach was to achieve closer co-operation and greater integration between all the services to support children and their families through joint planning and commissioning of services.
294. The Panel was advised of a Task and Finish Group established for a SEN Review and that the Authority had engaged Brian Lamb, a renowned national figure, to carry out a short piece of work in relation to the current position, gap analysis and what action needed to be taken. The Panel heard that 'Key Working' was an important element, whereby one person took a lead role and to bring together one plan, where a number of specialist services were working with a family. A number of concerns were expressed about the potential increasing number of families and difficulties in recruiting key workers with particular regard to families with more than one child with a disability and a higher level of children with increasing complex needs.
295. The Panel heard that the principles underlining the Code, identified that

the views and participation of children and their parent/carer and young people were central and supported throughout the system. Reference was made to recent outstanding Ofsted reports in respect of Middlesbrough's special schools and of the need to achieve a smooth transition following the implementation of the impending legislation.

296. The Panel was interested to explore how the new system would be funded. It was indicated that the impending legislation provided more clarification and the pilot scheme at Hartlepool was examining personal budgets, which would allow a certain degree of flexibility. An indication was given of the difficulties in determining the financial commitment given the rise in projected numbers, although the Joint Strategic Needs Assessment would assist in that regard taking into account such factors as increasing complex needs, migration and birth rate. Nonetheless, it was felt important to note that developing accurate financial demand forecasts for this group is notoriously difficult, as one extreme case can skew the budget for a whole year.
297. Some reservations were expressed regarding those children with personal care needs but who were not eligible for an EHC Plan and received no additional funding to assist with the level of support required. The Panel heard that there was a concern that a two-tier system would result. The importance of early identification of needs to ensure that respective organisations were able to intervene and provide the most appropriate support for a child and family was of paramount importance. It was reported that a co-ordinated approach was required culminating in a single plan. A strategic issue for respective organisations was the access arrangements to an assessment and appropriate mechanisms in place to provide a transparent process, which would deal with changing circumstances such as rising costs.
298. From the CCG's perspective they were responsible for commissioning for a whole range of needs for the overall population some of which were specifically directed from NHS England. The difficult task was to ensure that there would be effective opportunity to access all needs of the population the allocation of which would be based across all priorities taking into account such analysis as the JSNA and including feedback from partners as to where investment should be placed.
299. The Panel heard that despite measures in place, crisis situations would inevitably occur and in such circumstances, the Panel was keen to seek assurances that information was readily available on the points of contact for parents. In response the Panel was advised that as part of the package of a local offer it was very important to identify what and how to access support. The importance and long term benefits of early intervention were reiterated and how to engage with parents effectively providing appropriate information. From the CCG's perspective much investment was already tied up but there was recognition of the need to shift to prevention and early intervention but this would take time to work through.

Conclusions

The Panel is asked to consider the conclusions it would like to make

Recommendations

The Panel is asked to consider the recommendations it would like to make

**Councillor Eddie Dryden
Chair, Health Scrutiny Panel**

BACKGROUND PAPERS

Please see the Agenda and supporting papers from the following meetings

Health Scrutiny Panel 23 October 2012
Health Scrutiny Panel 5 December 2012
Health Scrutiny Panel on 17 December 2012
Health Scrutiny Panel 15 January 2013
Health Scrutiny Panel 26 February 2013
Health Scrutiny Panel 2 April 2013

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