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Scrutiny Health & Social Care Sub-Committee Agenda

To: Councillor Sherwan Chowdhury (Chair), Councillor Andy Stranack (Vice-Chair), Pat Clouder, Toni Letts, Andrew Pelling, Scott Roche and Gordon Kay (Croydon Healthwatch)

Reserve Members: Jamie Audsley, Jan Buttinger, Patsy Cummings, Stephen Mann, Helen Redfern and Callton Young

A meeting of the **Scrutiny Health & Social Care Sub-Committee** which you are hereby summoned to attend, will be held on **Tuesday, 26 March 2019** at **6.30 pm** in **Council Chamber - Town Hall**

Jacqueline Harris Baker
Council Solicitor & Monitoring Officer
London Borough of Croydon
Bernard Weatherill House
8 Mint Walk, Croydon CR0 1EA

Simon Trevaskis
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www.croydon.gov.uk/meetings
Monday, 18 March 2019

Members of the public are welcome to attend this meeting.
If you require any assistance, please contact the person detailed above, on the righthand side.

N.B This meeting will be paperless. The agenda can be accessed online at www.croydon.gov.uk/meetings

AGENDA – PART A

1. Apologies for Absence

To receive any apologies for absence from any members of the Committee.

2. Minutes of the Previous Meeting (Pages 5 - 14)

To approve the minutes of the meeting held on 18 December 2018 as an accurate record.

3. Disclosure of Interests

In accordance with the Council's Code of Conduct and the statutory provisions of the Localism Act, Members and co-opted Members of the Council are reminded that it is a requirement to register disclosable pecuniary interests (DPIs) and gifts and hospitality to the value of which exceeds £50 or multiple gifts and/or instances of hospitality with a cumulative value of £50 or more when received from a single donor within a rolling twelve month period. In addition, Members and co-opted Members are reminded that unless their disclosable pecuniary interest is registered on the register of interests or is the subject of a pending notification to the Monitoring Officer, they are required to disclose those disclosable pecuniary interests at the meeting. This should be done by completing the Disclosure of Interest form and handing it to the Democratic Services representative at the start of the meeting. The Chair will then invite Members to make their disclosure orally at the commencement of Agenda item 3. Completed disclosure forms will be provided to the Monitoring Officer for inclusion on the Register of Members' Interests.

4. Urgent Business (if any)

To receive notice of any business not on the agenda which in the opinion of the Chair, by reason of special circumstances, be considered as a matter of urgency.

5. Question Time: Cabinet Member for Families, Health & Social Care

Question time with the Cabinet Member for Families, Health & Social Care, Councillor Jane Avis.

Presentation slides to follow.

6. Annual Public Health Report 2018 (Pages 15 - 92)

The Sub-Committee is asked to review the report and considered whether it wishes to make any recommendations.

7. Croydon Healthwatch Update (Pages 93 - 152)

Presented for the Sub-Committee's information is the report from Healthwatch Croydon on Dementia Carers experiences of using Croydon's health and social care services.

8. Exclusion of the Press and Public

The following motion is to be moved and seconded where it is proposed to exclude the press and public from the remainder of a meeting:

"That, under Section 100A(4) of the Local Government Act, 1972, the press and public be excluded from the meeting for the following items of business on the grounds that it involves the likely disclosure of exempt information falling within those paragraphs indicated in Part 1 of Schedule 12A of the Local Government Act 1972, as amended."

PART B

Scrutiny Health & Social Care Sub-Committee

Meeting held on Tuesday, 18 December 2018 at 6.30 pm in Council Chamber, Town Hall, Katharine Street, Croydon CR0 1NX

MINUTES

Present: Councillors Sherwan Chowdhury (Chair), Councillor Andy Stranack (Vice-Chair), Pat Clouder, Andrew Pelling and Scott Roche

Apologies: Councillor Toni Letts

PART A

42/18 **Minutes of the Previous Meeting**

The minutes of the meeting held on 20 November 2018 were agreed as an accurate record.

The Chair confirmed to the Sub-Committee that following the previous meeting a letter had been sent to King's College Hospital NHS Trust to register the concerns of the Sub-Committee regarding the closure of the Community Dental Service in New Addington.

The Director of Public Health advised the Sub-Committee that the Trust should have informed her prior to any change being made to the service, which had not been the case. As such she was rigorously investigating how this had happened and also looking to investigate options with the Trust for the re-provision of the service in the local area.

43/18 **Disclosure of Interests**

There was none.

44/18 **Urgent Business (if any)**

The Chair advised the Sub-Committee that he had agreed to allow the progress report from the South London and Maudsley NHS Foundation Trust to be considered as an urgent item to ensure that the update was provided in line with the Sub-Committee's recommended timeframe set at their meeting on 28 September 2018.

45/18 **South London & Maudsley NHS Foundation Trust - Progress Report**

Beverley Murphy, the Director of Nursing at SLaM and Doctor Faisil Sethi, the Interim Service Director for the Croydon Executive Team of SLaM, were in attendance at the meeting to provide an update on the actions being implemented in response to the findings from a Care Quality Commission (CQC) inspection earlier in the year.

From the presentation the following information was noted:-

- An overview of the management structure for the team responsible for inpatient and community services in Croydon and Behavioural & Development Psychiatry (BDP) was provided. SLaM provided reassurance to the Sub-Committee that the right team was now in place to deliver improvement going forward.

- An Action Plan had been developed which focussed upon achieving the 'must do' recommendations within the CQC report. This included achieving a consistent standard of care across the organisation with work also needed to address concerns regarding the Ward Directorates.

- Weekly meetings chaired by the Chief Executive of SLaM had been set up to account for the implementation of the Flow Plan which had been created to improve the flow of patients through the service to discharge. The short term results had been encouraging with a reduction in the amount of people waiting in A&E, but it was essential to ensure that this good work continued moving forward.

- A Delivery Board chaired by the Director of Nursing, which met once a fortnight, had been set up to provide oversight of the improvement plans being delivered as a result of the CQC inspection. There were six improvement plans in place, each with actions relating to their respective areas. The plan for Croydon included 194 separate actions which varied from the straight forward to multi layered, detailed actions. The Delivery Board focussed its attention upon those actions that were not on track.

- From the 194 actions set out within the improvement plan for Croydon, highlights included having the Directorate Senior Management Team in place, continuous improvement around the recruitment and retention of a high quality and skilled workforce, continued improvement to address issues relating to patient flow and continued improvement in mental health transfers from emergency departments.

Following the presentation, members of the Sub-Committee were given the opportunity to question the representatives from SLaM. The first question concerned how SLaM commissioned services, with it confirmed that this would depend on the type of service being commissioned. Forensic and neurodevelopmental services would be commissioned on a regional or national level by NHS England, while others would be on a more local Croydon basis.

In response to a question concerning how data for mental health assessments was tracked, it was confirmed that daily reports were prepared for the Executive Management team. This information was also regularly reported to both the Board and the Quality Committee.

There was a concern raised that the work to improve patient flow was too management focussed and as such it was question whether improvements were being cascaded to frontline staff. It was confirmed that this was an important issue for SLaM with mechanisms being put in place to engage staff in the process. The new management structure had given clinical leadership more of a voice and a clearly defined role. Other changes included Matrons only working from one site and overseeing a smaller number of wards. Ward Manager posts had also been created to improve the oversight of improvements.

In relation to the 194 improvement actions for Croydon, the methodology being used to determine whether they were achievable or not was questioned. It was confirmed that the Quality Portfolio Board had approved a measurement strategy which accounted for the difference that would be made if all the actions were implemented. This took into account a range of factors including the length of patient stay, the use of restraint, staff turnover and staff satisfaction. All of which would be used as indicators of overall improvement.

In response to a question about how the objectives had been defined, it was advised that they had been identified following engagement with senior leaders in the organisation, partners and regulators, with both clinical and regulatory reasons for the four priority areas.

Regarding patient flow, it was questioned how the number of mental health assessments being cancelled could be reduced. It was advised that the reasons for cancellation varied, with some out of the organisations hands, such as needing police support for an assessment. However SLaM did have control over patient flow and would cancel an assessment if there were no beds available. By implementing the flow plan, it would improve the capacity of the service, reducing the need for cancellations as a result.

It was questioned how SLaM would go about achieving its targets for patient discharges per week. It was advised that Trust were aware that there were cases of people occupying beds that no longer needed to be there and needed to move on. At the time of the meeting the discharge rate was 56 patients per week and an average discharge rate of between 50 to 55 patients per week was needed to manage capacity.

A request was made for the complete list of 194 actions relating to Croydon to be shared with the Sub-Committee, which was agreed. It was also agreed to invite SLaM back to a future meeting to provide a further update on their improvement plans.

The Chairman thanked the representatives for attending the meeting and answering the questions of the Sub-Committee.

Conclusions

Following the discussion of this item, the Sub-Committee reached the following conclusions:

1. The Sub-Committee welcomed the progress made to date against the 194 actions in the Improvement Plan for Croydon and requested that a full list of the actions be shared with Members.

2. The Sub-Committee welcomed the fact that SLaM had moved to a geographical structure, but had a concern that the new approach was management lead and did not present enough opportunities for clinical input.

3. It was agreed to invite SLaM to a future meeting of the Sub-Committee to present a further update on the progress made with the improvement plan.

4. It was also agreed that the Croydon Clinical Commission Group would be invited to the same meeting as SLaM to allow for a joint discussion on commissioning and outputs for the borough.

46/18 **Winter Preparedness 2018-2019**

The Sub-Committee had invited representatives from the Clinical Commissioning Group (CCG) and the Croydon Health Service (CHS) along with representation from the Adult Social Care team from the Council to the meeting to provide an update on their preparations for the winter period. The following people were in attendance for this item:-

- Andrew Eyre – Accountable Officer for the CCG
- Stephen Warren – Director of Commissioning for the CCG
- Matthew Kershaw – Chief Executive for CHS
- Paul Richards - Head of Adult Mental Health Substance Misuse for Croydon Council

During the introduction to the report it was emphasised that plan for winter had very much focused on whole system working with a view to keeping people well and out of Accident & Emergency (A&E) where possible. The plan had been developed jointly by the CCG, CHS and the Social Care team at the Council. A key challenge to the delivery of the plan was the need to manage an increasing demand for services and as such it focused on the following areas:

- Strengthen Governance arrangements.
- Developing and delivering out of hospital initiatives.
- Working to improve capacity within services through the improved maintenance of patient flow.
- The launch of the new A&E facility at Croydon University Hospital.

Work to date on the plan included:-

- The recommissioning of urgent care services through the provision of three GP hubs, including the GP Extended Access Hub to provide additional appointments.

- Continued work on patient education to direct away from A&E towards more appropriate services such as GPs and pharmacists.

- The Winter Communications Plan included a Flu Campaign which raised awareness of the Flu Vaccination programme, with a particular focus on vulnerable groups and frontline NHS staff.

- The new Emergency Department opened on 2 December 2019 and was already delivering benefits such as improved ambulance handover times and improved escalation capacity and flexibility within the service.

- Mental Health Initiatives included multi-agency discharge events focussed on reducing the length of stay in the Emergency Department, with additional beds for mental health patients commissioned with the East London Foundation Trust.

Key challenges to the delivery of the plan were:

- The recruitment and retention of the staff, which remained a problem across London, particularly in paediatric care. However there had been an improvement since September with a reduction in the number of unfilled shifts in the Emergency Department.

- Patient discharge continued to be an issue, with work underway to improve discharge processes including enhancing the discharge team through the recruitment of a single manager working across the health service and social care service to improve the focus on discharge.

- There was a continued focus on long stay patients, with ‘stranded’ patients remaining a significant challenge. There were also a significant amount of patients from other boroughs which increased the complexity when discharging

- The Council had been given funding of £1.4m to assist with winter pressures including the delayed transfer of care, market stabilisations and LIFE demand.

- There was further opportunity to develop the GP Huddles which arranged for practices to meet with partners to discuss the care provision for those patients with complex needs.

Following the introduction of the item, the Sub-Committee were given the opportunity to question the representatives. The first question related to demand management and the savings made through educating patients to self-care where possible rather than using urgent services. In response it was confirmed that A&E attendance was stabilising through work with the GP

Hubs, but it was difficult to quantify the number of potential patients choosing to self-care. Intervention at an early stage provided a number of benefits including allowing people to remain well and independent. It also allowed the service to focus urgent care upon those who required it the most.

It was noted that demand management was difficult to predict and as such it was questioned how the risk of misdiagnosis was managed. It was advised that there was always the risk of misdiagnosis, but GPs would always refer patients to specialist services if they were not able to make a diagnosis themselves.

In response to a question about prescriptions and an increased expectation for savings to be delivered through patients paying for some medicines that would have previously been prescribed, it was highlighted that GPs had the clinical freedom to prescribe as needed.

It was noted that during spells of cold weather there was often a spike in the number of injuries relating to falls and as such it was questioned whether the health service was in position to cope with demand. It was advised that the spike in injuries was normally manageable, but there was an important differential between those people who were generally well suffering a fall and those with wider health issues. Work was being undertaken through community nurses and GPs to raise awareness of the need to take extra care.

It was questioned what could be done to improve the take up of the Flu Vaccination Programme, to which it was advised that a lot of the work to raise awareness would be carried out through GPs surgeries and other community based services. Other areas that could be targeted included care homes and the vaccination of frontline NHS staff, which was optional, but strongly recommended. It was noted that there was a need to shift the public perception on vaccinations which could often be negative.

In response to a question about bed occupancy rates, it was noted that it was currently at a high level, with some days approaching 100% capacity, which increased the challenge of ensuring flow through the system. There was an aim to reduce bed occupancy to below 90% to ensure there was greater flexibility within the system.

In regard to more vulnerable, elderly patients, it was questioned where they could be discharged to and how this was monitored. It was advised that discharge rates were monitored on a daily basis, with a list of patients who needed additional support being overseen by the integrated discharge team. There were a number of reasons that caused a delay in discharging a patient including the availability of care home places and the need for home adaptations to be installed.

As there was increasing pressure to improve discharge rates, it was questioned whether this had led to an increase in readmissions. It was confirmed that readmissions tended to fluctuate, particularly at this time of year. There were instances when people were discharged too early, but this was monitored and would be picked up if there was a significant issue.

As it was noted that the Winter Communications Plan was targeted at the South West London area rather than a local, Croydon level, it was questioned how any such communication would help patients negotiate through health service pathways locally. It was advised that the campaign had been designed to address the needs of each borough. It was agreed that further detail on the Winter Communication Plan would be shared with the Sub-Committee outside of the meetings.

From the perspective of the Croydon University Hospital it was noted that a strength of the Emergency Department was that it was well known and easy to access. As such it was important to direct people when first attending, with the first point of contact being a Screening Nurse to guide patients to the most appropriate service for their needs.

At a previous meeting of the Sub-Committee it had been noted that it could often be difficult for the street homeless to access services, as such it was questioned what support was available. It was highlighted that there was a big campaign underway to reassert that the homeless had a right to register with GPs, with the provision of a card to confirm this. It was also stated that entry into the health service for homeless people should be no different to others patients, but it was acknowledged that there could be additional difficulties around discharge when the patient did not have a home.

In response to concerns about the available capacity within the Emergency Department to meet demand and how much flex was available, it was confirmed that the service was currently using about half its flex capacity, but there was also an additional flex ward that could be deployed as needed. It was also highlighted that extended hours for GP Hubs were in operation with extra capacity available, with patients referred to the Hubs from their existing practices.

As it had been noted that additional capacity for mental health patients had been commissioned with the East London Foundation Trust, it was questioned how long the additional capacity was available and what support was being provided for relatives wanting to visit patients. It was confirmed that the additional capacity would be in place until the end of March 2019 to manage the current demand and provide the opportunity to reduce occupancy levels. It was also confirmed that there was support in place to ensure relatives were able to travel to visit patients.

In response to a question about why the length of bed stay was so long, it was confirmed that at present the numbers were high, but the department had the capacity to manage 70 patients for over 21 days, if the number of patients rose above this it would become more challenging to manage demand. It was highlighted that the average length of stay for non-elective surgery was under five days.

It was noted that at present a lower than expected number of patients were going through GP Huddles and as such it was questioned whether this was due to patients having to go through their GPs for referral. It was advised that Huddles were something the CCG would like promote further as they had

been shown to be effective. There now needed to be an expansion of scope to encourage other healthcare professionals to refer patients who were eligible.

As it was noted that there was 10,000 additional minutes available for appointments with GPs in the borough, it was questioned how this had been allocated. In response it was confirmed that the additional capacity was being provided at the GP Hubs.

In response to a question about the Red Bag Scheme it was confirmed that it had been based upon a similar scheme operated in Sutton and was targeted at care homes and would deliver savings through improving the preparation of people when being admitted to hospital.

It was questioned what would happen if the Emergency Department was at 100% capacity and a major incident occurred. It was advised that should this occur, then there was a mechanism in place to increase patient discharge.

In response to a question about the waiting times in the Emergency Department it was advised that this would depend on the level of care needed, with urgent care performance being good. For minor injuries, most patients were seen within four hours and discharged the same day.

Regarding ambulance conveyancing at the new Emergency Department it was confirmed that this was sometimes higher than it should be, but this could be down to ambulance staff wanting to test the new service.

It was confirmed that facilities for mental health patients had been improved within the Emergency Department with separate rooms for adults and children.

The Chairman thanked the representatives for attending the meeting and answering the questions of the Sub-Committee.

Conclusions

Following the discussion of this item, the Sub-Committee reached the following conclusions:

1. The Sub Committee were concerned to note that the Emergency Department was operating at near 100% of its capacity, when there had not been any flu outbreaks or bad weather and as such questioned how prepared they were to meet any increase in demand?

2. The Sub-Committee were also concerned about the guidance provided to GPs on prescription costs and discretionary prescribing, as it was felt that this may lead to some patients not getting the medicine they required.

3. The Sub-Committee were concerned that the Winter Communication Plan had been developed on a South West London level and as such questioned whether it would be more effective on a local Croydon level.

4. The Sub-Committee welcomed the approach of using a multi-service discharge team and agreed that it would like to receive further information about this approach.

5. The Sub-Committee agreed that it would be important to have a follow-up report on Winter Preparedness in March to find out whether it had been effectively managed.

Recommendations

1. That the GPs Collaborative be invited to a future meeting to provide further information on discretionary prescribing.

2. That representatives from the interagency Discharge Team be invited to a future meeting to provide further information on their work.

3. That the representative from the CCG, CHS and the Social Care team be invited back to the meeting of the Sub-Committee in March to provide an update on the delivery of their Winter Plans.

47/18 **Healthwatch Croydon**

Gordon Kay, the Manager of Healthwatch Croydon provided an update for the Committee on their recent activities. It was confirmed that application period for new members of the Board had recently closed, with the selection process underway. It was hoped that the new Board Members would be in place by the end of January to begin business planning for April. Mr Kay thanked those Members who had helped to raise awareness of the vacancies.

48/18 **South West London and Surrey Joint Health Overview and Scrutiny Committee**

The Vice-Chair provided an update on a recent meeting of the South West London and Surrey Joint Health Overview and Scrutiny Committee, at which the review on the future of Accident & Emergency and Maternity services at Epsom, St Helier and Sutton Hospitals was considered. A key concern for Croydon would be the closure of these services at St Helier Hospital, as projections had indicated that this would significantly increase demand at the Croydon University Hospital.

The Chairman also provided an update from the meeting of the Pan London Joint Health Overview and Scrutiny Committee Forum, which had met recently. The discussion at the meeting had focused on the ongoing issues around staffing in the NHS across London, with an emphasis on looking at new ways for different organisations to work together.

49/18 **Exclusion of the Press and Public**

This motion was not needed.

The meeting ended at 8.55 pm

Signed: .....

Date: .....

For general release

REPORT TO:	**Health and Social Care Sub-Committee** **26 March 2019**
SUBJECT:	**Annual Public Health Report 2018** **Early experiences last a lifetime** **The first 1000 days from conception to the age of two**
LEAD OFFICER:	**Rachel Flowers, Director of Public Health**
CABINET MEMBER:	**Councillor Jane Avis, Cabinet Member for Families, Health & Social Care**
PERSON LEADING AT SCRUTINY COMMITTEE MEETING:	**Rachel Flowers, Director of Public Health**

CORPORATE PRIORITY/POLICY CONTEXT/AMBITIOUS FOR CROYDON: The Annual Public Health Report has taken national and international evidence about the importance of the first 1000 days to life-long health and happiness to inform system wide recommendations to ensure that children in Croydon have the best start in life. Implementing these recommendations, such as training for staff about Adverse Childhood Experiences and improving mental health pathways will help ensure that issues are prevented before they become problems, and that Croydon becomes a more equal place. Corporate Plan for Croydon 2018-2022

ORIGIN OF ITEM:	**The Annual Public Health Report forms part of the Work Programme for the Health & Social Care Sub-Committee.**
BRIEF FOR THE COMMITTEE:	**The Sub-Committee is asked to review the report and considered whether it wishes to make any recommendations.**

1. EXECUTIVE SUMMARY

1.1 It is a statutory requirement for the Director of Public Health to produce an Annual Report and for the Council to publish this as detailed by the Health and Social Care Act 2012.

1.2 The 2018 report focused on the first 1000 days of children's lives from conception to age 2 (See published report in appendix 1).

1.3 The report highlights that working together to ensure that children experience the best possible first 1000 days is a vital prevention activity that will enable us to change the future health of Croydon residents.

1.4 The report focuses on five areas:

- The setting for the first 1000 days – the role of the wider environment
- Preparing for pregnancy
- Pregnancy
- Infancy
- Adverse Childhood Experiences (ACEs)

1.5 The report introduces the concept of Adverse Childhood Experiences (ACEs), such as neglect and abuse. Some ACEs may occur during the first 1000 days of life, and may have a long lasting impacts. Each additional ACE that a child is exposed to increases the risk of poorer health outcomes.

1.6 The report proposed three principles to guide our future actions:

- Know your role: we all have a role to play in helping children thrive during the first 1000 days - however we need to understand what this role is and how best we can contribute through a whole systems approach
- Health in all policies: we all should shift the focus from managing ill health to creating the right conditions for good health through a health in all policies approach
- Breaking the inequalities cycle: tackling the socio- economic determinants of health- (such as jobs, homes, social cohesion, education, income) is key in reducing inequalities in early years that, in turn, become inequalities across the life course. We all have a role to play in breaking this cycle

1.7 The report makes 34 recommendations for action including:

- Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.
- All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.
- 1000 front line staff in the council, NHS, police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact, in 2019
- Develop and Implement a plan of action for increasing the levels of awareness about pre pregnancy health and the importance of preparing for pregnancy by the end of 2019

1.8 The information, principles and recommendations presented in the report are intended to focus our efforts to make the most of our collective resources across the Borough to ensure each child has the best possible first 1000 days.

1.9 The Health and Wellbeing Board (HWB) agreed at its February 2019 meeting to form a task and finish group to oversee the delivery of the recommendations contained in the report. The presentation in appendix 2 shows which existing or new work streams are implementing each of the recommendations.

2. Annual Public Health Report 2018

See Appendix 1 – Annual Public Health Report 2018

See Appendix 2 – Slide presentation

Appendices

Appendix 1- Annual Public Health Report 2018

Appendix 2 - Slide presentation

CONTACT OFFICER: *Rachel Flowers, Director of Public Health*

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WE ARE CROYDON

EARLY EXPERIENCES LAST A LIFE TIME

The first 1000 days from conception to the age of 2



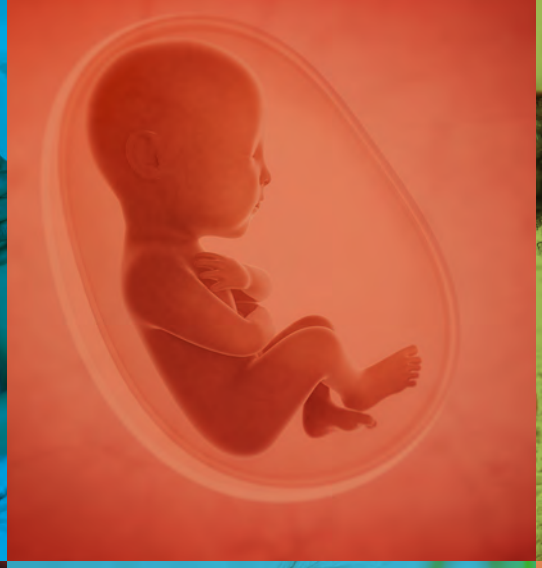







DIRECTOR OF PUBLIC HEALTH ANNUAL REPORT — 2018 —

Delivering for Croydon | CROYDON www.croydon.gov.uk









FOREWORD BY TONY NEWMAN, LEADER OF THE COUNCIL

I am delighted to provide my introduction to Rachel Flowers' third Annual Public Health Report for Croydon. All Directors of Public Health are required to produce an independent annual report on the health of their population, highlighting key issues that impact on the population.

Rachel and I have been working together over the last few years looking at how we can best address the historic inequalities here in Croydon. This report is a strong statement and provides a range of recommendations at a time when we have competing priorities and not enough resource. It comes, however, at the right moment, when we are focusing on prevention and increased locality working.

The first 1000 days of a child's life lay the foundations for their own and Croydon's futures. In last year's report Rachel highlighted that there are stark health inequalities between communities just a 30 minute bus ride apart. In this report she will be showing what this means for early childhood and what opportunities there are to make a difference and to reduce these health inequalities.

The more we understand about the first 1000 days and what influences them at borough, community, locality, family and individual level, the more chance children in Croydon will have, to thrive equally.

Croydon Council is committed to working with all our communities and partners, to put prevention at the heart of all our work. Although we will not see some of the impacts of our work for 10 years or more, we know that early experiences last a lifetime!

HOUSING

NEIGHBOURHOODS

ENVIRONMENT

EDUCATION

INCOME & WORK

HEALTHCARE

SOCIAL SUPPORT AND COMMUNITY NETWORKS

DISCRIMINATION, STRESS & TRAUMA

INTRODUCTION BY RACHEL FLOWERS DIRECTOR OF PUBLIC HEALTH

Within Croydon we are starting to embrace a prevention model, working with communities at a locality level to reduce the likelihood or impact of a range of issues.

Over the last few years evidence from across the world and all communities, has been demonstrating the importance of the first 1000 days - the period from conception to when the child reaches the age of 2. These first 1000 days for a child are fundamentally important because they lay the foundations for the rest of their lives. A healthy start in life gives each child an equal chance to thrive and grow into an adult who makes a positive contribution to the community.

Children born into secure and loving families, where their physical and emotional needs are met, are more likely to grow up to be better educated, more financially secure, and healthier - emotionally, mentally and physically. They are more likely to give their own children the same good start in life and are less likely to be involved in acts of violence, either as the perpetrator or victim or misuse substances.

It is well accepted that inequalities result in poor health, social, educational and economic outcomes across the whole of the life course and across generations. Many people do not appreciate how much of a person's brain development is completed by the age of 2, well before most people are able to remember. By focusing this report on the first 1000 days we can identify the opportunities we have to make a difference to lives of parents and babies and narrow the inequalities gap.

This report will reflect on the role that the wider environment, the socio-economic situation of families and the issues such as age, ethnic group, disability and sexual orientation, play in the first 1000 days of a child.

I will also talk about Adverse Childhood Experiences. These are experiences that impact negatively on later childhood. Indeed, work undertaken by colleagues from Croydon's Safeguarding Children's Board has identified how many of the young people impacted by knife crime and youth violence have experienced Adverse Childhood Experiences. Evidence shows that children who experience stressful and poor quality childhoods are more likely to: develop health-harming and anti-social behaviours, perform poorly in school, be involved in crime and are ultimately less likely to be a productive member of society. Although not all Adverse Childhood Experiences will occur within the first 1000 days, I feel they are important to emphasise in my report, because of evidence showing that people who experience four or more ACEs in their childhood are, for example, 14 times more likely to be involved in violence .

My report proposes three principles to guide our future actions:

- **Know your role:** We all have a role to play in helping children thrive during the first 1000 days- however we need to understand what this role is and how best we can contribute through a whole systems approach
- **Health in all policies:** All partners should shift the focus from managing the burden of ill health to promoting actions that create the right conditions for good health by a health in all policies approach
- **Breaking the inequalities cycle:** tackling the socio-economic determinants of health- e.g. job, homes, social cohesion, education, income is key in reducing the inequalities in early years that become the inequalities in health and life chances. We all have a role to play in reducing these inequalities.

Nearly **6000** children are born in Croydon each year. With each one of these children we have an 'unparalleled opportunity' to shape 'the brains of the children who will build the future'. [1] This report makes recommendations for action over the next year, which I believe will start having a significant impact not only on the children under 2 now but for the rest of their lives.

While there are recommendations throughout the report, there are four that I would like to highlight here:

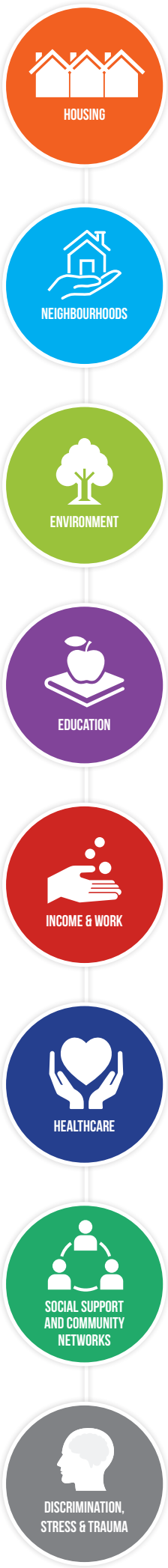
1. Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.

2. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.

3. A 1000 front line staff in the council, NHS, police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact, in 2019

4. Develop and Implement a plan of action for increasing the levels of awareness about pre pregnancy health and the importance of preparing for pregnancy by the end of 2019

I would like to thank the Croydon Youth Congress for their help in shaping some of the messages in this report. They represent Croydon's future.



CHAPTER 1

PARENTS AND CARERS WORLDS: THE SETTING FOR THE FIRST 1000 DAYS

All children's first 1000 days are influenced by their parents' or carers' worlds and the environment these provide.[2]

These worlds are shaped by a diverse range of social, economic and environmental factors including household income, homes, educational attainment, health, relationships, community networks, pollution and neighbourhoods.[3] [4] [2] Together these factors are known as the wider determinants of health and it has been estimated that they account for between 40% and 50% of differences in health.[5]

Due to the importance of these wider determinants in shaping the first 1000 days and in perpetuating inequalities, I have included evidence of their impact throughout the report. The icons on the image opposite will appear on each page as a reminder.

Individual characteristics such as age, ethnicity and disability will also influence the first 1000 days. The age of parents when they have their children can affect pregnancy and child outcomes; both young and older women may experience poorer outcomes.[6] In 2015, **174** children in Croydon were born to mothers under 20 and **297** were born to mothers over the age of 40.[7]

Croydon is a diverse Borough. For example, 45% of births in 2016/2017 were to mothers from black, asian and minority ethnic (BAME) groups.[8] This diversity impacts the first 1000 days. Mothers from ethnic minority groups are, for example, more likely to breastfeed their babies[9] and BAME groups are at greater risk from diseases such as sickle cell and diabetes, both of which can affect pregnancy outcomes.[10] [11]

Croydon is also home to a wide range of cultures and languages, whose role and influence needs to be understood. Records show that in 2015, **3503** births in Croydon were to mothers not born in the UK.[12] Apart from possible difficulties relating to language and culture, women who have recently arrived in the country may lack social support,[13] and those who are asylum seekers or refugees may have experienced trauma.[14]

CROYDON HAS A DIVERSE POPULATION

50.7% Black, Asian and Minority Ethnic (BAME)

49.3% of Croydon are White*

(includes 'White British', 'Other White' and 'White Irish')

PRE PREGNANCY — DAY 1 — DAY 1000

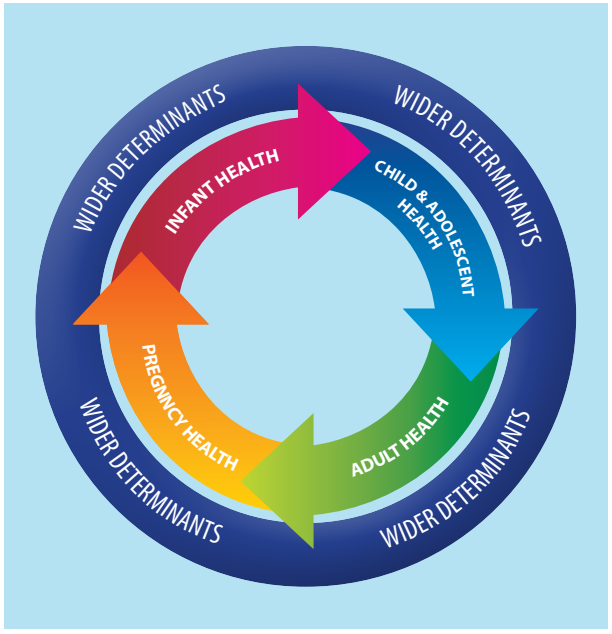
WIDER DETERMINANTS AND INDIVIDUAL CHARACTERISTICS	HEALTH BEFORE PREGNANCY	PARENT AND FAMILY FEATURES	IMPACT ON CHILD
• Parents' age and ethnic group • Income/Job Status • Housing • Neighbourhood	• Parents' diet, weight, stress, smoking status • Father's diet, weight, smoking status • Maternal grandmother's diet and weight	• Physical and Mental health and wellbeing • Family and wider relationships • Parents' skills and capabilities	• Child health and development

Adapted from: Feinstein et al. 2004 [15]

Parents' and carers, experiences of poverty, homelessness, social isolation, discrimination, poor housing, as well as their relationships and experiences, can affect their child's development and physical and mental health.[16][3]
For example, higher levels of stress and depression are experienced by people who live in deprived communities and parents' stress and depression can affect the first 1000 days of children's lives.[3]

Impacts of inequalities

- Young mothers (under 25 years old) living in low income households and/or deprived areas are more likely to have a baby born with a low birth weight[17]
- There is a higher infant mortality rate among Pakistani, Black Caribbean and Black African groups[12]
- Mothers with higher socioeconomic status are more likely to set a regular bed time and read to their child. These mothers experience lower levels of postnatal depression[3] [19]
- Evidence shows that safe public spaces, with pavements to walk on and lighting, are part of the physical infrastructure that helps people to maintain social connections. These factors cut across the whole of the life course as part of sustainable communities and places in which people are born, grow, live, work and age[19]



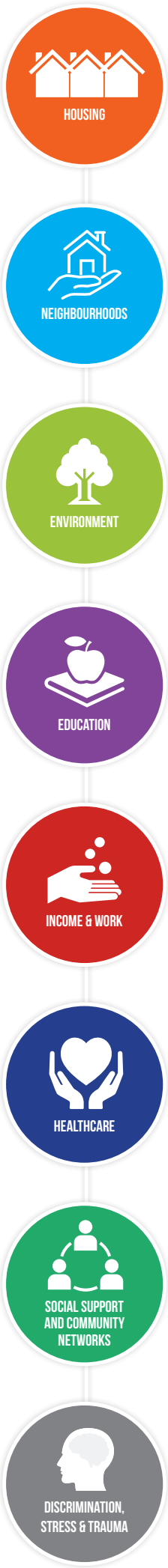
The wider social and economic factors are a key source of inequalities. They result in poorer health and worse social, educational and economic outcomes across the whole of the life course and for many, the cycle will continue into future generations.[3][20] It is only by addressing inequalities from before birth and supporting children and their families, that we can break the cycle and help children achieve their potential.[3]

'The fact that in England today people from different socio-economic groups experience avoidable differences in health, well-being and length of life is, quite simply, unfair and unjust'.[3]

Definition

Health inequalities are

'Avoidable and unfair differences in health status between groups of people or communities' [20]



CHAPTER 1

PARENTS AND CARERS WORLDS: THE SETTING FOR THE FIRST 1000 DAYS

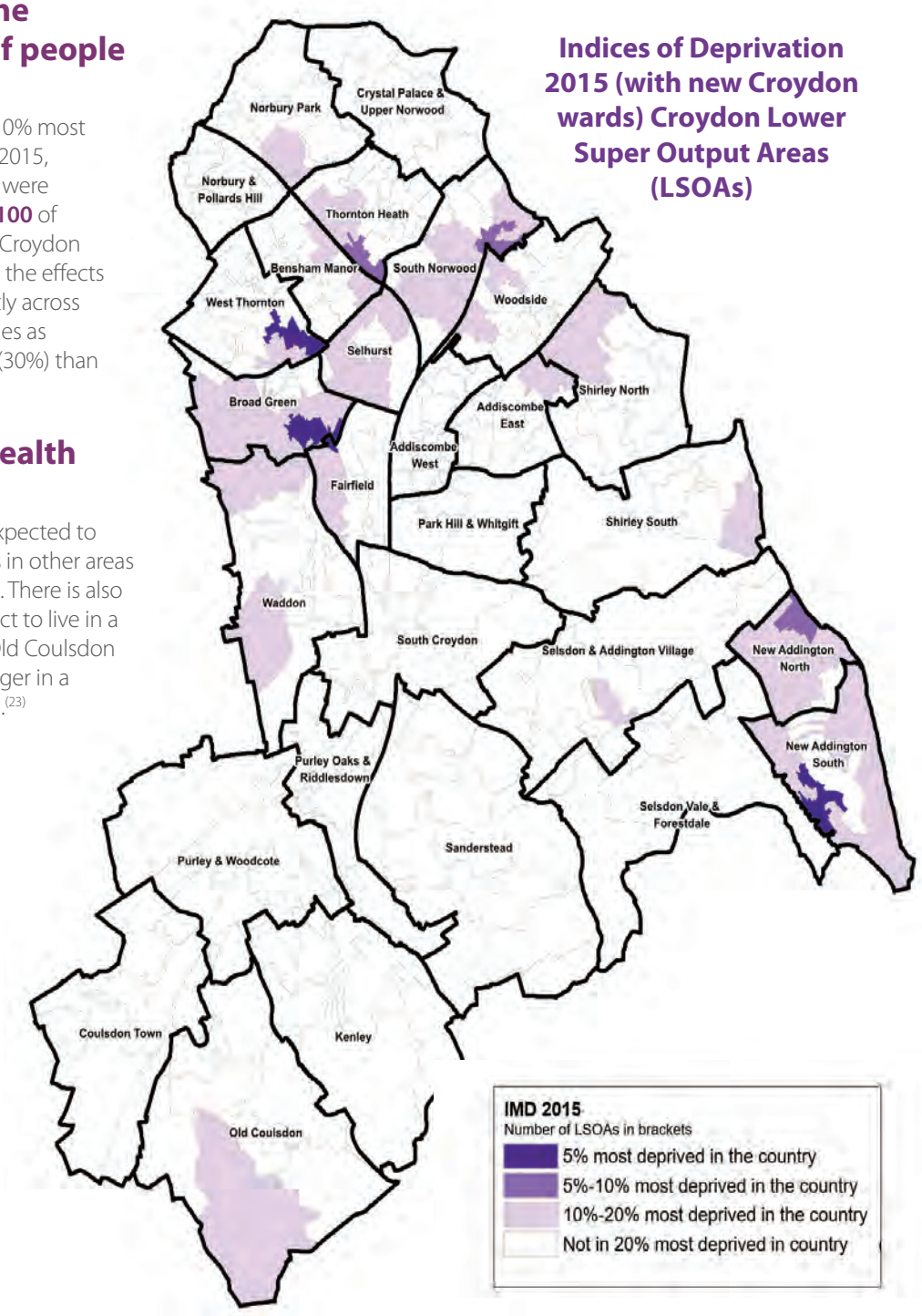
What do we know about the economic circumstances of people and children in Croydon?

Some areas in Croydon are amongst the 10% most deprived in the country. We know that in 2015, almost a fifth (18.7%) of Croydon children were living in poverty.[8] This means that over **1100** of the nearly **6000** babies born each year in Croydon may have their first 1000 days touched by the effects of poverty. Child poverty varies significantly across the Borough. For example almost four times as many children live in poverty in Fieldway (30%) than Sanderstead (8%).

What do we know about health inequalities in Croydon?

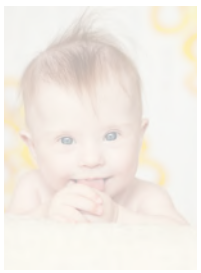
Girls born in some areas of Croydon are expected to live six years more than their counterparts in other areas and for boys, the difference is over 9 years. There is also a difference in how long people can expect to live in a healthy state. As an example, women in Old Coulsdon are expected to live at least nine years longer in a healthy state than women in Broad Green.[23]

Indices of Deprivation 2015 (with new Croydon wards) Croydon Lower Super Output Areas (LSOAs)

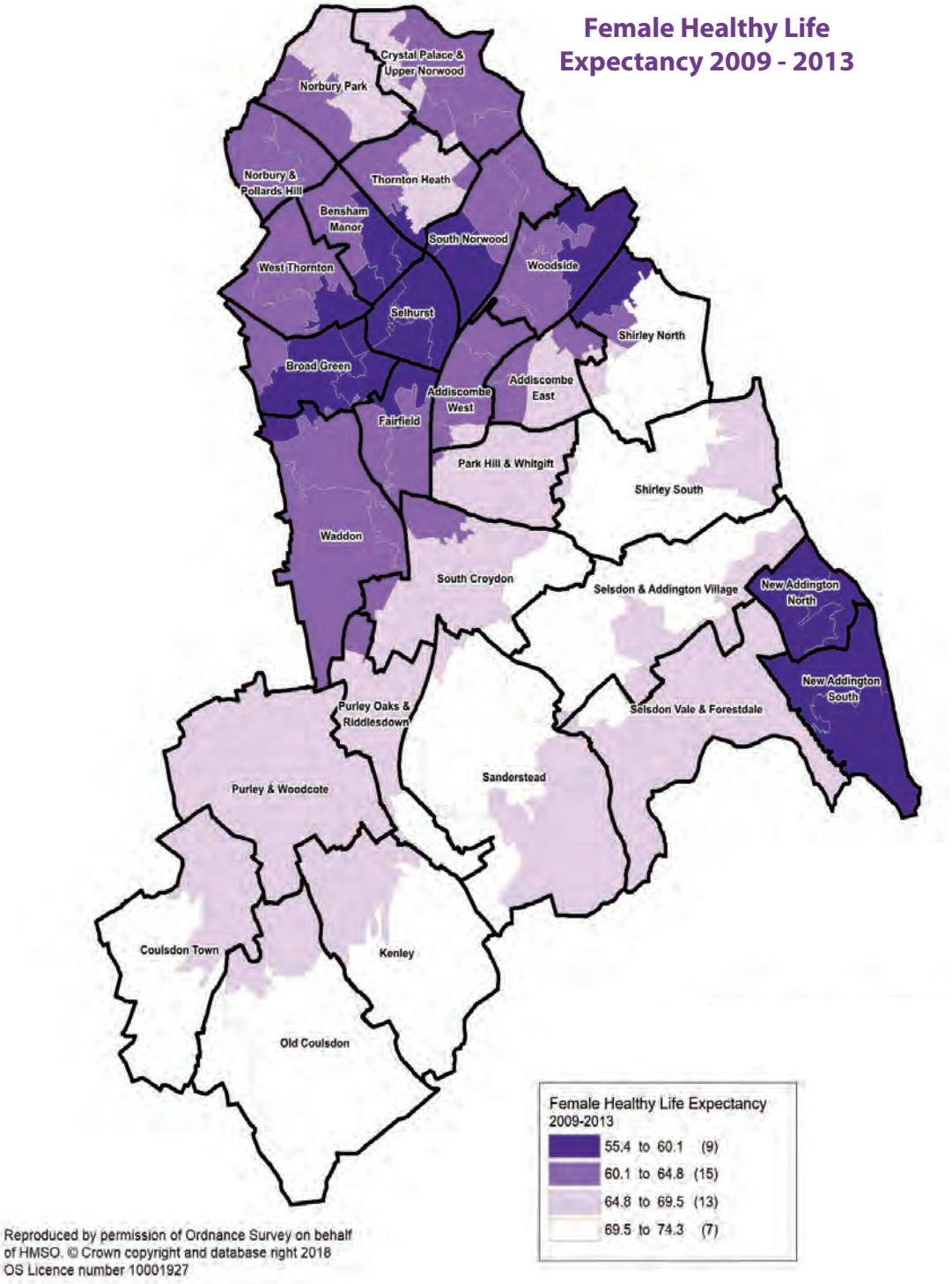


PRE PREGNANCY — DAY 1 — DAY 1000




Female Healthy Life Expectancy 2009 - 2013



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DISCRIMINATION, STRESS & TRAUMA

CHAPTER 1

PARENTS AND CARERS WORLDS: THE SETTING FOR THE FIRST 1000 DAYS

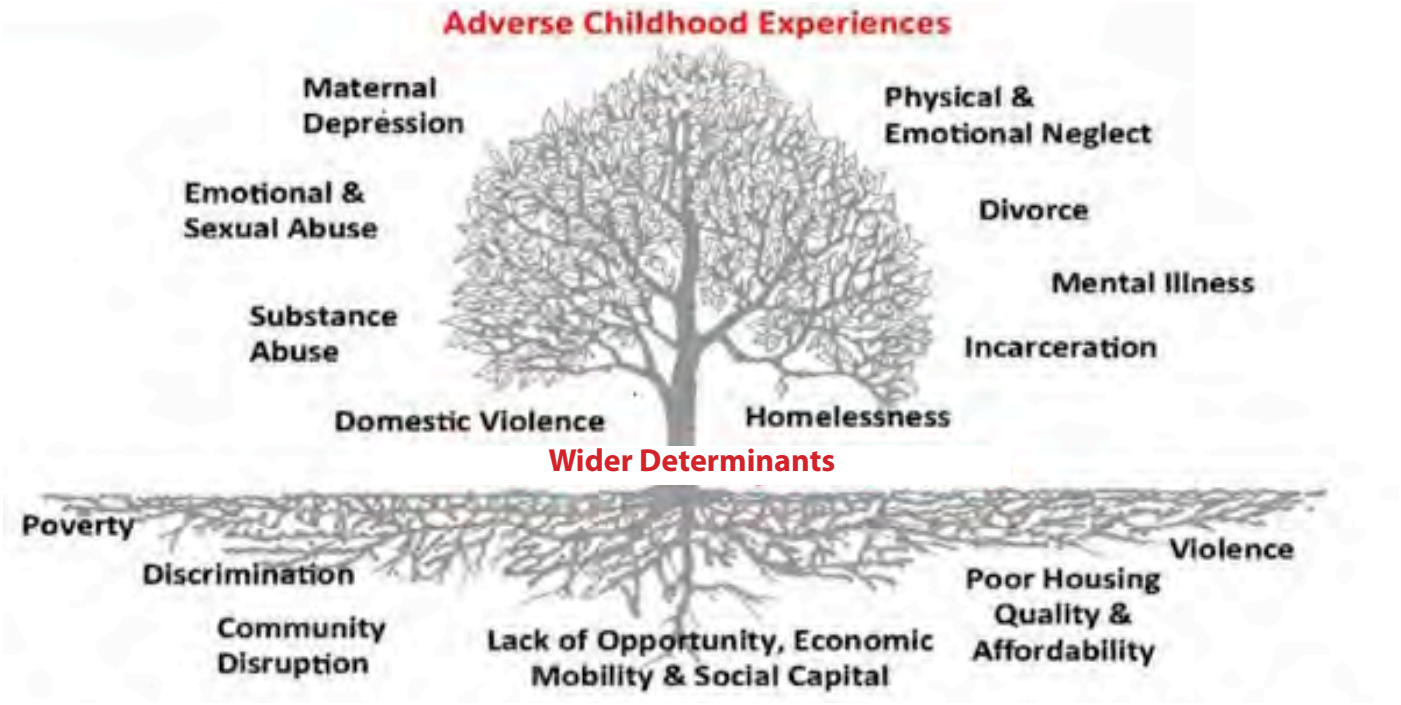
In my introduction, I mentioned Adverse Childhood Experience (ACEs). There is a danger that some experiences during the first 1000 days will turn into ACEs with long lasting impacts, into adolescence and beyond. I would like to reflect briefly here that whilst ACEs are present throughout all sections of society, children living in poverty or in disadvantaged areas are both more likely to be exposed to ACEs such as homelessness and neglect, and are more likely to experience a 'cluster' of them.[24] I will talk about ACEs, their sources and long term impact on children later in the report.

The relationship between parents' and carers' social and economic circumstances, their own physical and mental health and that of their children, shows how vitally important it is for us all to understand the wider needs and circumstances of each family and their community.[3] With this understanding, action and support can be offered, by the right people, at the right time, in the right place

It may seem that circumstances such as income, housing and educational level cannot be easily changed, yet there is considerable evidence about the many ways in which communities, families, individuals and statutory and voluntary services can work together to ensure that all children have the opportunity to experience the best possible first 1000 days.[26]

Focusing this report on the first 1000 days provides us with an opportunity to direct our collective attention to making an even greater difference to the lives of parents and babies in Croydon and on narrowing the inequalities gap.

Adverse childhood experiences and the wider determinants of health



Adapted from: Ellis and Dietz, 2017[25]

PRE PREGNANCY — DAY 1 — DAY 1000

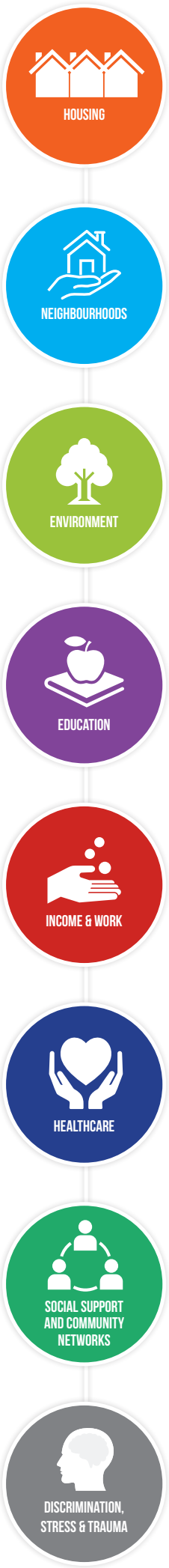
The setting for the first 1000 days

Examples of what we are doing in Croydon

- Gateway and Welfare Services are providing a pathway to financial stability, improved housing options and employment support through initiatives such as Community Connect: The Food Stop and food poverty reduction schemes
- Croydon Council is a London Living Wage employer and through the Croydon Good Employer Charter is encouraging other employers in Croydon to sign up too
- We are making better homes available to Croydon residents (via our Brick by Brick programme)
- Through the community Safety Strategy we are focusing on violent crime and antisocial behaviour and particularly on improving the safety of children and young people

Recommendations

1. Ensure training raises awareness among staff of the importance of the first 1000 days and pre pregnancy health, the impact of wider determinants such as poverty and how they can make a difference in their role for children and their families
2. Use population and community level intelligence at borough and locality level to target resources and services to those individuals and communities most in need



CHAPTER 2

HEALTH BEFORE PREGNANCY, PLANNING PREGNANCY AND TEENAGE PARENTS

There is a large and growing body of evidence that good health before pregnancy provides the best start for children.[13] [27] [28] [29] Planning pregnancy, looking after our health and getting support when needed, are all aspects of preparing for pregnancy.[28]

PLANNING PREGNANCY | **FIT FOR PREGNANCY**

HEALTHY BEHAVIOURS
Includes: a healthy diet, folic acid supplements, regular physical activity, promoting emotional wellbeing and ensuring cervical screening, sexual health checks and immunisations are up to date.

RISK FACTORS
Includes: Smoking, alcohol, substance misuse, obesity, long-term physical and mental health conditions, previous pregnancy complications, genetic risks, maternal age, adverse childhood experiences, domestic abuse, migrant health factors.

WIDER DETERMINANTS
Includes: relationships and support, education, housing, employment, financial stability, environment, community safety and cohesiveness.

Source: PHE, Making the case for preconception care, 2018 [13]

Many parents will have pre-existing health and social needs, some of which may be complex. Whilst it is never too late to start to address these needs, the optimum time to identify and manage them, is before pregnancy.[27]

One way my annual report can contribute to improving the first 1000 days and reducing inequalities is to highlight what being healthy before pregnancy means.

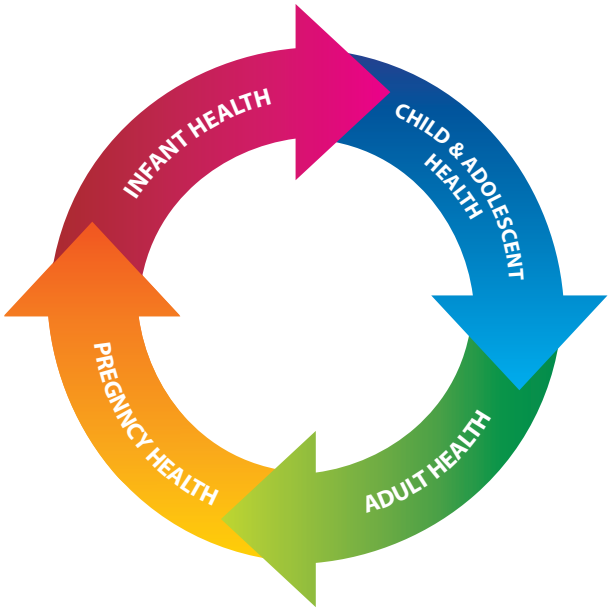
To begin with, **DID YOU KNOW** that few of us actually know what being healthy for pregnancy means? [30] [28]

Lack of awareness of the importance of pre-pregnancy health may result in parents not making changes to their health behaviours, or not seeking the support that would have positive benefits.

DID YOU KNOW that it is not just the mother's pre-pregnancy health that is important? A father's health also has an impact on the long term health of a child.[32]

PRE PREGNANCY — DAY 1 — DAY 1000

And it is not just the health of the present day parents which is important. **DID YOU KNOW** that what parents themselves experienced in their own first 1000 days and earlier can be passed onto their children?[34] This leads to cycles of poor health across generations which together we need to break.



EVIDENCE

Pre pregnancy health awareness

- Women rarely tell health professionals that they are planning to become pregnant [31]
- Most future parents do not make changes to prepare for pregnancy and only start considering it once pregnant [31]
- Health professionals have been found to have a lack of knowledge about pre pregnancy health, but also they report a lack of demand from patients for advice on pre pregnancy care [30]
- Where people had received advice from health professionals, they were more likely to make changes to their behaviour before pregnancy [30]

The good news is that there are things we can all do to improve health before pregnancy. Planning for pregnancy is an important step but **DID YOU KNOW** that only two thirds of us clearly plan a pregnancy? [31]

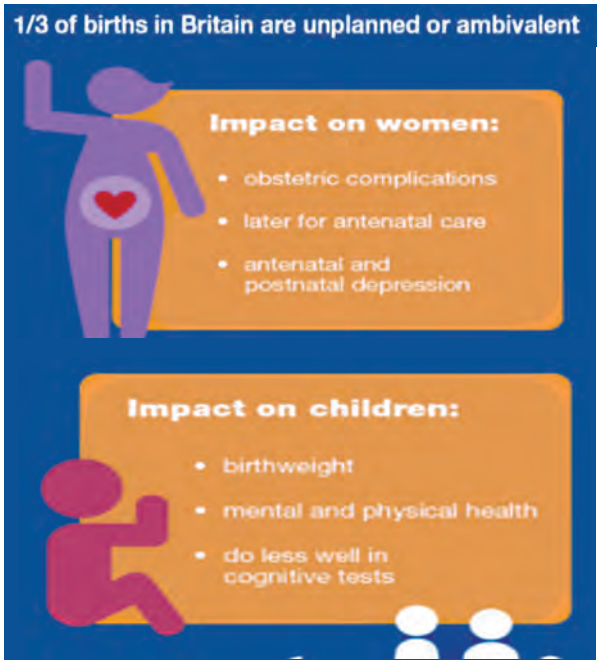
DID YOU KNOW that planned pregnancies are less risky? Planned pregnancies result in fewer premature births, fewer babies born with low birth weights, and greater involvement from fathers once the child is born.[35] [36]

Planning between pregnancies is also very important; a gap of 18-59 months between babies is safer for mother and baby.[37] The period between pregnancies is an ideal time to try and resolve any issues that may affect the first 1000 days of the next baby. [13]

EVIDENCE

Impact of the father's health on a child

- A father who smokes increases the risk of congenital heart defects, cancers, brain tumours and leukaemia in their children [32]
- A father's BMI is associated with their child's BMI and body fat [33]



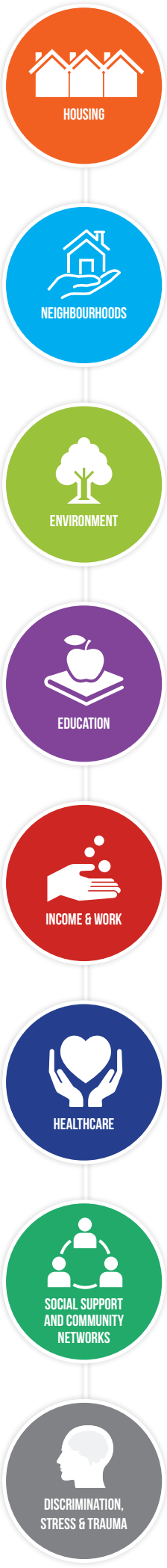
Source: PHE Health matters: reproductive health and pregnancy planning, 2018 [31]

What do we know about unplanned pregnancy in Croydon?

Taking the national rates we have estimated that each year approximately **2000** babies will be born where the pregnancy was unplanned. Women with recent experiences of smoking, drug use, and depression are more likely to report an unplanned pregnancy.[38]

Only just over half (55%) of teenage mothers say they had planned their pregnancy.[38] Teenage parents are more likely to have a baby with low birth weight and are almost two thirds (64%) more likely to bring up their child in poverty.[39] There is much that we do in Croydon to support this group.

"You read up on all the stuff about being healthy during a pregnancy, but nothing really before that. It never occurred to me, we just started trying and a few months later, it happened". [13]



CHAPTER 2

HEALTH BEFORE PREGNANCY, PLANNING PREGNANCY AND TEENAGE PARENTS

EVIDENCE

Unplanned pregnancies have

- A 31% increased risk of the baby being delivered before 37 weeks, known as premature birth [35]
- A 36% increased risk of being born with a low birth weight.[35] This has important consequences for the development of the child which are explored later
- Fathers of unplanned pregnancies are less likely to live with the mother and less likely to be involved in caregiving and play [36]

What do we know about teenage parents in Croydon?

It is very positive that the number of teenagers becoming pregnant in Croydon has reduced, as it has nationally. There were **175** teenage (under 18) conceptions in 2016 compared to **262** in 2010 although this is still high compared to London and England. [8] There were 36 predicted births to teenagers under the age of 18 and 153 to teenagers aged 19 and under in 2018. [38]

EVIDENCE

Teenage pregnancy

- Low birth weight is increased by 30%
- Still birth is increased by 24%
- Infant mortality is increased by 75%
- 21% of teenagers not in education, employment or training are teenage parents
- Teenage parents have the highest rate of poor mental health up to 3 years after birth [39]
- Teenage parents are three times more likely to smoke throughout pregnancy, with 28% smoking compared to 7.5% of over 25s [41]

Young parents

Some examples of what we are doing in Croydon

- The Croydon Healthy Schools programme and Croydon Youth Engagement Team provide programmes focusing on mental and physical health for vulnerable young parents
- Croydon's Young People's Sexual Health outreach team is working with schools and in places where young people congregate
- The 'Be Sex Safe' section on the Just Be website hosts a range of self-help tools and resources to promote healthy relationships
- Young first time mothers (age 19 and under at conception) are supported by the Family Nurse Partnership through pregnancy and early childhood to maximise their own, and their child's, potential

Recommendations

3. Provide senior strategic support from across the partnership to the borough's teenage pregnancy action plan and ensure that its work is widely understood and linked to other strategies and programmes
4. Increase awareness among young people of all sexes of the importance of being healthy before pregnancy and planning pregnancies through implementation of the teenage pregnancy action plan and maximising the opportunities created by the statutory changes both in SRE (sex and relationship) education and in PSHE (personal, social, health and economic) education
5. Ensure the findings of Croydon's Vulnerable Adolescent Mental Health deep dive are acted upon to identify when, where and how to provide support to children and teenagers

VOICE OF CROYDON'S FUTURE:

'Make sure you are ready for pregnancy'
N, age 13

PRE PREGNANCY — DAY 1 — DAY 1000

Women are increasingly entering pregnancy with more health problems.[42] Long term health conditions such as diabetes, sickle, cell severe asthma, heart disease, high blood pressure, epilepsy and psychiatric conditions can effect pregnancy and women with long term conditions should all see a doctor before planning to become pregnant.[43] [10]

Almost two thirds of women who died in the UK between 2013 and 2015 in pregnancy had pre-existing physical or mental health problems.[42]

Some women are at greater risk of having a long term health condition. Type 2 diabetes is, for example, more common in South Asian, Black Caribbean and Middle Eastern women.[29] Sickle cell and thalassaemia are more common in women of black ethnicity and these conditions increase the risk of premature labour and problems with growth of the baby.[10] Diabetes in pregnancy is becoming more common as more women are overweight or obese and are older when becoming pregnant.[44]

DID YOU KNOW that an estimated one in four women have a health condition that would benefit from pre-pregnancy counselling? A study found that these women were no more likely to seek or receive specific pregnancy advice.[30]

What do we know about pre-existing health conditions in Croydon?

Using national data, we have estimated that **1500** or more babies born in Croydon each year have a mother with a pre-existing health condition.

Knowledge about pre-pregnancy health and pregnancy planning

Some examples of what we are doing in Croydon

- Live well and Just Be are signposting and supporting people around 'Be Sex Safe', 'Be Active', 'Be Alcohol Aware', 'Be Food Smart', 'Be Smoke Free' and 'Be Happy'
- We are delivering a partnership led Borough wide healthy weight action plan

Recommendations

6. All agencies to maximise opportunities to raise awareness of the importance for both parents of planning for pregnancy and addressing health issues before becoming pregnant.
7. Use existing and new media to promote pre-pregnancy health messages, particularly about smoking and being overweight or obese for people living and working in Croydon

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GETTING FIT FOR PREGNANCY

There are things we can do to prepare for pregnancy which will positively improve a child's first 1000 days.

Smoking, weight, diet, alcohol and drug use can all affect a pregnancy.[28] These are all what is known as 'modifiable behaviours' that is they are things that we can change.[45]

DID YOU KNOW that stopping smoking in pregnancy avoids the greatest risk to birth outcomes?[27] Babies in the womb need oxygen to grow and smoking not only reduces the oxygen in the mother's blood,[20] it can also restrict the growth of the baby and is a cause of low birthweights.[46]

Although stopping smoking is a positive action at any point, it is better to stop smoking before becoming pregnant.[47] Women who receive counselling prior to pregnancy are three times more likely to quit smoking before conceiving than those that don't.[48]

Smoking is more common in certain groups. Asian and Pakistani women have much lower smoking rates than women of White ethnicity, and people living in the most deprived areas are more likely to smoke and less likely to quit.[49]

DID YOU KNOW it is not just maternal smoking that affects babies? Babies with a father who smokes also have a higher risk of a low weight at birth[32] AND children who grow up in households where there are smokers are at increased risk of sudden infant death and are more likely to have respiratory problems.[27]

What do we know about smoking in Croydon?

Although overall, 12% of adults in Croydon smoke, pregnant women report lower rates.[58] In 2016/2017 6.6% of women in Croydon reported smoking at the time they gave birth, which means that about **353** babies were born to mothers who smoked.[59] More will be born in households that smoke. We also know that across Croydon there are areas with higher rates of smoking for example, in Fieldway and New Addington (see map on page 17).

Smoking and pregnancy

Examples of what we are doing in Croydon

- We provide one to one support to women who are pregnant or postnatal to help them stop smoking with Livewell Croydon
- Everyone can access stop smoking tools, advice and support on our website.
- All Croydon foster carers are required to have smokefree homes

Recommendations

8. Develop a pathway for pregnant smokers and their partners into smoking cessation support that is opt out rather than opt in

9. Identify the groups continuing to smoke through pregnancy and review the evidence base to identify the best approaches for helping them to stop smoking

10. Develop a smoke free homes programme with social and private landlords

PRE PREGNANCY DAY 1 DAY 1000

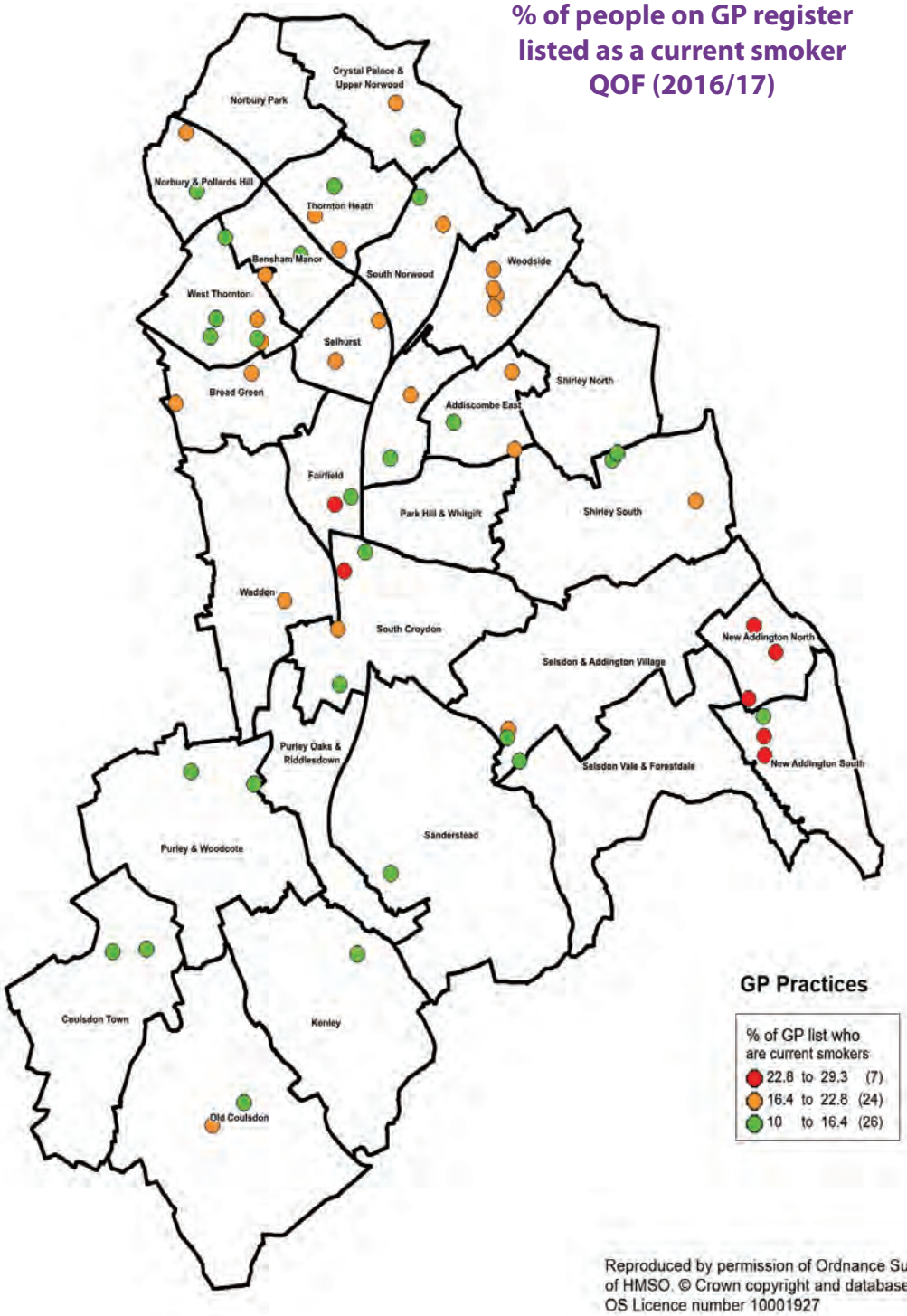
EVIDENCE

Smoking

Smoking is associated with an increased risk of:

- Miscarriage by over 30% [50] and still birth by nearly 50% [51]
- Low birth weight and reduced growth [46] [48] [52]
- Childhood asthma [53] [54]
- Obesity in childhood [54] [55]. There is nearly twice the risk of being overweight as a teenager [56] and up to four times the risk of being overweight as an adult [57] [53]

% of people on GP register listed as a current smoker QOF (2016/17)



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CHAPTER 2

GETTING FIT FOR PREGNANCY

The numbers of overweight and obese adults is a high profile national issue with 59% of adults in England being overweight and obese[8] with an estimated annual cost to the NHS of £6.1 billion.[60]

"UK MOST OVERWEIGHT COUNTRY IN WESTERN EUROPE"

says OECD 2017

DID YOU KNOW that over 40% of women in England are overweight, and more than one in five are obese at the start of pregnancy? [61]

Although overweight and obesity is an issue for the country as a whole, some parents and groups are more at risk. For instance, 46% of black women are overweight or obese compared to 39% of White and Asian women.[49]

Environments can help us maintain a healthy weight [62] but we know that the environment in Croydon varies across the borough. For example, there are more fast food outlets in Fairfield than Kenley (see map on page 19); some areas have greater access to green spaces, and walking is easier and safer in some neighbourhoods than others.

Due to the complex web of issues underpinning the current epidemic of overweight and obesity, our collective efforts are required to reduce its influence over the first 1000 days of children in Croydon.[62]

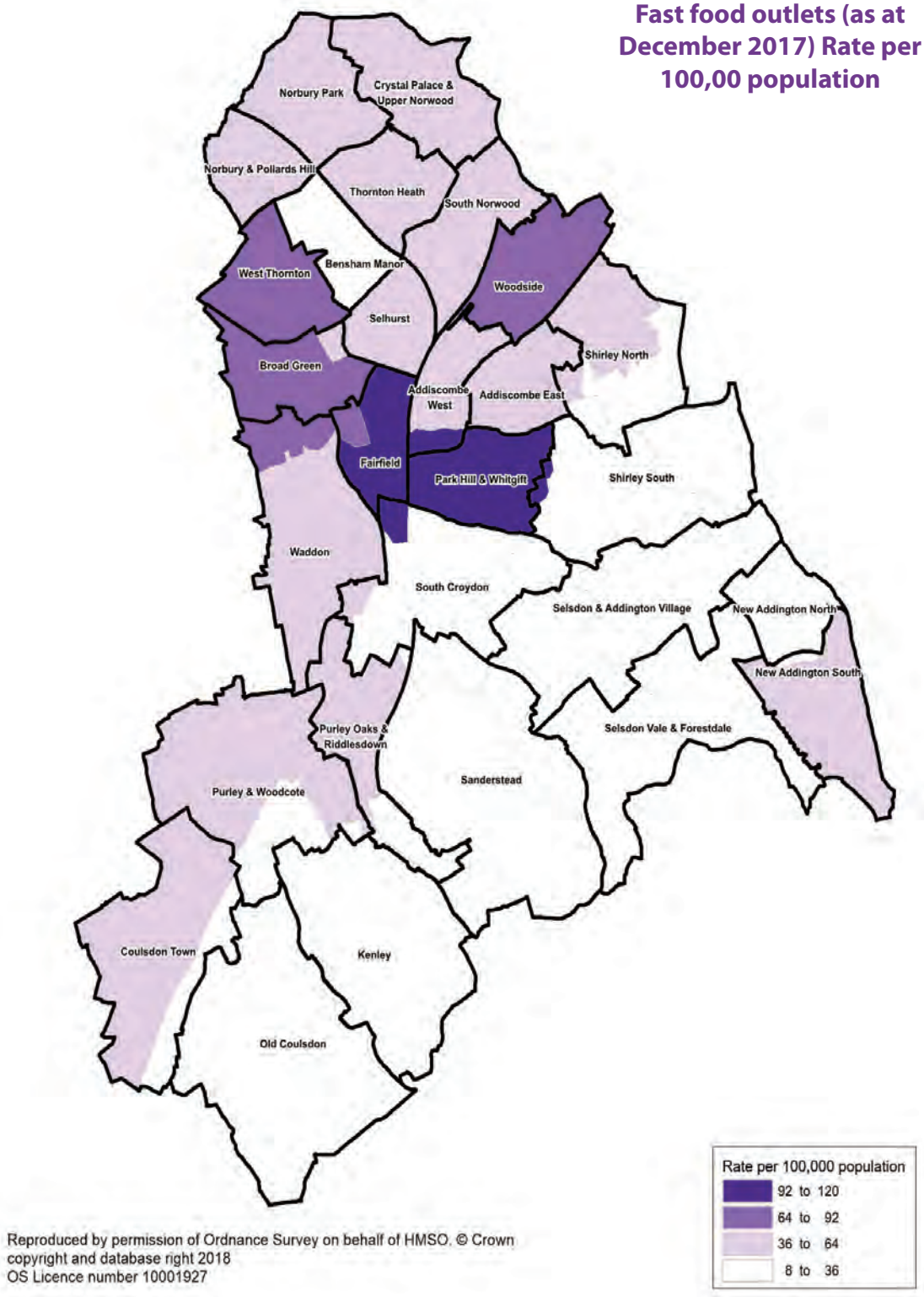
IMPACT OF INEQUALITIES

Overweight, obesity and underweight

- 38% of women living in the most deprived areas are overweight at the start of pregnancy compared to 29% in the least deprived [13]
- Women over 40 are more likely (40%) to be overweight or obese at the start of pregnancy [49]
- 11% of young mothers (under 18 years) are underweight at the start of their pregnancy [49]

PRE PREGNANCY — DAY 1 — DAY 1000

Fast food outlets (as at December 2017) Rate per 100,00 population



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GETTING FIT FOR PREGNANCY

Overweight and obesity in either the father or mother can affect pregnancy. For example, a mother who is overweight has four times the risk of developing diabetes in pregnancy compared to mothers who are a healthy weight.[63] It also affects the long term health of their child.[65]

DID YOU KNOW that children whose parents are a healthy weight, are less likely to be overweight or develop type 2 diabetes?[34] [54]

EVIDENCE

Obesity during pregnancy:

- Doubles the risk of caesarean section
- Triples the risk of pre-eclampsia (a condition of high blood pressure in pregnancy which can be dangerous for mother and baby)
- Increases the risk of premature delivery by 30% and antenatal and postnatal depression by 35% [63]

A child whose mother is overweight or obese prior to pregnancy:

- Is more likely to be obese in childhood [54] and grow up to be obese in adulthood [65]
- Has a higher risk of type 2 diabetes and high blood pressure [34]
- Has a 30% increased risk of asthma and wheeze [65]

What do we know about overweight and obesity in Croydon?

59% of adults in Croydon were classified as overweight and obese in 2016/2017.[66] We have estimated from the national rates that nearly **half** of the **6000** babies born in Croydon this year will have mothers who are overweight or obese. This has important health implications for mothers and children and is a source of potential long term health inequalities.

"If I'd known the impact of carrying all this extra weight when I was pregnant…. then I might have tried to lose weight before. They didn't tell me". [13]

VOICE OF CROYDON'S FUTURE:

What is important for the first 1000 days?

Not smoking, eating bad foods, drugs, overexercising, not to get too stressed
Z, age13

PRE PREGNANCY — DAY 1 — DAY 1000

Diet and nutrition before pregnancy can also have long term impacts. For example, taking folic acid before pregnancy prevents babies having severe problems with the formation of their spine and nerves.[67] Women living in the least deprived areas are more likely to take folic acid.[49]

What do we know about folic acid in Croydon?

Using the national rates we have estimated that **1200** babies each year in Croydon have mothers who did not take folic acid before pregnancy.

POTENTIAL IMPACTS OF INEQUALITIES

Folic acid

- 20% of white women take folic acid before pregnancy compared to 12% of black women and 13% of Asian women
- 10% of women aged 20-24 don't take folic acid compared to 25% of women aged over 45
- 10% of women living in the most deprived areas take folic acid compared to 26% of least deprived[49]

DID YOU KNOW that a baby's development in the womb is dependent not just on the mother's diet during pregnancy, but also on the stored nutrients and fats from through her lifetime?[68] [64] So although it is important to eat well during pregnancy, it is also important to eat well before pregnancy.[64]

The long term implications of our own health as parents on our children's health is a recurring theme in this report. A baby girl is born with all the eggs for her own children and the quality of these eggs will reflect her mother's health; a mother's nutritional state can even affect her grandchildren's health! [34] A new baby in Croydon therefore represents past, present and future health which is another key reason for this focus on health before pregnancy and the first 1000 days.

Parental weight, diet and nutrition

Some examples of what we are doing in Croydon

- We have a coordinated, collaborative approach to helping children and families achieve and maintain a healthy weight. The programme aims to influence the system at many levels including the borough's food culture, opportunities to be physically active and wider determinants
- Croydon has a very strong schools food programme that encourages food growing, cooking skills and healthy eating
- The Sugar Smart campaign, which encourages people to eat less sugar, was launched in Croydon in 2018
- We are improving environments and encouraging people to use parks and green spaces

Recommendations

11. Continue to provide senior strategic support to the borough's Healthy Weight steering group, and ensure it promotes pre pregnancy health
12. Ensure that all programmes that promote pre pregnancy health (see previous recommendation box) include key messages around the importance of being a healthy weight and having a healthy diet before pregnancy
13. Incorporate the recommendations of the London Mayor's Food Strategy (due to be published in December 2018) into local plans

CHAPTER 3

PREGNANCY AND BIRTH

Pregnancy is a hugely exciting and positive time for most families and their babies.

Good mental and physical health during pregnancy provide the best possible support for the babies first 1000 days and beyond.[69]

Parents' mental, emotional and physical health, their relationships, their weight, their diet and their drug, alcohol and tobacco use can all effect a baby's brain and physical development.[71] [72] [73] [74]

A key message is how important pregnancy is for babies' developing brains. Brain development starts just after conception and continues at a rapid pace through the first years of life; when our brains grow the fastest.[75]

DID YOU KNOW that experiences during pregnancy can change a baby's brain? Although it is genes that predict babies early brain development, their early experiences will shape it.[75] These experiences can affect how genes are switched on, or whether they are switched on at all.[76] This can lead to genetic changes by a process called epigenetics and these changes can pass down through the generations.[76] These changes have both physical and mental causes.[77]

DEFINITION BOX

Epigenetics

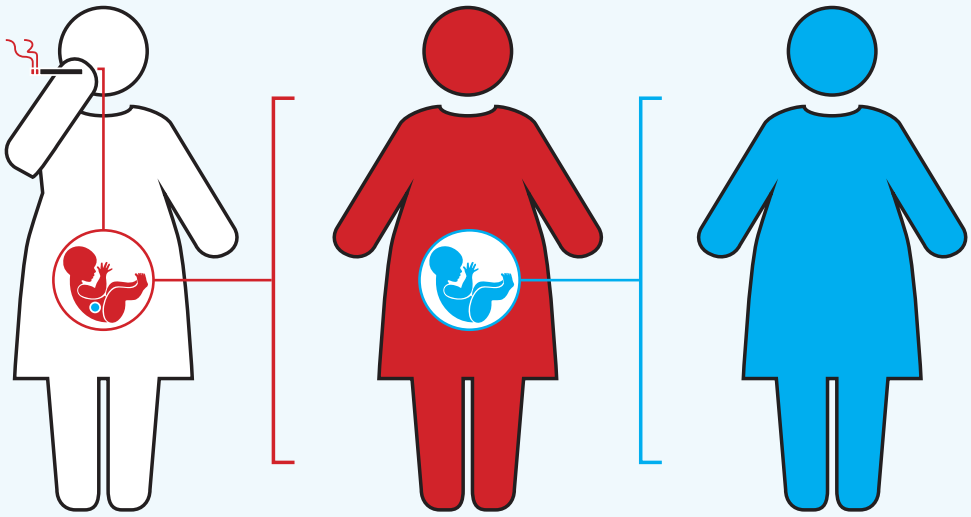
"Epigenetic influences are one of the biological mechanisms through which the environment of relationships, the physical, chemical, and built environment, and early nutrition all get "under the skin" and influence lifelong learning, behaviour, and health. These changes can be passed on to affect the health and well-being of future generations".[76]

Good mental health during pregnancy helps provide the positive conditions every baby needs.

DID YOU KNOW that as many as one in four women experience mental health problems during pregnancy and the first year after birth?[79]

Supporting parents' mental health is important because untreated antenatal depression and depressive symptoms can effect brain and child development, and lead to behavioural problems during adolescence.[71]

PRE PREGNANCY — DAY 1 — DAY 1000



A woman who smokes while pregnant induces epigenetic changes in three generations at once: in herself, her unborn child and her child's reproductive cells

Source: Jude Huffon, Harvard Magazine, 2017 [78]

EVIDENCE

Effects of depression

- Women with depression are likely to have a shorter duration of breastfeeding.[80] Children are more likely to have behavioural problems and poor social emotional development even into adolescence [55]
- Maternal anxiety during pregnancy has been shown to change the brain structure and function in offspring in infancy up to late adolescence [81]
- Maternal suicide is the leading cause of death in the postnatal period [82]

Receiving the right support and treatment can help improve a mother's mental health and ensure a child's development is not affected.[83] Positive relationships and social support during pregnancy are beneficial.[72]

Although poor mental health during pregnancy can be experienced by anyone, some women are more at risk. This includes women without good social support, women who have experienced domestic violence or previous abuse, women living in deprived areas, and women with a history of mental health problems.[84]

It is not only a mother's mental health that is important. **DID YOU KNOW** that the father's mental health can also affect children in early life? 1 in 10 fathers will develop depression after the birth of their baby.[86]

When this effects the relationship between parents, or results in hostile or detached parenting from the father, this can lead to problems with child and adolescent emotional and behavioural development.[87]

EVIDENCE

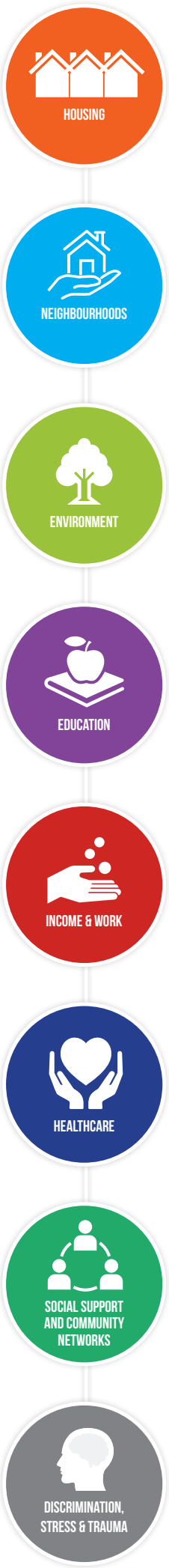
Numbers of women who experience anxiety and depression during pregnancy

- More than 10% of women experience issues with mood during pregnancy
- 3.3% of pregnant women will experience major depression
- 17% of teenage parents will experience major depression [71]

IMPACT OF INEQUALITIES

Depression

- Social determinants are an important cause of depression in pregnant women and mothers [4]
- Up to 26% of pregnant women in poor, urban communities have depression [85]
- Women from minority ethnic backgrounds are more likely to live in deprived environments and therefore may be at higher risk of depression in pregnancy [85]



CHAPTER 3

PREGNANCY AND BIRTH

DEFINITION BOX

Perinatal period

The perinatal period commences at 22 completed weeks (154 days) of pregnancy and ends seven completed days after birth. [88]

What do we know about the mental health of parents in Croydon?

In 2015/2016 it was estimated that between **525** and **1600** women in Croydon during the perinatal period had a mild to moderate depressive illness anxiety or adjustment disorders.[22]

Supportive relationships and social support during pregnancy have positive effects on outcomes. Unfortunately not all women have a positive relationship and some women lack social support; migrant women, especially asylum seekers and refugees, are vulnerable to being socially isolated and a study has shown that they are at higher risk of having a premature birth or mental health problems.[14] This may also be related to past traumatic experiences, challenges with accessing health care before and during pregnancy and other social circumstances such as poverty.[14]

EVIDENCE

Supportive relationships and social support

- Mothers in supportive relationships are more likely to be physically active during pregnancy [89] and have smaller risks of pregnancy complications such as infections [89]
- Women without social support are more likely to develop symptoms of depression during pregnancy [72]
- After delivery, social support is associated with better breastfeeding, maternal self-esteem and adapting to care for the baby [90]

Mental health in pregnancy and beyond

Examples of what we are doing in Croydon

- Croydon has a strong community perinatal mental health team
- Specialist delivery of the Live Well Croydon programme by Mind
- Our new partnership Early Help offer working in local communities will ensure the needs for vulnerable families with young children are provided for

Recommendations:

14. Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.

15. Ensure all staff have the skills to identify parents and prospective parents with potential mental health concerns and are able to support and signpost them appropriately

16. Ensure that all programmes that promote pre-pregnancy health (see previous recommendation box) address mental health concerns before pregnancy

PRE PREGNANCY — DAY 1 — DAY 1000

What do we know about the potential for lack of social support in Croydon?

Some parents are more likely to lack social support and this includes lone parents, those living in temporary accommodation and asylum seekers. In 2014 **447** babies in Croydon (7.9% of births) were registered by just one parent.[31] This is one sign that there may be parents in Croydon who lack social support. Another is the number of children or expected children living in temporary accommodation. In March 2018 there were **864** Croydon children or expected children living in temporary accommodation.

Relationships which cause stress, anxiety and trauma can negatively affect the unborn child.[70] A key source of stress is domestic abuse.

DID YOU KNOW that domestic abuse is likely to start or escalate during pregnancy?[70]

Women experiencing abuse may find it difficult to access antenatal care and there are risks to the child including low birth weight.[70] Disabled women are twice as likely to suffer physical abuse from their partner than non-disabled women and are likely to be particularly vulnerable to pregnancy abuse.[91]

What do we know about domestic abuse in Croydon?

Based on national figures, we have estimated that between **240** and **540** babies are born each year to mothers who may have experienced domestic violence during pregnancy.

EVIDENCE

Domestic abuse

Possible consequences of domestic abuse include:

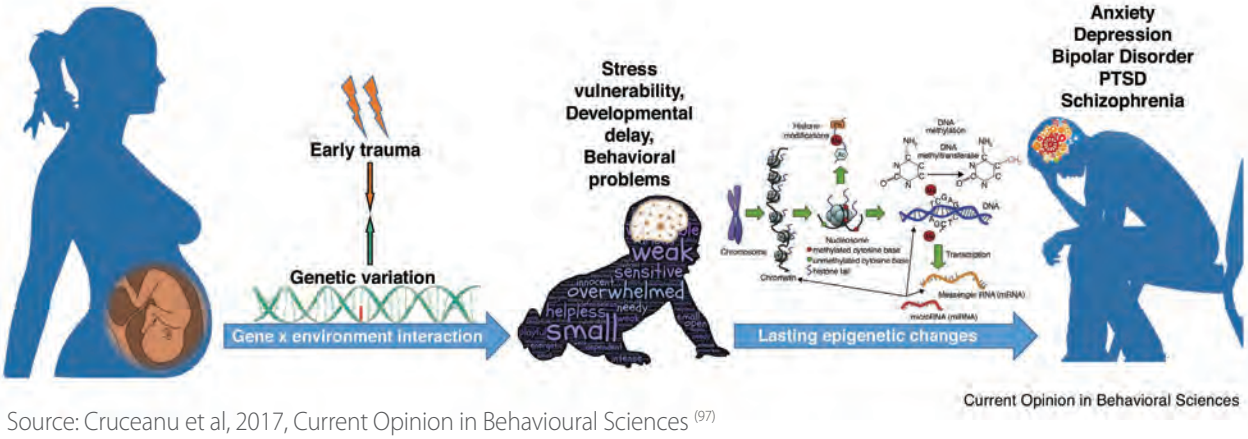
- Mothers who may find it difficult to access antenatal care
- An Increased risk of premature birth
- An increased risk of low birth weight
- Poorer development of the foetus and the child [70] [92]

EVIDENCE

Who experiences domestic abuse?

- It is estimated that 7.4% of women and 4.8% of men experience domestic abuse each year
- It is estimated that between 4% and 9% of women experience domestic abuse during pregnancy [92]
- Young women, those with long term disability or mental health problems and who are pregnant or have recently given birth are particularly at risk [93]

Excess stress during pregnancy can have long lasting effects on the baby and on through to adulthood. Babies who experience higher stress in the womb are more likely to have emotional, behavioural and learning problems later in life. [94] [95] [96]



Source: Cruceanu et al, 2017, Current Opinion in Behavioural Sciences [97]

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EVIDENCE

Effects of excess stress during pregnancy

- Different hormones can cross the placenta making the child more reactive to stress and threat themselves
- Children may have longer-term problems with emotional and cognitive functioning (Thompson,2014) and an increased risk of behavioural problems[98]

What do we know about stress affecting women and their families in Croydon?

We know that depression and anxiety, financial insecurity, unplanned pregnancy, lack of support and domestic violence are all potential sources of stress[71] [72] and that some women will experience more than one of these sources of stress. We have estimated that at least **1000** of the **6000** babies born each year in Croydon are at higher risk from stress during pregnancy.

Relationships, social support and excess stress during pregnancy

Examples of what we are doing in Croydon

- A multi-agency vulnerable women's group identifies pregnant women who need additional support
- The Family Justice Centre is available to all women in insecure and unhealthy relationships who experience domestic violence
- Our partnership Early Help offer prioritises working with children and their families where there is domestic abuse
- Homestart runs a support group for asylum seeking women in hostel accommodation from 6 weeks before babies are born until 6 weeks afterwards
- We are implementing a borough wide approach to prevention and early intervention that will strengthen community based knowledge and support and through the partnership Early Help offer we will support people at the right time and in the right place

Recommendations

17. Review the effectiveness of the current arrangements for identifying women who need more social support and make recommendations to address any system wide gaps that are identified

18. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019

19. 1000 front line staff in the council, NHS, police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact in 2019

PRE PREGNANCY — DAY 1 — DAY 1000

GOOD PHYSICAL HEALTH

Good physical health during pregnancy contributes to creating the best possible environment for the first 1000 days.

Being overweight or underweight, smoking, drinking alcohol and using drugs during pregnancy have long term impacts on children.(64) (99)

The impacts of overweight and obesity and smoking were discussed earlier, here I would like to touch on the effects of drinking alcohol, drug misuse, diet and exercise.

DID YOU KNOW that even mild to moderate alcohol consumption especially during the first three months can cause changes in brain development, and cause behavioural problems in childhood? (100) (101)

Drinking more than one unit a day in pregnancy increases the possibility of pre term birth and low birth weight.(102) Children's height, behaviour, fine motor skills, cognitive development and mental health can be changed by drinking alcohol during pregnancy. (99) (102)

Nationally 1% of women declare that they consume alcohol during pregnancy although actual levels of drinking during pregnancy are thought to be higher. (49) There is evidence that 3% of children under the age of one live with a harmful drinker and 9% live with a hazardous drinker. (104)

What do we know about drinking in pregnancy in Croydon?

Using the national rate of 1% we have estimated that **60** of the **6000** babies born each year will have mothers who drink. We have also estimated that about **700** children under one live in households where there is harmful or hazardous drinking. (104)

Source: Mentalhelp.net (103)

Taking drugs during pregnancy can also harm both the woman and her baby. Physical damage to the baby is most likely during the first 4-12 weeks of pregnancy. (101)

It is estimated that 4.5% of pregnant women use drugs(10) and that 7% of children under one live with a drug using parent. (106)

EVIDENCE

Effect of taking drugs

- Taking cannabis, cocaine and opioids during pregnancy can increase the possibility of low birth weight,(107) (108) premature birth and perinatal and cot death (108)
- Drugs taken later in pregnancy can effect growth, cause intoxication or withdrawal symptoms (73)

What do we know about drug use during pregnancy in Croydon?

Using the national rates we estimate that **300** of the **6000** babies born each year will be born to mothers who took drugs during pregnancy and over **400** infants will be living with a drug taking parent.

CHAPTER 3

PREGNANCY AND BIRTH

NUTRITION AND PHYSICAL ACTIVITY DURING PREGNANCY

It is vital that women eat well during pregnancy.[109] When babies in the womb have to adapt to insufficient nutrients it can lead to permanent changes which may be the origins of diseases in later life such as coronary heart disease, diabetes, stroke and hypertension.[110]

However, "eating for two" should also be avoided.[111] No increased food intake is needed in the first six months of pregnancy and only an extra 200 calories per day for the third trimester.[112]

Aside from folic acid, there are other vitamins and minerals important for pregnancy. Some people, for example, may need to take more vitamin D. A deficiency in iron in pregnancy can harm the development of the child and a supplement may be advised if women are not getting enough from their diet.[113] Other important nutrients in pregnancy include vitamin C and calcium, which can be obtained through a balanced diet.[114]

Along with good nutrition, being physically active can help women maintain a healthy weight throughout pregnancy. Women should aim for 150 minutes of moderate intensity exercise per week.[115]

EVIDENCE

Physical activity in pregnancy:

- Helps control weight gain
- Helps to reduce high blood pressure problems
- Makes it 30% less likely women will develop gestational diabetes[116]
- Improves fitness
- Improves sleep
- Improves mood[115]

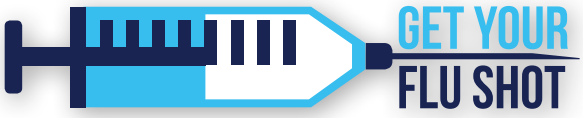
Adapted from: UK Chief Medical Officer 2017[117]

Accessing timely and good quality **antenatal care**, including scans, immunisations and examinations, physical and mental health advice and support, is a key component of supporting parents through pregnancy.

IMPACT OF INEQUALITIES

Antenatal care

- Women in low income households are 60% less likely to have had any antenatal care in pregnancy [118]
- 28% of black women and women of 'other' ethnicity attended their first pregnancy appointment after 13 weeks compared to 15% of women of white ethnicity [49]
- 77.3% of women with the highest level of deprivation had their first antenatal appointment within 13 weeks compared to 86.7% of the least deprived women [49]



DID YOU KNOW that some women are less likely to have antenatal care or access care later than recommended? [49] [118]

Women should have their first antenatal appointment within the first 13 weeks of pregnancy and ideally by 10 weeks.[119] Some women are more likely to attend later in their pregnancy putting themselves and their child at extra risk, for example women aged between 18 and 24 and women living in more deprived households. [49]

Immunisations in pregnancy are important for both the mother and child are an easy and effective way of preventing certain illnesses.

DID YOU KNOW only 45% of (pregnant) women in England had the flu vaccine in 2016/17? [120]

Pregnant women are recommended to have the seasonal flu vaccine because they are more likely to develop serious illness.[121] One in 11 maternal deaths between 2009-2012 was a result of flu.[82] Pregnant women are also advised to have the whooping cough (pertussis) vaccination between 20 and 32 weeks, or until labour, to help protect the baby from whooping cough in their first few weeks of life.[122]

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LOW BIRTH WEIGHT

Reducing the number of babies born with a low birth weight will improve child health and development and long term health.[53] [55]

Some women are at higher risk of having a baby with a low birth rate, for example women who smoke or have unplanned pregnancies. [35] [46]

What do we know about the numbers of babies with a low birth weight in Croydon?

In 2016 **158** babies born after 37 weeks had a low birth weight. **445** of all babies in 2016 (7.7%) were born with a low birth weight and of these **73** were born with a very low birth weight. [7] The map shows that the percentage of babies born with a low birth of weight varies across the Borough and is more common in deprived areas.

Definition

Pre term birth and low birth weight

- **Pre term is defined as being born before 37 weeks [123]**
- **A low birthweight baby weighs less than 2500g (5lb 8oz) and a very low birth weight is below 1,500g (3lb 8oz) [7]**

EVIDENCE

Impacts of low birth weights

- Low birth weight is associated with worse child health, even up to 11 years of age [55]
- Low birth weight babies are twice as likely to have problems with cognitive development or need specialist support in school and are also more likely to have physical problems such as asthma and high blood pressure and high cholesterol in adulthood [53]

EVIDENCE

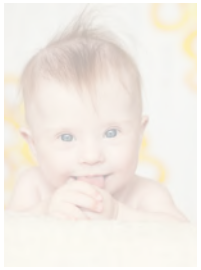
Factors effecting birth weights

- Low birth weights are more common in women of black ethnicity and women with higher levels of deprivation [49]
- Babies whose mothers are aged under 20 years have around a 20% higher risk of low birthweight; this can be partly explained by the higher than average smoking rates in pregnancy [49]
- Maternal smoking is associated with a birth weight reduction of around 250g.[46] Paternal smoking is also linked to low birth weights [46] as is maternal passive smoking [49]
- Unplanned pregnancy increases the possibility of low birth weight by 36% and pre term birth by 31% [35]
- Drinking more than one unit of alcohol per day [102], taking cannabis, cocaine and opioids [108] and experiencing domestic abuse also increase the risk of having a baby with a low birth weight [70]

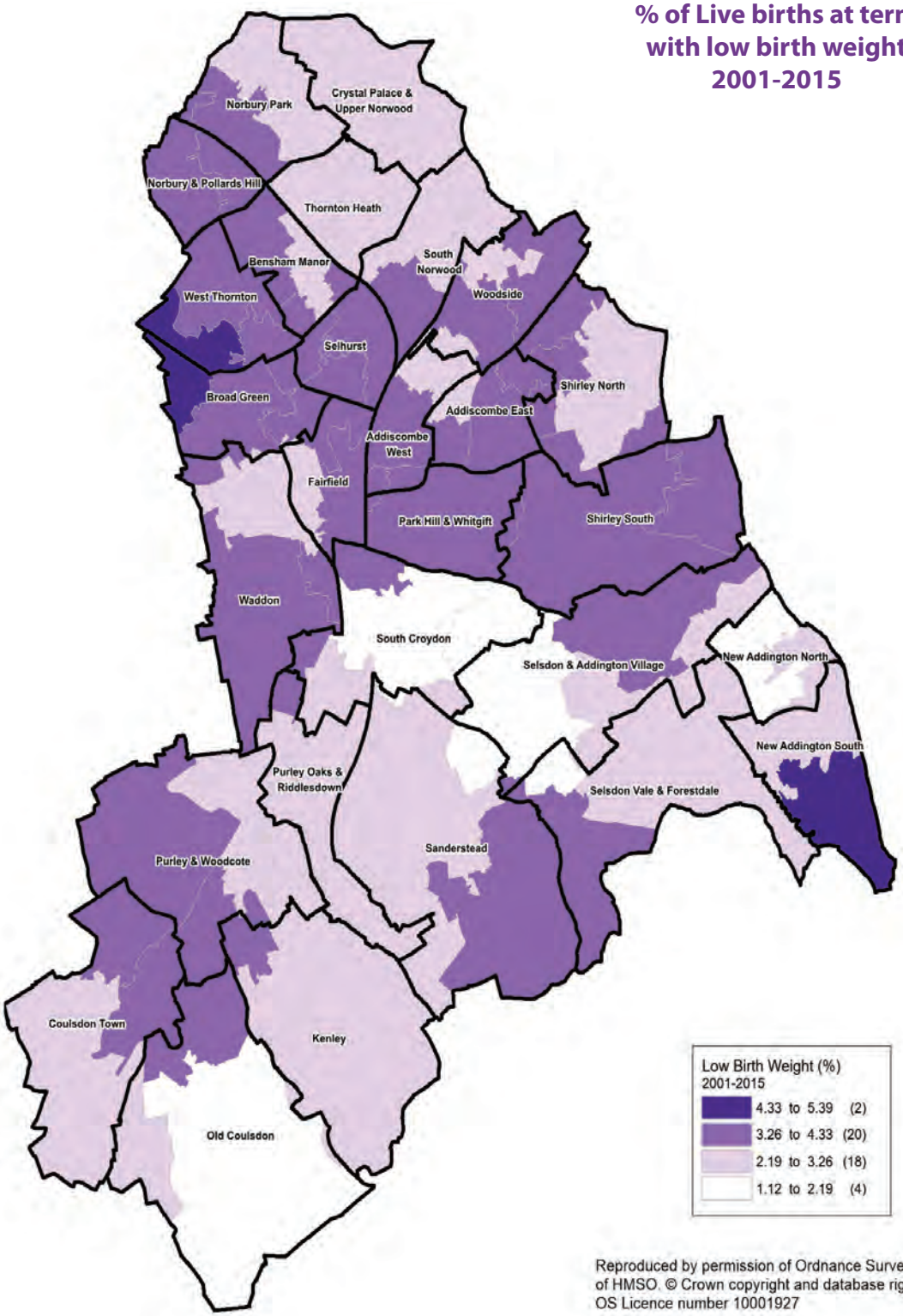
PRE PREGNANCY — DAY 1 — DAY 1000






% of Live births at term with low birth weight 2001-2015

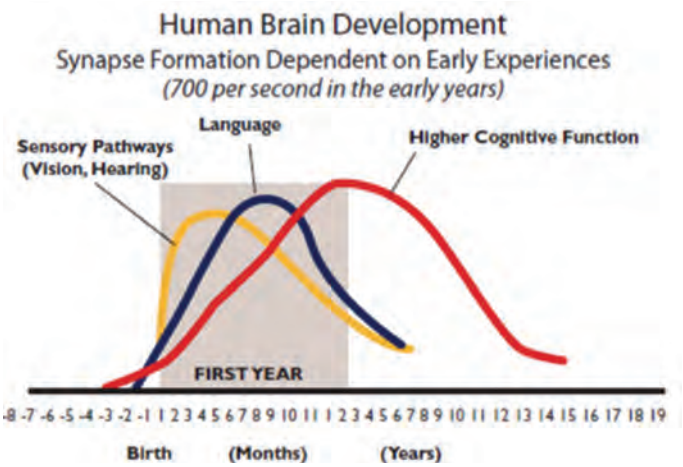


CHAPTER 4

INFANCY

The first two years of life are a time of great opportunity for children, their families and the wider community. (2)

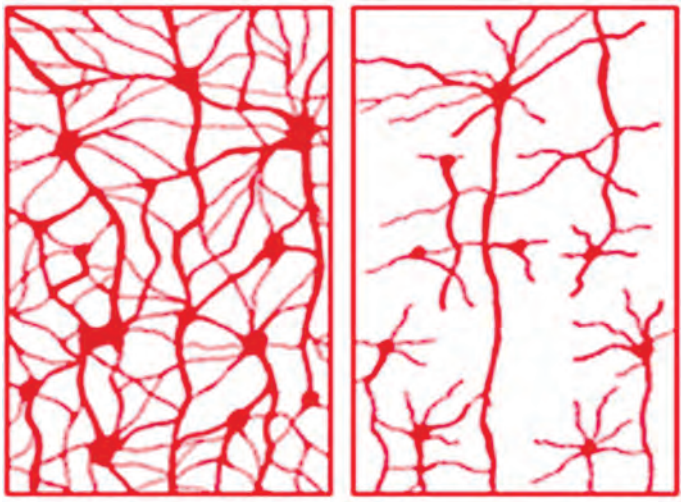
The rate of brain development during the first two years of life is extraordinary (124) with more than a 1 million new neural connections formed every second (125) but it does not all happen on its own. While we are all born with many billions of brain cells, they need help connecting with each other. (2)



Source: 'Human Brain Development: Neural Connections for Different Functions Develop Sequentially'. Graphic courtesy of the Center on the Developing Child at Harvard University. Data Source: C.A. Nelson (2000).

DID YOU KNOW that stimulating environments and positive relationships encourage the development of these connections?(2) Talking, love, a hug, engaging, playing, reading, singing all help form the connections. (1)

Positive, warm and predictable social relationships with parents, carers, the extended family, the community, child care providers, are all of vital importance to young children's brain development. (2) (3) (74) (94) (126)



Section of a stimulated brain | Section of a unstimulated brain

How children's brains develop during the first 1000 days lays the foundations for future educational success, income and health. (3) (76) Without positive brain stimulation there is less development, and getting a child back on track later requires significant effort and cost. (75)

The strength of the early influences on the brain means that the first 1000 days are a time of great opportunity but also great vulnerability for children. (126)

A study of 19 000 babies born between September 2000 and September 2002 reported that behaviours and characteristics from early childhood affected children's performance six to ten years later. (55)

The one and two year development checks undertaken by the health visitors provide an early opportunity to a child's progress and whether they and their family may need some extra support. Children who attend day care will also have progress checks with, for example their nursery or childminder.

An important and nationally available measure of a child's social, emotional and cognitive development is school readiness. Not all children are equally ready for school; nationally, girls have a higher level of school readiness than boys and pupils that are eligible for free school meals are 20% less likely to be school ready. (127)

PRE PREGNANCY | DAY 1 | DAY 1000

Source: Picture courtesy of the Center on the Developing Child at Harvard University [76]

EVIDENCE

Impact of positive relationships and stimulation on child development

- Children with good parent child relationships in the first year are more likely to develop stronger cognitive skills and progress better at school [3]
- Children whose parents do not think stimulation is important have significantly more difficulties [55]
- Higher parent / child closeness is associated with higher verbal ability and more pro social behaviours such as helping and sharing [128]

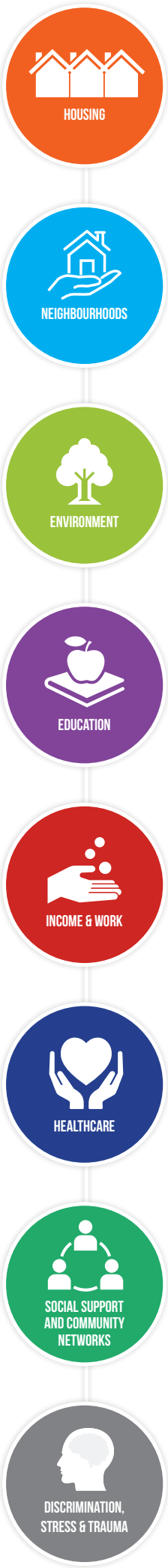
IMPACT OF INEQUALITIES

Child development

- By the age of three, disadvantaged disadvantaged children are almost a year and a half behind, on average, in their early language development [129]
- On average 40% of the overall gap between disadvantaged 16 year olds and their peers has emerged by the age of five [130]
- At the ages of five, seven and eleven, single parenthood is associated with lower test scores [55]
- Low maternal education has a negative impact on all cognitive outcomes at 5, 7 and 11 [55]

VOICE OF CROYDON'S FUTURE:

Help children to stimulate their brain through music, puzzles, trying to talk with them.



CHAPTER 4

INFANCY

What do we know about school readiness in Croydon?

In Croydon in 2016/2017, 73.4% of all children achieved a good level of development at the end of reception, however only 62.8% of children receiving free school meals achieved a good level of development.[7] While both these percentages have improved significantly since 2012, and compare well to London and England averages,[7] if the current trends continue, **1500** of the **6000** babies born in Croydon this year may not be ready for school.

Definition

School readiness

School readiness is a measure of how prepared a child is to succeed in school, cognitively, socially and emotionally. If a child is not school ready at age 5 this has a strong impact on future life chances. [131]

The majority of children will have safe nurturing environments which foster good child development. When, however, the child's immediate environment is a source of stress it can have long lasting negative effects.[76] Learning to cope with adverse situations is a normal part of child development but continuous high levels of stress may cause a child to experience what is called "toxic" or "chronic stress". Chronic stress can lead to physical and chemical disruptions in the brain that can last a lifetime and affect learning capacity, physical and mental health.[76]

A relationship with a supportive adult can block the effects of stress and therefore some children will be impacted less than others by adverse circumstances.[132]

Chronic stress can be caused by extreme poverty, abuse, neglect, maternal withdrawal, caregiver substance misuse or parental mental health issues. [76] [132] [134]

POSITIVE
Brief increases in heart rate, mild elevations in stress hormone levels

TOLERABLE
Serious temporary stress responses, buffered by suportive relationships

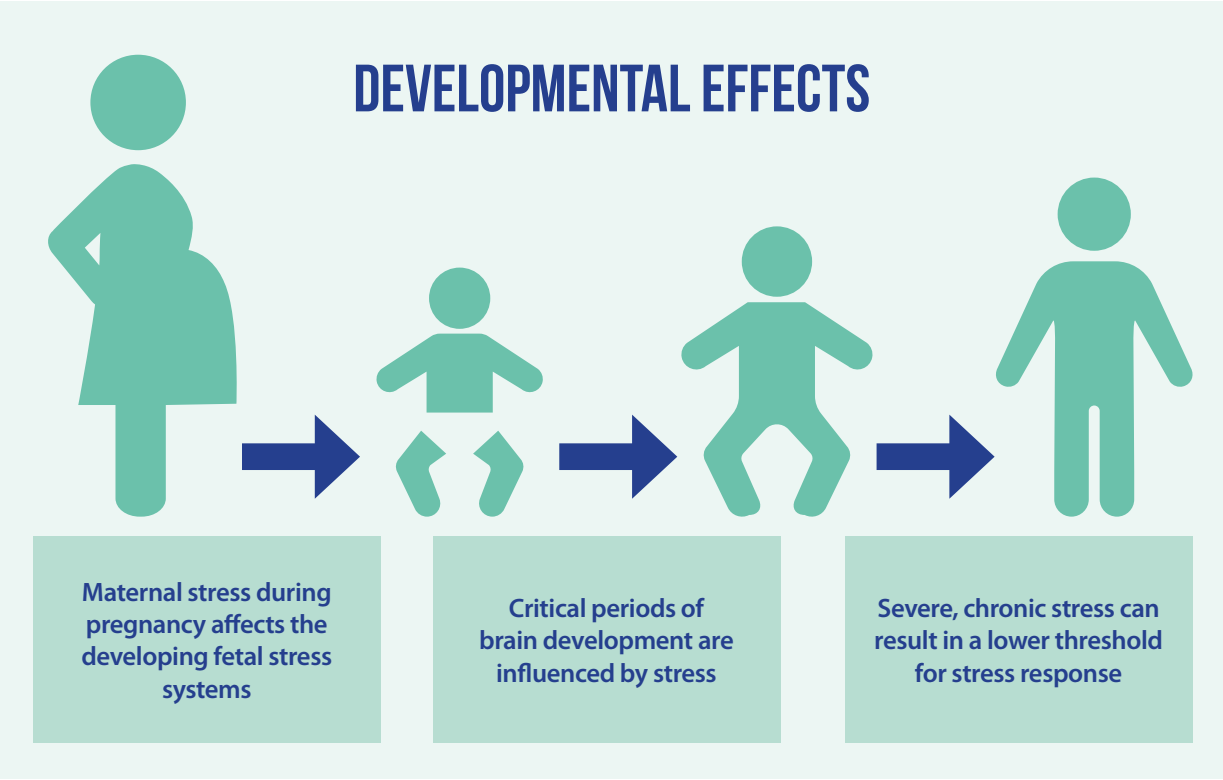
TOXIC
Prolonged activation of stress response systems in absence of protective relationships

Source: Kansas University[133]

PRE PREGNANCY — DAY 1 — DAY 1000

VOICE OF CROYDON'S FUTURE:
'Don't neglect; Love and care'

Early excess stress can also affect future generations. **DID YOU KNOW** that problems experienced in childhood can pass on to future generations due to lasting genetic changes?[94] This means that we need to take every opportunity we can to support families and children and increase the chance of breaking the cycle.



Source: Short, Derek 2016 [135]

Positive environments, child development and stress in infancy

Examples of what we are doing in Croydon

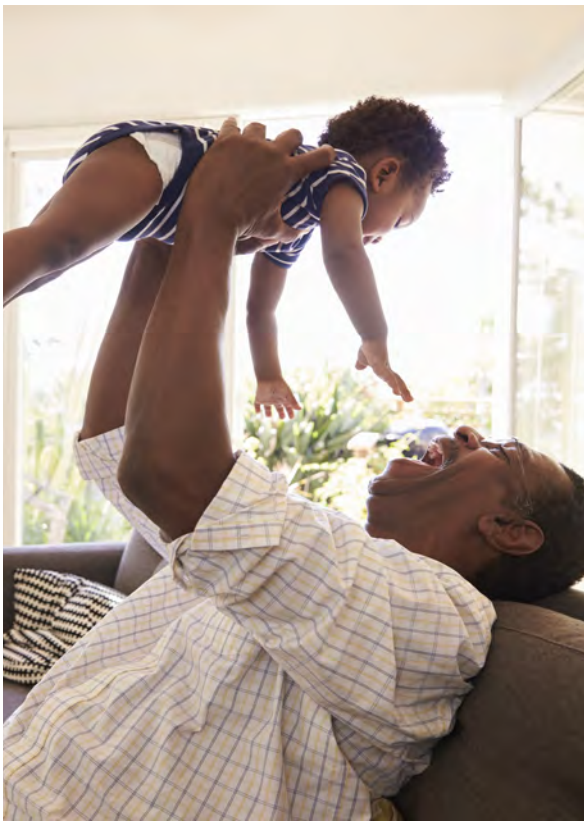
- Croydon's partnership Early Help offer delivers a range of evidence based programmes including parent support
- Parents are informed about activities and support through Best Start antenatal welcome evenings and through social media
- Improvements are being made to parks and recreational spaces to increase opportunities for play

Recommendations

20. Ensure maximum delivery of the health visiting development checks, from the antenatal visit to the 2 year check

21. Ensure all parents who may need additional support know what options are on offer and where to access them.

22. All practitioners working with children and families understand what toxic stress is, its sources and what impact it may have



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CHAPTER 4

INFANCY

PHYSICAL HEALTH NEEDS IN INFANCY

Immunisations, screening, breastfeeding, healthy diet, being active, being safe, good oral hygiene all contribute to a healthy start in life. [70]

The national childhood immunisation programme is offered to every child. Immunisation is a proven and cost effective way of eliminating damaging and life threatening infectious diseases. [20] Children who have not received all their immunisations are more likely to be admitted to hospital by nine months. [136]

What do we know about immunisation rates in Croydon?

Croydon is doing much worse than nationally. Taking MMR (Measles, mumps and rubella) as an example, the Croydon MMR vaccination rate in 2017/2018 for two doses by age five (required for full coverage) was **67%**, which is considerably lower than the national average of 87.2% (still far lower than the recommended 95%) and is no higher than the rate was five years ago.[8] There is a similar picture for the other childhood immunisations.[8] If we apply the current MMR percentage to the **6000** babies born in Croydon this year, we estimate that over **1500** babies will not receive two MMR doses by age 5 and other vaccines leaving them vulnerable to infections that can have very serious complications. Croydon had a number of measles cases during the outbreak in 2018.

POTENTIAL IMPACTS OF INEQUALITIES

Uptake of immunisations

Children are less likely to be fully immunised if they:

- Are from an minority ethnic background
- Are from a disadvantaged ward
- Are from a larger family
- Have a single parent or teenage parents
- Have a mother who smoked in pregnancy [136]

Immunisation rates

Examples of what we are doing in Croydon

- An active Health Protection Forum (HPF) meets regularly to scrutinise immunisations and other health protection issues. Croydon is one of few areas to have such a forum
- Croydon Council obtained funding for a research project with the national behavioural insights team to understand the barriers to MMR uptake with Croydon

Recommendations

23. All GP practices to reach 95% of MMR immunisations

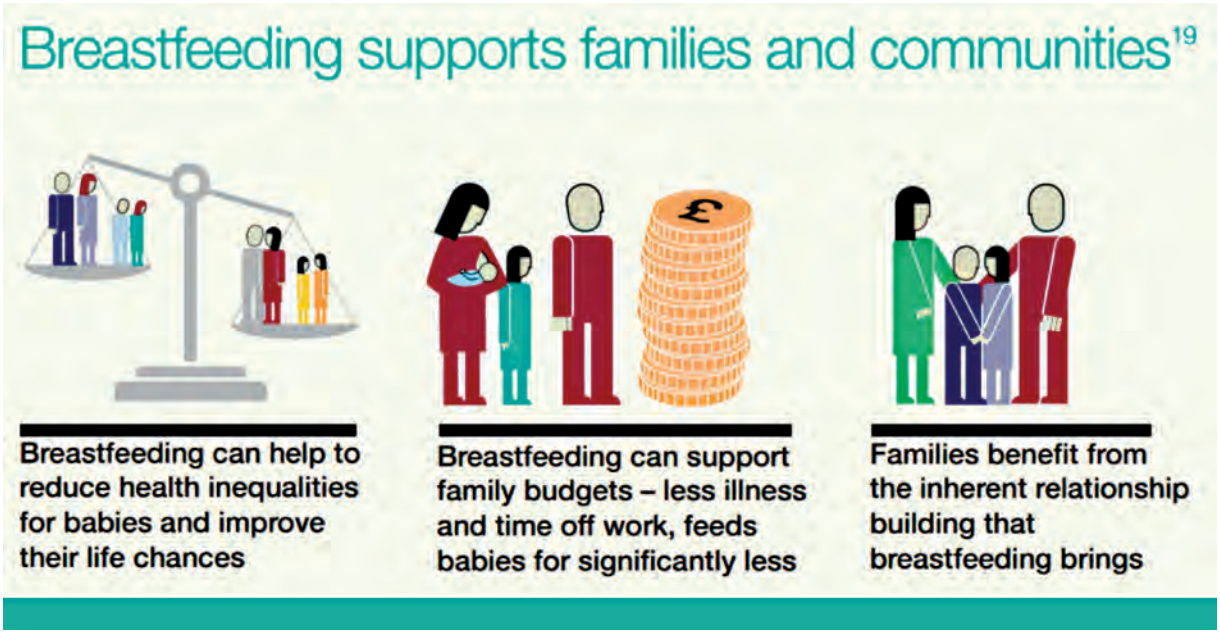
24. Implement comprehensive vaccination for vulnerable groups

We hear a lot about **breastfeeding** **BUT DID YOU KNOW** that breastfed babies are less likely to be overweight and obese or have type 2 diabetes?[137] Breastfeeding also helps bonding between mothers and their babies.[138] The cost to the NHS every year of treating just five types of illnesses linked to babies who were not breastfed is at least £48 million.[139]

The UK government recommends exclusive breastfeeding for around six months.[140] In England 74% of mothers start to breastfeed, with 44% breastfeeding at 6 weeks and only 1% exclusively breastfeeding until 6 months. [141]

Older mothers and some ethnics groups are much more likely to breastfeed whereas young, white mothers working in routine and manual jobs and who left education early are least likely to breastfeed.[139] Health inequalities experienced by mothers and children in low-income families would be reduced if babies were breastfed exclusively for the first six months. [141]

PRE PREGNANCY — DAY 1 — DAY 1000



Source: Source: PHE Commissioning Infant feeding service 2016 [139]

What do we know about breastfeeding rates in Croydon?

The number of babies who were breastfed at birth in 2016/2017 was 84%. Local data from the health visiting service shows that between January and March 2018 72% of babies (where breastfeeding status was known) were being breastfed at 6 to 8 weeks. Breastfeeding rates vary across the Borough with less than 40% of babies being breastfed in some areas at 6 to 8 weeks.

We have estimated that of the **6000** births expected this year, **1000** babies will not be breastfed from birth and at least **1300** of them will not be breastfed at 6 to 8 weeks.

EVIDENCE

Health and development benefits of breastfeeding

- Breastfed babies are 13% less likely to be overweight or obese and 35% less likely to have type 2 diabetes [145]
- Babies who are breastfed up to six months have higher test results at ages 7 and 11 [55]

Breastfed babies have lower rates of: gastroenteritis, respiratory infections, allergies, ear infections and tooth decay. [139]

Being physically active and having a healthy diet are important from the earliest stages of life. [70]

The UK Chief Medical Officer recommends at least three hours of movement every day from birth to five years. [142] Timely introduction to solid foods, a healthy family diet, along with physical activity are key to helping children maintain a healthy weight and healthy teeth. [143] [144] Surveys of children's weight and teeth at age five give us some idea about our success in helping Croydon children to be active and eat healthily.

Source: PHE Commissioning Infant feeding service 2016 [139]

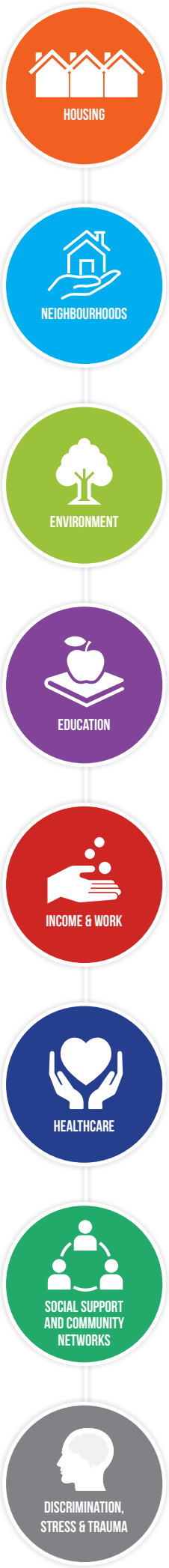
Breastfeeding in Croydon

Examples of what we are doing in Croydon

- There are baby cafes with peer supporters and breastfeeding clinics in different localities in the Borough
- There is a peer support programme in Fieldway / New Addington where low breastfeeding rates were identified

Recommendations:

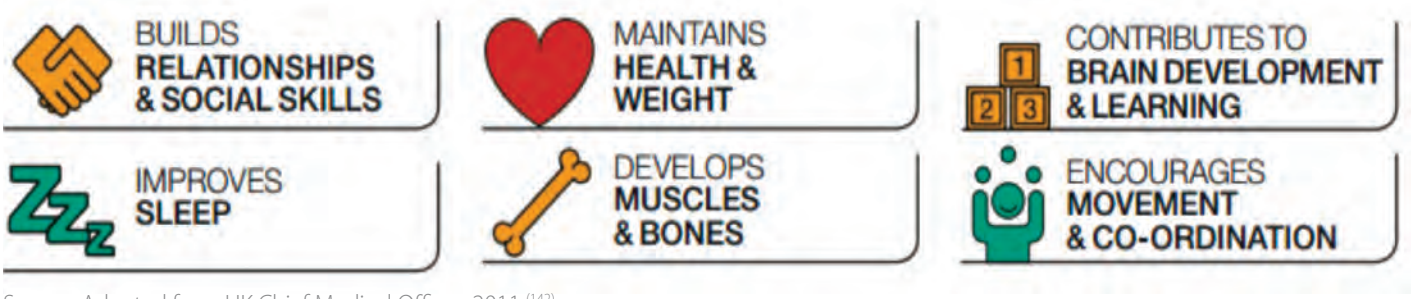
25. Reset targets for increasing breastfeeding rates at 6 to 8 weeks and 6 months across the Borough and within particular localities
26. Achieve level 3 of the UNICEF Baby Friendly award
27. Turn Croydon into a breastfeeding friendly Borough, so women feel comfortable breastfeeding when they are out and about [139]



CHAPTER 4

INFANCY

ACTIVE CHILDREN ARE HEALTHY, HAPPY, SCHOOL READY AND SLEEP BETTER



Source: Adapted from UK Chief Medical Officer, 2011 [142]

What do we know about children's teeth in Croydon?

Five year olds in Croydon have higher than the average levels of tooth decay. [149] Over 28 % of five years olds in 2016/2017 had experienced tooth decay. [146] If this trend continues over **1700** of the **6000** babies born in Croydon this year will have tooth decay by the age of five which not only has an impact on them and their families, but puts them at increased risk of disease in their permanent adult teeth. [147]

What do we know about the children's weight in Croydon?

In 2017/2018 **995** children (21.9%) in Croydon were overweight or obese in reception, which is similar to the London average. [148] This is down from a peak of **1140** children (23.7%) in 2016 /2017 which was the highest number since 2011/2012. Children from more deprived areas and from black ethnic groups have the highest levels of overweight or obesity. [8]

If current trends continue **1300** of the **6000** babies born this year will be overweight or obese by the time they start school.

Child healthy weight, physical activity and diet

Examples of what we are doing in Croydon

- The early years providers (nurseries, childminders) are implementing a new programme to improve children's health (Healthy Early Years London)
- There are healthy weight and food sessions for parents and young children at Children's Centres
- Families, schools and early years providers are being encouraged to sign up to the Sugar Smart campaign

Recommendations

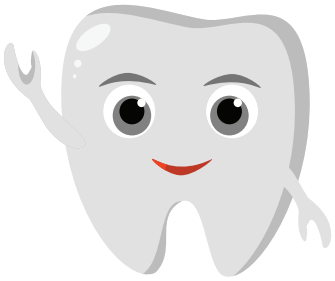
28. Review the Child Healthy Weight action plan in light of this report and amend to increase its focus on the first 1000 days

29. All families with young children, nurseries and other early years' providers to be encouraged to become Sugar Smart and their pledges monitored. For example nurseries and early years providers to only be giving children in their care water and milk to drink by 2020

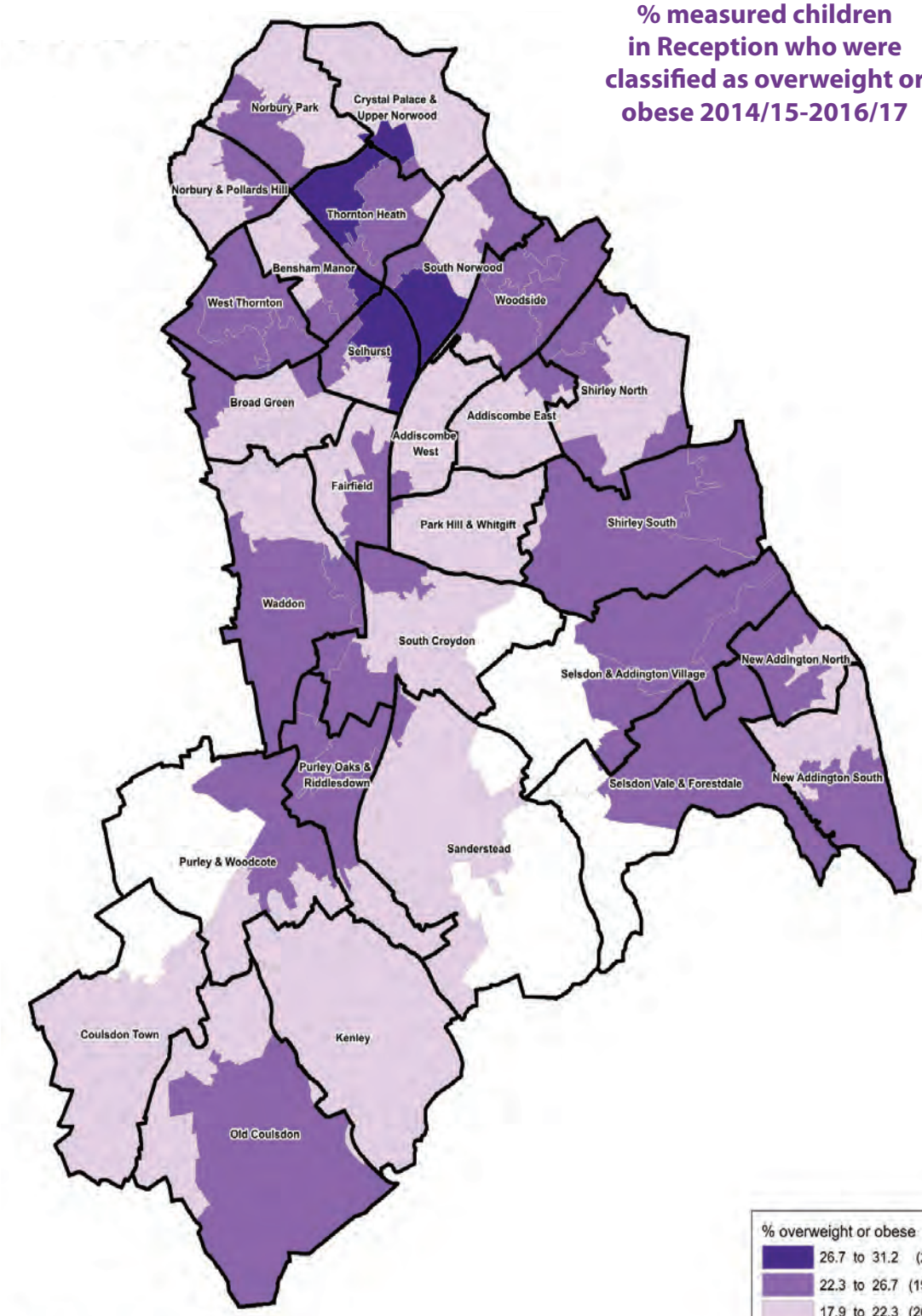
30. Increase the numbers of young children who go to the dentist

31. Increase the numbers of eligible families claiming their healthy start vouchers for fruit and vegetables and vitamins from pregnancy (uptake is currently 63%).

PRE PREGNANCY — DAY 1 — DAY 1000



% measured children in Reception who were classified as overweight or obese 2014/15-2016/17



HOUSING

NEIGHBOURHOODS

ENVIRONMENT

EDUCATION

INCOME & WORK

HEALTHCARE

SOCIAL SUPPORT AND COMMUNITY NETWORKS

DISCRIMINATION, STRESS & TRAUMA

CHAPTER 5

ADVERSE CHILDHOOD EXPERIENCES

DID YOU KNOW that chronic or excessive stress in the early years can change brain and physiological development and cause long term damage over the life course? (149)

Adverse Childhood Experiences (ACEs) are a source of this chronic stress. ACEs include experiences such as abuse, domestic violence, neglect, homelessness, parental relationship breakdown, parental incarceration and substance misuse. (149) ACEs are common, with about half of the population reporting that they had experienced at least one ACE between the ages of 0 to 18 years and 8% experiencing four or more ACEs. (149) Many ACEs may be experienced in the first 1000 days of life.

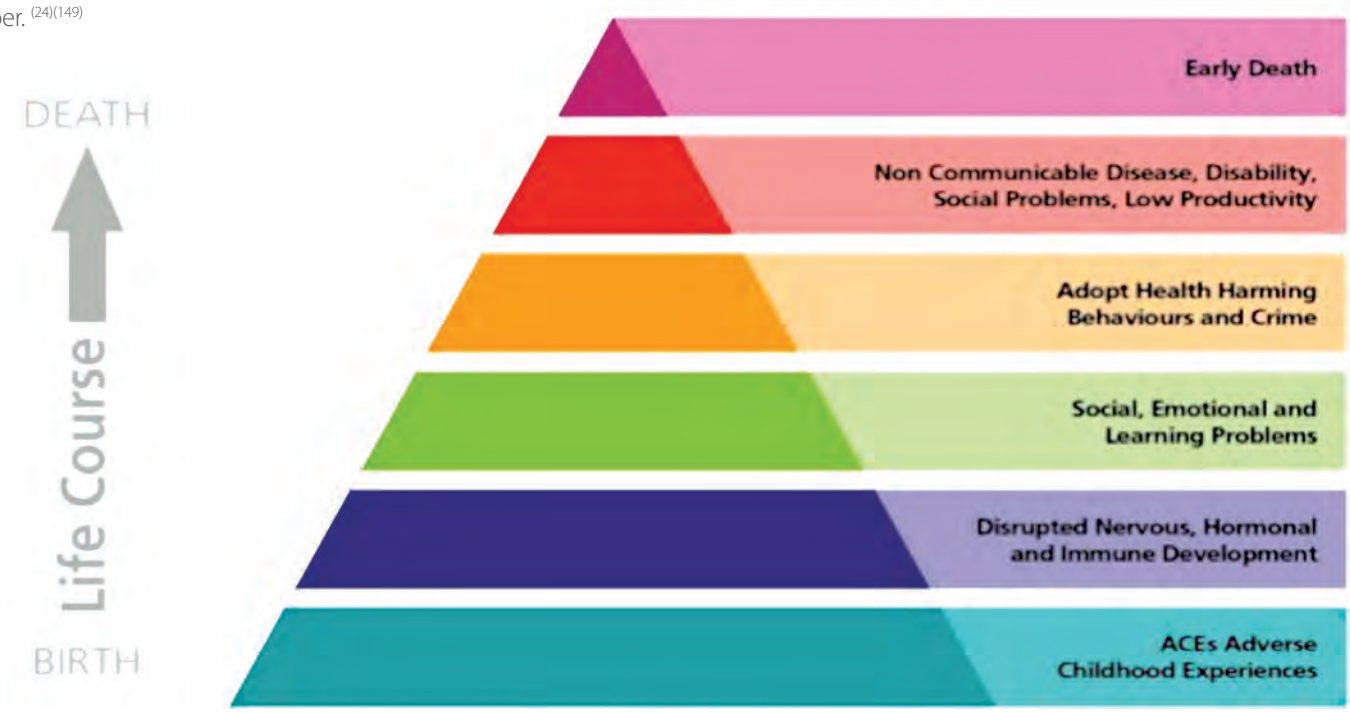
Children who experience chronic stress from ACEs are more likely to develop antisocial and health harming habits and suffer from the earlier onset of chronic diseases as an adult. (132) The more ACEs a child experiences the higher the risk of developing these health harming behaviours and suffering poor adult health. (134)

ACEs affect children at all levels of income, however children growing up in poverty, are more likely to experience a greater number. (24)(149)

A UK study found that nearly 13% of children in the most deprived group experienced four or more ACEs compared to just over 4% in the least deprived group. (150) Furthermore, as poverty itself increases stress it is likely to heighten the risk of ACEs. (24)

A joint study with the WHO found that children who had experienced four or more ACEs compared with children who had experienced no ACES were:

- 30 times more likely to have attempted suicide
- 10 times more likely to have problem drug use
- 8 times more likely to have committed a crime
- 6 times more likely to have problem alcohol use
- 4 times more likely to have depression
- 4 times more likely to have been a teenage parent



Source: Felitti 1998. CDC, Image credit to Warren Larkin Associates Limited

PRE PREGNANCY DAY 1 DAY 1000

People with four plus ACEs are more likely to have contact with health services than those with no ACEs. [150] [153] For example, 64% of those in contact with substance misuse services had more than 4 ACEs

- **2.1 x** more likely to have **visited their GP in the last 12 months**
- **2.2 x** more likely to have **visited A&E in the last 12 months**
- **2.3 x** more likely to have **more than ten teeth removed**

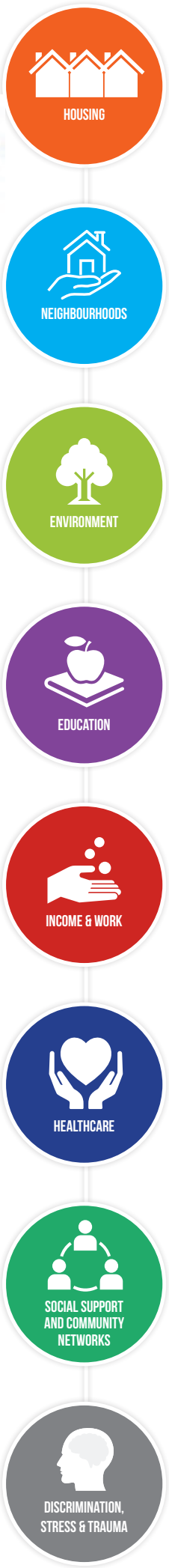
ACEs can also increase the risk to the child of asthma, gastrointestinal conditions and headaches; the higher number of ACES a child has, the greater number of health problems. [132]

It is incredibly important to emphasise that not everybody who experiences ACEs goes on to suffer from emotional and physical health problems.

Even children who have experienced multiple ACEs can, through resilience, transform potentially damaging stress into a more tolerable form. [154] A trusted adult, community support and cultural engagement can help the child develop the resilience and the capacity to thrive, despite growing up facing adversity. [2] [132]

ACEs AND RESILIENCE

Source: Mark A. Bellis, WHO Collaborating Centre on Investment in Health and Well-being, Public Health Wales (2017)



CHAPTER 5

ADVERSE CHILDHOOD EXPERIENCES

DID YOU KNOW that one of the reasons ACEs are not detected early is that professionals and the public were not aware of the links between adverse experiences in early childhood and later problems? [155]

Source: Lancashire NHS Foundation Trust [155]

What do we know about ACES experienced in Croydon?

Using national survey data, we estimate that of the **6000** babies born each year almost **500** (8.4%) will have experienced four or more ACEs by the time they reach 18 years, placing them at very much higher risk of experiencing worse outcomes as an adult.

Children born into deprived communities are more likely to experience multiple ACEs. Of the estimated 1,200 babies in the least deprived group, approximately **50** will experience 4 or more ACEs, whereas three times that number, **150** of the 1200 babies in the most deprived group will experience four or more ACEs. Using this same survey, we have estimated (below) the number of babies born in Croydon each year that will be affected by each type of ACE by the time they reach 18 years of age. Almost a quarter (**1,422** babies) will experience two or more of them. [152]

National survey responses applied to the 6000 children born each year- in Croydon

Alcoholism	9%	540
Drug abuse	4%	240
Mental illness	12%	720
Incarceration	4%	240
Domestic violence	12%	720
Physical abuse	14.3%	858
Parental separation	22%	1320

The studies of ACEs have largely focused on how they have impacted on adult health and behaviour. I would, however, like to reflect briefly on how ACEs may already be affecting adolescents in Croydon.

PRE PREGNANCY — DAY 1 — DAY 1000

What do we know about vulnerable adolescents in Croydon?

There are adolescents in Croydon whose risky and health harming behaviours may have their origins in the chronic stress caused by ACES in earlier childhood. Children excluded from school and those admitted to hospital for self-harm and alcohol are two possible examples.

We do not have a complete picture but we know that in Croydon there were: (PHE, 2018)

223	first time entrants to the youth justice system (2017) [8]
1452	secondary school exclusions (2015/2016) [8]
91	admissions for substance misuse [7] in15 to 24 years olds (2014/15- 2016/2017) [7]
166	hospital admissions as a result of self-harm among 10 to 24 year olds (2016/2017) [7]
56	admissions for alcohol specific conditions for under 18s (2014/2015 to 2016/2017) [7]
970	16 and 17 year olds not in education and training (2016) [7]

We have a range of opportunities to identify and support children at higher risk of multiple ACEs. To begin with, everyone working with children and their families' needs to understand that ACEs can have a profound impact on children and their life chances (155). Other key opportunities are reducing the underlying risk factors such as poverty, deprived neighbourhoods and poor housing and strengthening family relationships and community support so that where ACEs do occur each child has the capacity to thrive despite circumstances.

Adverse childhood experiences

Examples of what we are doing in Croydon

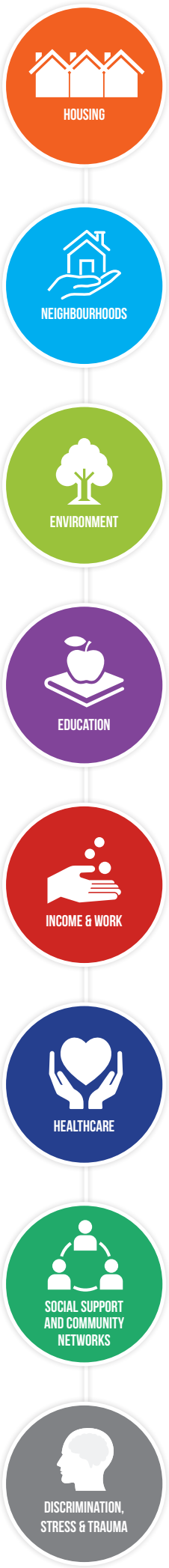
- The council and its partners are focusing on prevention, engagement with residents and using intelligence to target evidence based and cost effective approaches
- We are improving public realm through neighbourhood regeneration and increased use of parks and open spaces

Recommendations

32. Working as a partnership, develop evidence based actions to champion the importance of ACEs and the first 1000 days, and to identify and support children and families most vulnerable to ACEs

33. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.

34. 1000 front line staff in the council, NHS police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact in 2019



CHAPTER 6

MY RECOMMENDATIONS

I would like us all to ask ourselves: 'Do I know what impacts on the health of children in their first 1000 days of life? And what can I, or my organisation, do to reduce inequalities?'

My three high level principles are:

Know your role: We all have a role to play in helping children thrive during the first 1000 days - however we need to understand what this role is and how best we can contribute through a whole systems approach

Health in all policies: We all should shift the focus from managing ill health to creating the right conditions for good health through a health in all policies approach

Breaking the inequalities cycle: Tackling the socio- economic determinants of health - (such as jobs, homes, social cohesion, education, income) is key in reducing the inequalities in early years that, in turn, become inequalities across the life course. We all have a role to play in breaking this cycle

Throughout the report I have identified recommendations that will help us deliver these principles; some are specific and some more general that require further development and co-creation. (The full list is in appendix A) I recommend that the Health and Wellbeing take the responsibility for the oversight of these recommendations and the monitoring of their implementation and impact. My four key recommendations are:

1. Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.
2. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.
3. 1000 front line staff in the council, NHS, police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact, in 2019
4. Develop and Implement a plan of action for increasing the levels of awareness about pre pregnancy health and the importance of preparing for pregnancy by the end of 2019

EPILOGUE

Writing this report has reminded me how early in life inequalities start, and that no single person or organisation can change this on their own. We have to work together to ensure that no child is left behind. My aim in this report was to share the evidence and highlight what we can do to give Croydon's children the best possible chance.

I must stress again that the first 1000 days of a child's life is inextricably linked with the lives and health of their parents and carers, neighbourhoods and communities. It is hugely important to reduce the impact that social and economic factors such as poor housing, low income and deprived neighbourhoods have on perpetuating inequalities.

What a child experiences in the first 2 years can be passed on to their own children which can trap some families and communities in a cycle of poorer outcomes. This is wrong.

Everything I have read has underlined the importance of prevention in breaking this cycle and has shown that there are many things we can do together to make a difference for our children. I know that Croydon is up for the challenge

"Childhood, after all, is the first precious coin that poverty steals from a child" Anthony Horowitz

VOICE OF CROYDON'S FUTURE:

'Women should breastfeed; Parents should make sure that they are in good health as well as their baby; They should keep in good shape and eat healthily; They should not neglect their child and make them feel loved and cared for'
C, 13

PRE PREGNANCY — DAY 1 — DAY 1000

ACKNOWLEDGEMENTS

I would like to thank the project team (see below), in particular its leader and co-ordinator, Rachel Tilford and Damian Brewer for all their contributions to this report:

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- **Craig Ferguson**
- **Susan Mubiru**
- **Anna Ramsbottom**
- **Nicola Vousden**

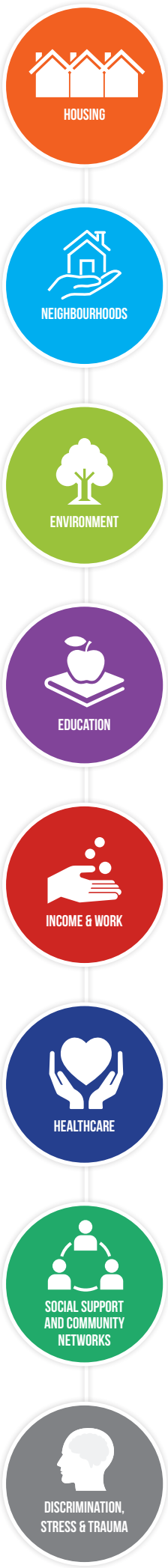
Many other people have contributed to this report along the way and I would just like to thank each and every one for their inputs and insight.

A very special thanks to Andy Martin, deputy manager of the council's design team, for his patience and superb interpretation of my design ideas.

GIVE US YOUR FEEDBACK

Do let me know your comments on the report, either by emailing me at **rachel.flowers@croydon.gov.uk**

or by post to:
Croydon Council,
Public Health, Health, Wellbeing and Adults Department
2nd floor Zone E, Bernard Weatherill House
8 Mint Walk, Croydon, CR0 1EA



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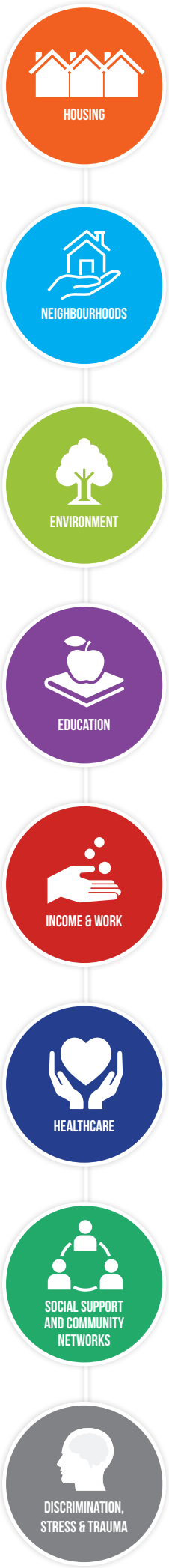

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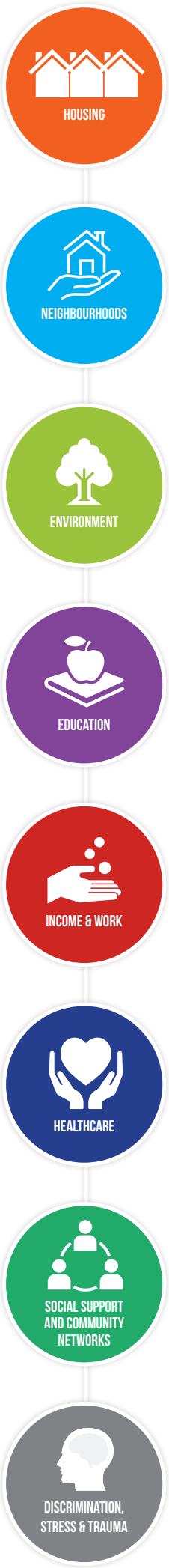

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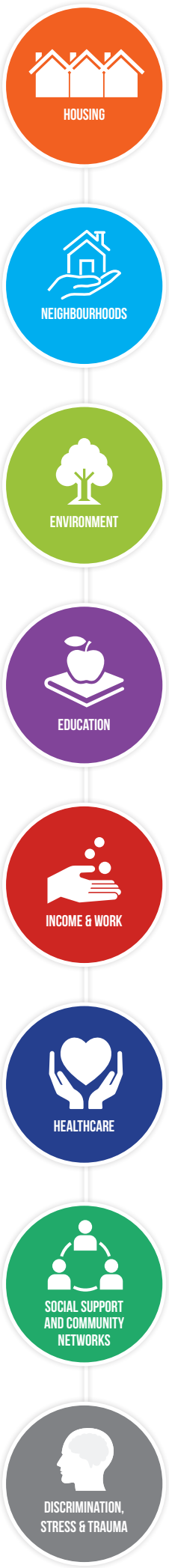


APPENDIX A: THE RECOMMENDATIONS FROM DIRECTOR OF PUBLIC HEALTH REPORT 2018

Four key recommendations drawn from different chapters in the report

1.Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.

2.All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.

3.1000 front line staff in the council, NHS, police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact, in 2019

4.Develop and Implement a plan of action for increasing the levels of awareness about pre pregnancy health and the importance of preparing for pregnancy by the end of 2019

Recommendations from individual sections of the report

The setting for the first 1000 days

1.Ensure training raises awareness among staff of: the importance of the first 1000 days and pre pregnancy health; the impact of wider determinants such as poverty and how they can make a difference in their role for children and their families

2.Use population and community level intelligence at borough and locality level to target resources and services to those Young parents

3. Provide senior strategic support from across the partnership to the borough's teenage pregnancy action plan and ensure that its work is widely understood and linked to other strategies and programmes

4. Increase awareness among young people of all sexes of the importance of being healthy before pregnancy and planning pregnancies through implementation of the teenage pregnancy action plan and maximising the opportunities created by the statutory changes both in SRE (sex and relationship) education and in PSHE (personal, social, health and economic) education

5. Ensure the findings of Croydon's Vulnerable Adolescent Mental Health deep dive are acted upon to identify when, where and how to provide support to children and teenagers

Knowledge about pre-pregnancy health and planning for pregnancy

6. All agencies to maximise their use of existing opportunities to raise awareness of the importance for both parents of planning for pregnancy and addressing health issues before becoming pregnant.

7. Use existing and new media to promote pre-pregnancy health messages, particularly about smoking and being overweight or obese for people living and working in Croydon

Smoking and pregnancy

8. Develop a pathway for pregnant smokers and their partners into smoking cessation support that is opt out rather than opt in

9. Identify the groups continuing to smoke through pregnancy and review the evidence base to identify the best approaches for helping them to stop smoking

10. Develop a smoke free homes programme with social and private landlords

Parental weight, diet and nutrition

11. Continue to provide senior strategic support to the partnership's Healthy Weight steering group, and ensure its work plan includes pre pregnancy health.

12. Ensure that all programmes that promote pre-pregnancy health (see previous recommendation box) include key messages around the importance of being a healthy weight and having a healthy diet before pregnancy.

13. Incorporate the recommendations of the London Mayor's Food Strategy (due to be published in December 2018) into local plans

Mental health in pregnancy and beyond

14. Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners by 2019.

15. Ensure all staff have the skills to identify parents and prospective parents with potential mental health concerns and are able support and signpost them appropriately

16. Ensure that all programmes that promote pre-pregnancy health (see previous recommendation box) address mental health concerns before pregnancy.

Relationships, social support and excess stress during pregnancy

17. Review the effectiveness of the current arrangements for identifying women who need more social support and make recommendations to address any system wide gaps that are identified.
18. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.
19. 1000 front line staff in the council, NHS police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact in 2019

Positive environments, child development and stress in infancy

20. Ensure maximum delivery of the health visiting development checks, from the antenatal visit to the 2 year check
21. Ensure all parents who may need additional support know what options are on offer and where to access them.
22. All practitioners working with children and families understand what toxic stress is, its sources and what impact it may have

Immunisation rates in Croydon

23. All GP practices to reach 95% of MMR immunisations
24. Implement comprehensive vaccination for vulnerable groups

Breastfeeding in Croydon

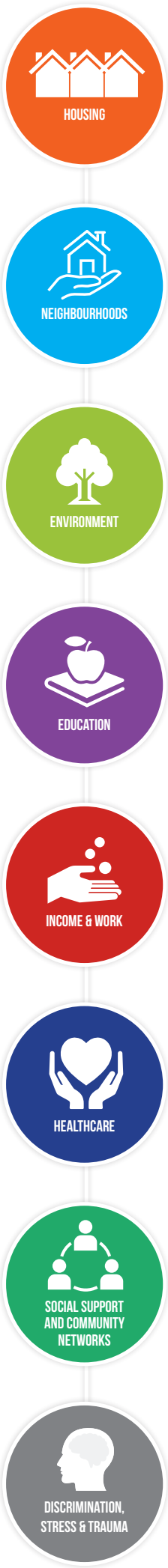
25. Reset targets for increasing breastfeeding rates at 6 to 8 weeks and 6 months across the Borough and within particular localities
26. Achieve level 3 of the UNICEF Baby Friendly award
27. Turn Croydon into a breastfeeding friendly Borough, so women feel at ease to breastfeed when they are out and about (PHE, 2016)

Child healthy weight

28. Review the Child Healthy Weight action plan in light of this report and amend to increase its focus on the first 1000 days.
29. All families with young children, nurseries and other early years' providers to be encouraged to become Sugar Smart and their pledges monitored. For example nurseries and early years providers to only be giving children in their care water and milk to drink by 2020
30. Increase the numbers of young children who go to the dentist
31. Increase the numbers of eligible families claiming their healthy start vouchers for fruit and vegetables and vitamins from pregnancy (uptake is currently 63%).

Adverse childhood experiences in Croydon

32. Working as a partnership, develop evidence based actions to champion the importance of ACEs and the first 1000 days, and to identify and support children and families most vulnerable to ACEs
33. All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple Adverse Childhood Experiences by the end of 2019.
34. 1000 front line staff in the council, NHS police and voluntary sector to have training around Adverse Childhood Experiences, their causes and impact in 2019



WE ARE CROYDON

EARLY EXPERIENCES LAST A LIFE TIME

The first 1000 days from conception to the age of 2

DIRECTOR OF PUBLIC HEALTH ANNUAL REPORT 2018

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WE ARE CROYDON

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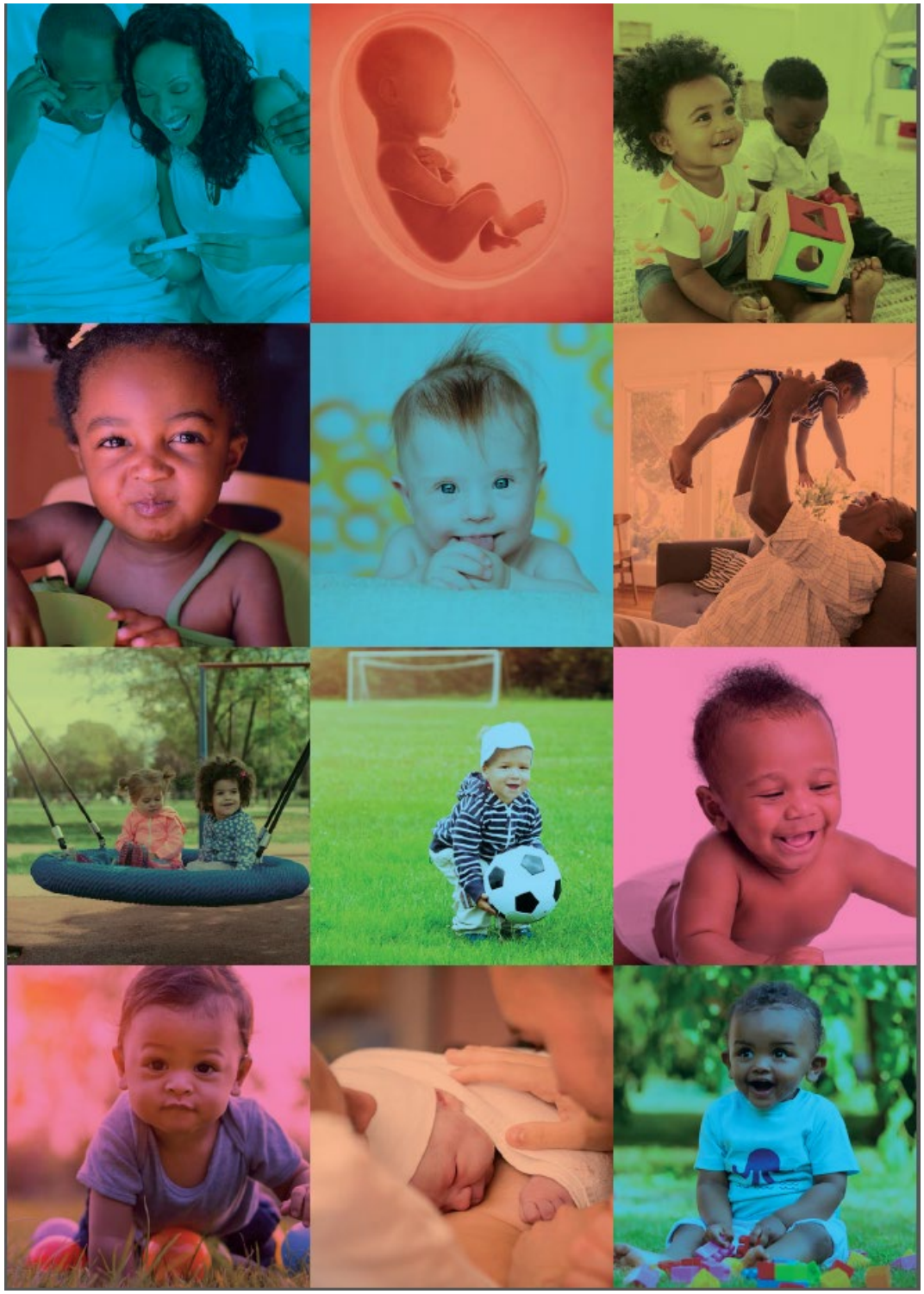


The importance of first 1000 days of life

OUR FUTURE

- Nearly **6000** babies are born each year in Croydon

- ‘What a child experiences during the early years lays down a foundation for the whole of their life’ (Marmot 2010)

The opportunity to make a difference for the 6000 babies born in Croydon each year

OUR FUTURE

1100 born into poverty

1300 will not be breastfeed at 6 to 8 weeks

1500 may not receive 2 MMR doses

2000 babies unplanned

1500 may not be school ready

1300 will be overweight or obese when they start school

1700 may have tooth decay by 5

700 live in households where there is harmful or hazardous drinking

Over **350** mothers smoked in pregnancy

Between **525** and **1600** mothers with mild to moderate depressive illness

Adverse Childhood experiences

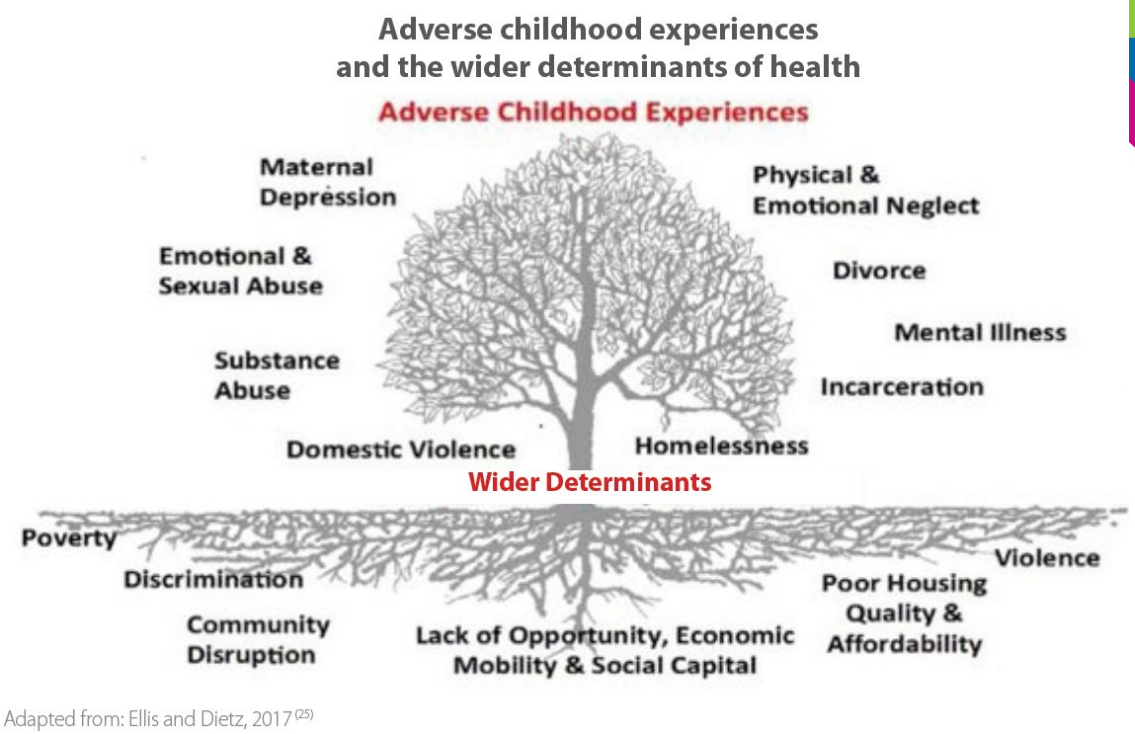
OUR FUTURE

500 / 6000 will experience 4 or more ACES

858 will experience physical abuse

720 will have parents with a mental illness

1320 will experience parental separation



Adapted from: Ellis and Dietz, 2017 [25]

POSITIVE
Brief increases in heart rate, mild elevations in stress hormone levels

TOLERABLE
Serious temporary stress responses, buffered by suportive relationships

TOXIC
Prolonged activation of stress response systems in absence of protective relationships

Source: Kansas University [133]

Resilience

A trusted adult, community support and cultural engagement can help the child develop the resilience and the capacity to thrive, despite growing up facing adversity. (2) (132)

Five key messages

OUR FUTURE

- The wider determinants such as housing, neighbourhoods, level of education, and household income affect each child's first 1000 days
- A mother's (and father's) health before getting pregnant, as well as during pregnancy and after the baby is born, can affect the baby's current and future health
- Experiences in the first 1000 days of life from conception to age of 2, shape lifelong health and wellbeing
- Some Adverse Childhood Experiences (ACEs), such as neglect or abuse can effect the rest of a baby's life
- It's a **complex problem** that needs a whole systems partnership approach (and we can make a difference)

A question and three key principles to keep in mind

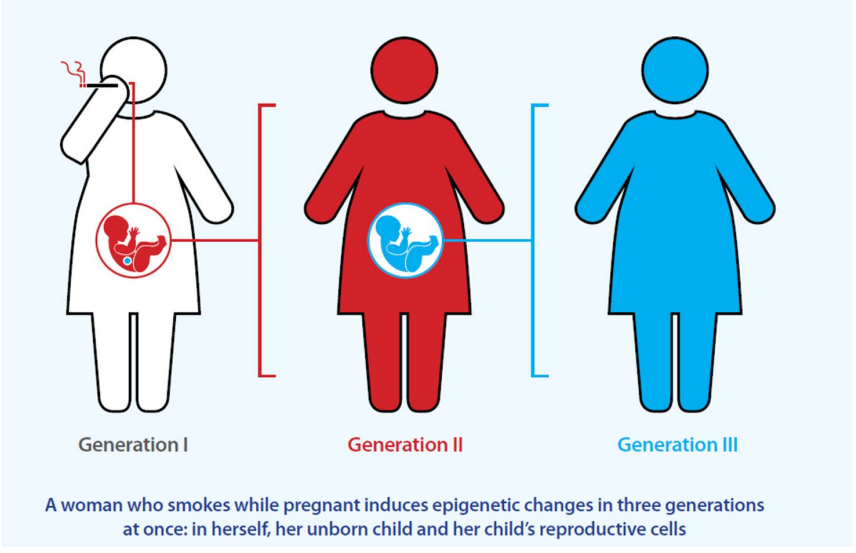
OUR FUTURE

I would like us all to ask ourselves: 'Do I know what impacts on the health of children in their first 1000 days of life? And what can I, or my organisation, do to reduce inequalities?'

Know your role: everyone can make a difference

Health in all policies: create the right conditions for good health

Breaking the inequalities cycle: helping the babies of today helps the next generation



A woman who smokes while pregnant induces epigenetic changes in three generations at once: in herself, her unborn child and her child's reproductive cells

4 key recommendations

Recommendation	In progress	Lead group, key partners /programmes
Review, revise and join up the maternal mental health pathways		New: Perinatal mental health partnership group to report in September 2019
100% of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple ACEs 1000 front line staff in the council, NHS, police and voluntary sector to have ACES training, their causes and impact		New: ACEs working group and Trauma informed care work stream with community safety
Increase levels of awareness about pre pregnancy health and the importance of preparing for pregnancy		? Lead group. Approach is being scoped This is not just a Croydon issue

The setting for the first 1000 days

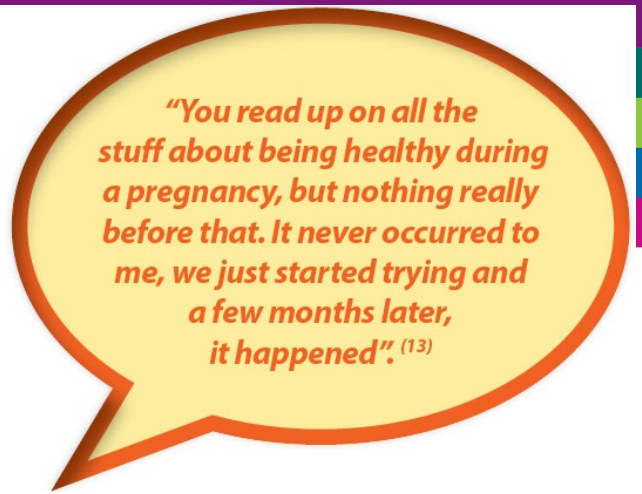
Recommendation	In progress	Lead group, key partners /programmes
1. Ensure training raises awareness among staff of: • the importance of the first 1000 days and **pre pregnancy health** • the impact of wider determinants such as poverty • how they can make a difference in their role for children and their families		Early Help (and partners) training programmes Children's Services Gateway Services Primary Care
2. Use population and community level intelligence at borough and locality level to target resources and services to those individuals and communities most in need		Population Health Management approach Children's JSNA Council Operating model Early Help and Gateway Services

Young parents

OUR FUTURE

Recommendation	In progress	Lead group, key partners /programmes
3. Provide senior strategic support from across the partnership to the borough's teenage pregnancy action plan		Partnership teenage pregnancy action plan
4. Increase awareness among young people of all sexes of the importance of being healthy before pregnancy and **planning pregnancies**:		Healthy Schools Action Plan, Implementation of the new SRE programme from 2020
5. Ensure the findings of Croydon's Vulnerable Adolescent Mental Health deep dive are acted upon to identify when, where and how to provide support to children and teenagers		CYP Emotional Wellbeing and Mental Health Board CSCB

Pre-pregnancy health and planning for pregnancy



Recommendation	In progress	Lead group, key partners /programmes
6. All agencies to maximise their use of existing opportunities to raise awareness of the importance for both parents **of planning for pregnancy and addressing health issues before becoming pregnant.**		? Lead group Partnership Teenage Pregnancy Action Plan SRE in schools
7. Use existing and new media to **promote pre-pregnancy health messages,** particularly about smoking and being overweight or obese for people living and working in Croydon		Joint Healthy Weight Steering Group Just be and Livewell

Smoking and pregnancy

Recommendation	In progress	Lead group, key partners /programmes
8. Develop a pathway for pregnant smokers and their partners into smoking cessation support that is **opt out rather than opt in**		Live Well Public Health CHS
9. Identify the groups continuing to smoke through pregnancy and review the evidence base to identify the best approaches for helping them to stop smoking		Live Well Public Health
10. Develop a smoke free homes programme with social and private landlords		Live Well Public Health

Parental weight, diet and nutrition

Recommendation	In progress	Lead group, key partners /programmes
11. Continue to provide senior strategic support to the partnership's Healthy Weight steering group, and **ensure its work plan includes pre pregnancy health.**		Partnership Healthy Weight Steering Group
12. Ensure that all programmes that promote pre-pregnancy health include key messages around the importance of being a healthy weight and having a healthy diet before pregnancy.		Partnership Healthy Weight Steering Group Live Well / Just Be Primary Care
13. Incorporate the recommendations of the London Mayor's Food Strategy into local plans		Partnership Healthy Weight steering group

Mental health in pregnancy and beyond

Recommendation	In progress	Lead group, key partners /programmes
14. Review, revise and join up the maternal mental health pathways from the community, and primary care, through midwifery and health visiting and other partners		New: Perinatal mental health partnership group to report in September 2019
15. Ensure all staff have the skills to identify parents and prospective parents with potential mental health concerns and are able support and signpost them appropriately		New: Perinatal mental health partnership group to report in September 2019 ACEs working group EH strategy
16. Ensure that all programmes that promote		? Lead group. Approach

Relationships, social support and excess stress during pregnancy

Recommendation	In progress	Lead group, key partners /programmes
17. Review the effectiveness of the current arrangements for identifying women who need more social support and make recommendations to address any system wide gaps that are identified		New: ACEs working group and Trauma informed care Work stream with community safety EH steering group
18. See ACES recommendation		
19. See ACES recommendation		

Child development and stress in infancy

Recommendation	In progress	Lead group, key partners /programmes
Ensure maximum delivery of the health visiting development checks, from the antenatal visit to the 2 year check		Commissioning and contract monitoring
Ensure all parents who may need additional support know what options are on offer and where to access them		Early Help Steering Group **New:** ACEs working group
All practitioners working with children and families understand what toxic stress is, its sources and what impact it may have		**New:** ACEs working group

Immunisation rates in Croydon

Recommendation	In progress	Lead group, key partners /programmes
All GP practices to reach 95% of MMR immunisations		CCG Health protection forum Child health steering group
Implement comprehensive vaccination for vulnerable groups		CCG Health protection forum Child health steering group

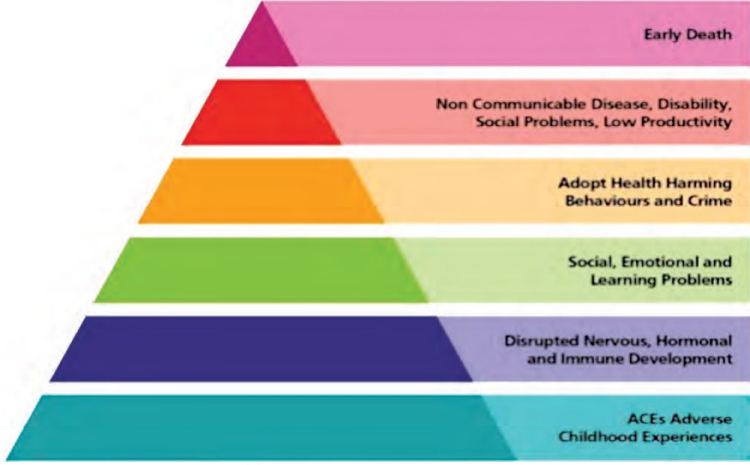
Breastfeeding in Croydon

Recommendation	In progress	Lead group, key partners /programmes
Reset targets for increasing breastfeeding rates at 6 to 8 weeks and 6 months across the Borough and within particular localities		Commissioning and contract monitoring
Achieve level 3 of the UNICEF Baby Friendly award		New: Breastfeeding working group
Turn Croydon into a breastfeeding friendly Borough, so women feel at ease to breastfeed when they are out and about		New: Breastfeeding working group

Child healthy weight

Recommendation	In progress	Lead group, key partners /programmes
Review the Child Healthy Weight action plan in light of this report and amend to increase its focus on the first 1000 days		Partnership healthy weight steering group
All families with young children, nurseries and other early years' providers to be encouraged to become Sugar Smart and their pledges monitored.		Healthy Early Years programme Sugar Smart
Increase the numbers of young children who go to the dentist		Public Health team and LDC, Health visiting
Increase the numbers of eligible families claiming their healthy start vouchers for fruit and vegetables and vitamins from pregnancy		Food poverty action plan and healthy Start working group

ACEs in Croydon



Recommendation	In progress	Lead group, key partners /programmes
Working as a partnership, develop evidence based actions to champion the importance of ACEs and the first 1000 days, and to identify and support children and families most vulnerable to ACEs		New: ACEs working group Early Help
All (100%) of midwives and health visitors in Croydon to receive training around recognising and supporting families with risk of multiple ACEs		New: ACEs working group and Trauma informed care Work stream with community safety
1000 front line staff in the council, NHS police and voluntary sector to have training around		New: ACEs working group and

Next steps and governance

OUR FUTURE

- Do work plans need to be adapted to ensure delivery of the APHR recommendations?

- Establishment of Health and Wellbeing Board task and finish group which will have an assurance role for the delivery of the recommendations.

For general release

REPORT TO:	**Health and Social Care Sub-Committee** **26 March 2019**
SUBJECT:	**Healthwatch Croydon Update** **Dementia Carers Experiences of using Croydon's health and social care services**
LEAD OFFICER:	**Gordon Kay. Healthwatch Croydon Co-optee**
CABINET MEMBER:	**N/A**
PERSON LEADING AT SCRUTINY COMMITTEE MEETING:	**Gordon Kay. Healthwatch Croydon Co-optee**

ORIGIN OF ITEM:	**This item forms part of the Health and Social Care Sub Committee Work Programme 2018/19**
BRIEF FOR THE COMMITTEE:	**To receive and examine the information provided by Healthwatch Croydon.**

1. EXECUTIVE SUMMARY

1.1 Healthwatch Croydon, as a co-opted committee member, submits regular updates to the Health & Social Care Sub Committee.

1.2 The latest report from Healthwatch Croydon on the experiences of Dementia Carers in Croydon in using local health and social care services is attached as Appendix 1 to this report.

Appendices

Appendix 1: Healthwatch Croydon Report: Dementia Carers Experiences of using Croydon's health and social care services

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CONTACT OFFICER: Gordon Kay, Healthwatch Croydon Manager

BACKGROUND DOCUMENTS: None

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healthwatch Croydon

Dementia carers experiences of using Croydon's health and social care services

February 2019

Findings in brief

GPs
are crucial to carer experience

There is a need for **right support** at the **right time**

Clear pathways
for support are very important

Experience of NHS quite positive but **inconsistency** between providers

Social care
advice seems to focus on finances first before care options

Need for a clearer **consistent approach** across services

Recommendations in brief

Ensure GPs are well trained and compliant with latest national guidelines

Present clear pathway information for support and consistent signposting

Each NHS service to review and look at best practice for dementia patients and carers

Look at customer journey as a whole with an integrated approach

Review social service information and support to focus on care options before considering finances

Continued dementia carer experience monitoring through One Croydon Alliance

Executive Summary

Dementia is a key issue for Croydon with over 3,611 people aged 65+ said to be living with this condition in the borough and 2,339 registered as having confirmed diagnoses by Croydon GPs in 2017/18. There is the expectation of an increase in people diagnosed in the years to come, due to an increasingly ageing population. This research was interested in collecting the experiences of carers for those with dementia, from diagnosis to information and support as well as the impact of becoming a carer. We received comments from 70 of those caring for people with dementia in Croydon who are actively using services having received these responses.

These are our findings:

- **GPs are crucial to the experience:** GPs have a critical role in being a gateway to services, so confidence in them diagnosing early and referring patients and carers effectively needs be good. Nearly 1 in 6 did not feel they had had this experience in Croydon.
- **There is confusion about pathways for support:** Having an understanding of a clear pathway for support is significant in helping patients and carers cope with their situation. Many patients in Croydon were confused about how they accessed the right sources of information and support.
- **Right support at the right time:** Appropriate support at the right time makes a difference to carers and patients experience. A third of those surveyed felt they did not get what they needed, when they needed it.
- **NHS service experience is mostly positive, but good practice needs to be shared:** A more consistent service experience would be beneficial.
- **Social care advice and support seems to focus on finances first before care options:** Carers felt there was lack of useful information or help with too much emphasis on financial aspects of providing care and process issues, instead of focusing on the caring and support needs that carers and patients wanted.

These are our recommendations linked to provider and commissioner:

Based on our findings we make the following recommendations for the Croydon Dementia Action Alliance (CDAA), Croydon Clinical Commissioning Group (CCG), GP Collaborative (GPC), Croydon Health Services (CHS), South London and Maudsley NHS Foundation Trust (SLAM), Croydon Council Social Services (CCSS) and voluntary organisations such as Age UK and Alzheimer's Society.

- **Ensure all GPs are fully compliant with national guidelines in diagnosis and response times for referrals. (For CCG,GPC)**
- **Ensure suitable and easy to access signposting for support is available from GP and community level. (For CCG, GPC, CHS)**
- **Present the appropriate pathways of support and information in clear way which can be easily understood by the carer, perhaps as a leaflet and online material. (For All)**
- **Each NHS service should review their service delivery where patients with dementia are involved to ensure they meet patient and carer needs at each stage in the customer journey, with an emphasis on working together to deliver a seamless service between providers. (For CHS, SLAM, CCG)**
- **Review social service information and support to focus on care options before considering finances. (For CCG and CCSS with the involvement of the CDAA)**
- **Continued monitoring of patient and carer experience by all service providers to see how service experience has changed in previous 12 months. (CHS, GPs, CDAA and Healthwatch Croydon).**
- **Apply the power of the One Croydon Alliance: One Croydon has the opportunity to bring key parties together to find solutions. The needs of dementia patients and their carers should be high on their agenda to make a more integrated service.**

1 Background

1.1 Context

About Healthwatch Croydon

Healthwatch Croydon works to get the best out of local health and social care services responding to your voice. From improving services today to helping shape better ones for tomorrow, we listen to your views and experiences and then influence decision-making. We have several legal functions, under the 2012 Health and Social Care Act.

National level -Dementia

Dementia has been a key priority for some years. In February 2015, the government published a Challenge for Dementia 2020 vision[1]. Some of the key aspirations of this vision were equal access to diagnosis for everyone; GPs playing a lead role in ensuring coordination and continuity of care for people with dementia; every person diagnosed with dementia having meaningful care following their diagnosis; and all NHS staff having received training on dementia appropriate to their role.

Since then, NHS England has focused on developing an appropriate access and waiting time for dementia so people with potential symptoms have equal access to diagnosis as for other conditions; setting the national average for an initial assessment at six weeks; achieving and maintaining the dementia diagnosis rate. NHS England agreed a national ambition for diagnosis rates that two thirds of the estimated number of people with dementia in England should have a diagnosis with appropriate post-diagnostic support. They agreed that the dementia diagnosis rate will be included in the CCG Assessment Framework. In terms of post-diagnostic care and support, NHS England proposed financial incentives to improve this,

[1] https://www.england.nhs.uk/mental-health/dementia/

including a care plan on discharge from secondary care services and increased health and wellbeing support offered to carers.

In addition, there is the development and publication of a 5-year transformation implementation plan called the 'Well Pathway for Dementia' which covers preventing well, living well, supporting well and dying well.

Dementia has had a significant mention in the recently-published *Long Term NHS Plan* (2019, p.17-18)[2]:

> "One in six people over the age of 80 has dementia and 70% of people in care homes have dementia or severe memory problems. There will be over one million people with dementia in the UK by 2025, and there are over 40,000 people in the UK under 65 living with dementia today. Over the past decade the NHS has successfully doubled the dementia diagnosis rate and halved the prescription of antipsychotic drugs. We have continued to improve public awareness and professional understanding. Research investment is set to double between 2015 and 2020, with £300m of government support.
>
> We will provide better support for people with dementia through a more active focus on supporting people in the community through our enhanced community multidisciplinary teams and the application of the NHS Comprehensive Model of Personal Care. We will continue working closely with the voluntary sector, including supporting the Alzheimer's Society to extend its Dementia Connect programme which offers a range of advice and support for people following a dementia diagnosis"

In terms of national advice to GPs, *Dementia diagnosis and management- A brief pragmatic resource for general practitioners* (2015) [3], states a crucial role for carers: "Carers are the most valuable resource in dementia care and we should have a high level of awareness of their needs. Carers may be referred for a carers

[2] https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf

[3] https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf

assessment and benefit check. Carers' groups provide support and information." (p7).

NICE guidelines, *Dementia - assessment, management and support - Involving people living with dementia in decisions about care* (2018) [4] states that:

"Provide good quality, timely information for the person living with dementia can help increase their involvement in key decisions and help them to have a share in the decision-making process… We must ensure that these regulations are used to work for the person living with dementia, not against them. This will often require working closely with other agencies in partnership to ensure the person living with dementia, their families and carers receive high quality support." (p.125).

National level - Carers

At a more general level for carers The Care Act 2014 which came into force in April 2015, aims to put disabled people and carers in control of their care and support. It gave local authorities such as Croydon Council a new general responsibility to promote a person's wellbeing when providing support. This includes doing an assessment, creating a care plan and providing practical support. Local authorities must ensure people in their area have accurate information and advice to make an informed decision about care and support. New national eligibility criteria for providing support have been introduced for all local authorities in England. Carers and people who need support have separate eligibility criteria. Carers have the same right to an assessment as disabled people. This means they no longer have to provide a 'regular' or 'substantial' amount' of care to get a Carers Assessment. [5]

[4] https://www.nice.org.uk/guidance/ng97/documents/full-guideline-updated

[5] https://www.carersinfo.org.uk/useful-information/faqs

Local level:

Dementia is a key issue for Croydon with over 3,611 people aged 65+ said to be living with dementia[6]in Croydon and 2,339 having been diagnosed by Croydon GPs in 2017/18.[7]

This health issue led the formation of the Croydon Dementia Action Alliance (CDAA) in March 2017 which is a partnership working to raise awareness about dementia and helping to make Croydon a dementia friendly borough that is inclusive for people living with the condition. Members include voluntary organisations such as Age UK and the Alzheimer's Society, Croydon Mencap, Croydon Voluntary Action, as well as health service providers such as Croydon Health Services, Home Instead and Right at Home domiciliary care services, and One Croydon Alliance. Other active members include the fire brigade and police.

In 2017, the Carers Information Service in Croydon published research *Not Just a Patient*[8] on their carers detailing what they need from their GP stating:

> "Overall, carers are broadly positive about the healthcare they receive from their GP, but would like to be informed of carer support available to them. We therefore recommend that all surgeries in Croydon ensure that registered and identified carers are provided with information about the Carers Support Centre, and that carers are referred directly if in need of support."

In October 2018, the CDAA achieved the highest accolade from the Alzheimer's Society for their work across the whole borough.[9]

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[6] Statistics from Projecting Older People Population Information System (POPPI) http://www.poppi.org.uk/

[7] Statistics from Quality and Outcomes Framework of NHS England: https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18

[8] https://www.carersinfo.org.uk/assets/content/CIS-Not-Just-a-Patient-Report-Full-2017.pdf

[9] https://wp.croydon.gov.uk/newsroom/croydon-praised-for-efforts-to-make-the-town-dementia-friendly/

Healthwatch Croydon have worked with them to scope and define this research.

The South London Sustainability and Transformation Plan (2017) made reference to speeding up diagnosis and treatment for people with Dementia (p76) and the application of the blue band scheme in hospitals which was seen as an excellent tool to help staff be more aware of patients' mental health and take more time when explaining a procedure (p171). [10] More detail is expected to be published the new South West London Health and Care Plan due to be published later this year.

Croydon's Carers Strategy (2017) published in 2017[11] focused on improving support and information available having spoken to a range of carers including 29% who cared for people with dementia. Priorities in the Action Plan (p.39), included: review the provision of respite services in the borough and respond to the changing need of carers; increase the promotion of current services to ensure more carers benefit from them; improve integration of services between health and social care; ensure adult social care provide information packs for carers to include carers information which should be both online and in paper format; Increase awareness of carers in health and social care to ensure carers are identified earlier and involved in discussions, including young carers.

1.2 Rationale and Methodology

Our rationale for undertaking this research was to understand more about the issues around accessing health and social care services for people with dementia in Croydon, finding out what they think about existing services explore where there are gaps and know what is working well, to inform commissioners and providers

Due of these factors, Healthwatch Croydon wanted to look more closely at the pathway and identify areas of unmet need and gaps in services.

[10] https://www.swlondon.nhs.uk/wp-content/uploads/2017/11/STP-discussion-document-final.pdf

[11] https://www.croydon.gov.uk/sites/default/files/articles/downloads/Croydon%27s%20Carers%27%20Strategy%202018-2022.pdf

Having attended meetings of the Croydon Dementia Action Alliance (CDAA), Healthwatch Croydon considered how it could contribute to their work and suggested that a survey be created about carers experiences of the dementia services in Croydon. The members of CDAA agreed with this idea and advised us on the questions.

The Alliance aims to make Croydon more of a dementia-friendly environment for the borough. It is our aim to understand what residents really think about services, what is going well and what could be better, and then feedback to the One Croydon Alliance.

1.3 Method

We took the survey to the elderly wards of Croydon University Hospital and also distributed the survey via the Alzheimer's Society and their carers support groups at Carers Information Centre and at their own cafe events

We circulated the survey on social media and distributed the survey through the Carers Information Centre.

We asked carers and relatives the following:

- **Who did residents turned to with their concerns regarding their relative memory?**
- **Were those concerns taken seriously?**
- **How long before a diagnosis was made?**
- **Did they get the right services at the right time?**
- **Did they get the advice and support they needed?**
- **Who provided the advice and support?**
- **What were their experiences of NHS and Social Services?**
- **What support they would like to see?**

All surveys were filled in on a voluntary basis and some participants did not answer all the questions. We appreciate all the responses we received from carers during what may be a challenging and unsettled time of their life.

We also thank the staff at Croydon University Hospital and the Alzheimer's Society for helping us access carers using their surveys. In total 70 surveys were completed between May and November 2018.

Sources	Number
Croydon University Hospital	18
Smart Survey	14
Survey Monkey	2
Alzheimer's Society	11
Carers Information Service	11
Post- Via Alzheimer's Society	14
	Total - 70

Respondents were encouraged to tell us about the services and are included in the comments throughout this report.

Thank you

Thank you to Caroline Walker at Croydon University Hospital, Selma Hameed and Sue West at Alzheimer's Society and also Helen Thompson at the Carers Information Centre in Croydon along with their colleagues for their help.

We also thank our Healthwatch volunteers who supported the staff team in collating and analysing the data: Scoping - Gillian Khalighi; Outreach - Carole Hembest, Nick Maffia, Ginikachi Mbakwe, Pauny Ekanga and Brian Matthews; Analysis - Megan Nash.

Limits of the research

This is a hard-to-reach group. Carers, because their responsibilities spend most of the time, in the home or bedroom, are not easily found in the community. Most carers we spoke to were engaged in services, and it must be said that there are an unknown number of carers who are unheard and coping without help.

The sample is 70 which has limits in terms of statistical significance, but gives a good insight into the issues that carers of those with dementia are experiencing which can be used to improve services.

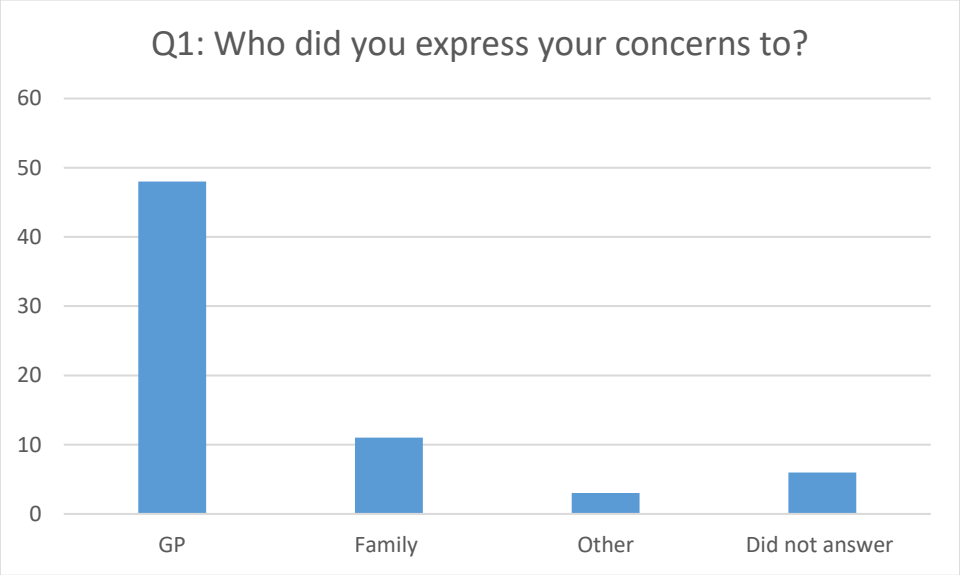
When looking at the NHS, we did not research the different services provided, although experiences of GPs are more defined. More patient and carer experience in specific areas, will add to any further specific future research.

There may well have been confusion by carers on who was responsible for funding and delivering services and this is reflected in some of the responses. For example, Croydon Clinical Commissioning Group commissions the Alzheimer's Society to deliver information and advice services on referral from the GPs, rather than Alzheimer's Society just providing this service independently. Likewise, many carers community services are provided by voluntary organisations like the Carers Support Centre, on contracts from Croydon Council Social Services, who believe that providing that support at that level is more effective than at a central council level. That said, since Croydon Council also provides an information and support service as well only adds to the confusion.

Ultimately, for the service user, it is about the ease, effectiveness and consistency of information that helps define whether they have a positive experience in getting the advice and help they need. This this emphasised in the recommendations.

2 Insight results

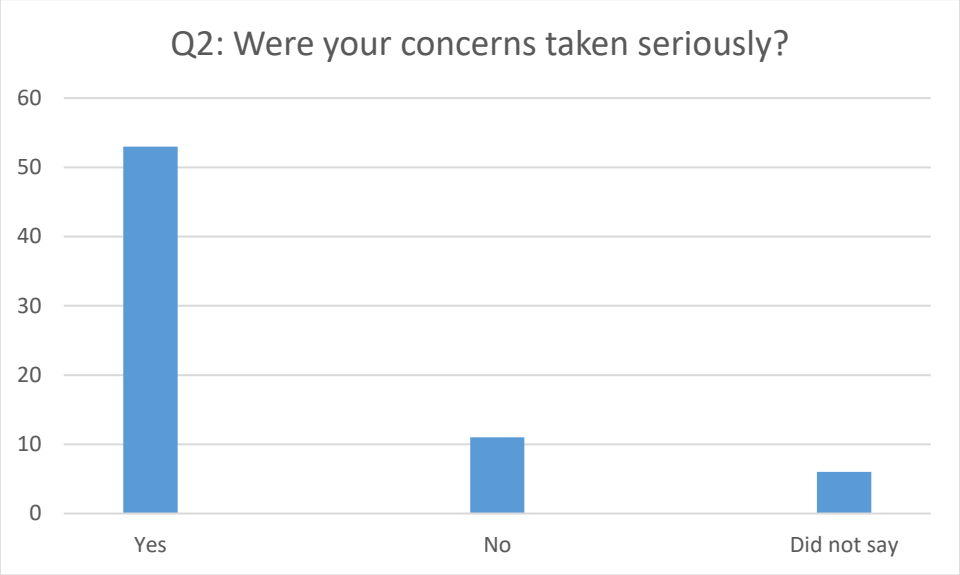
2.1 Who did carers first express their concerns to regarding their relative's memory?



Total=68

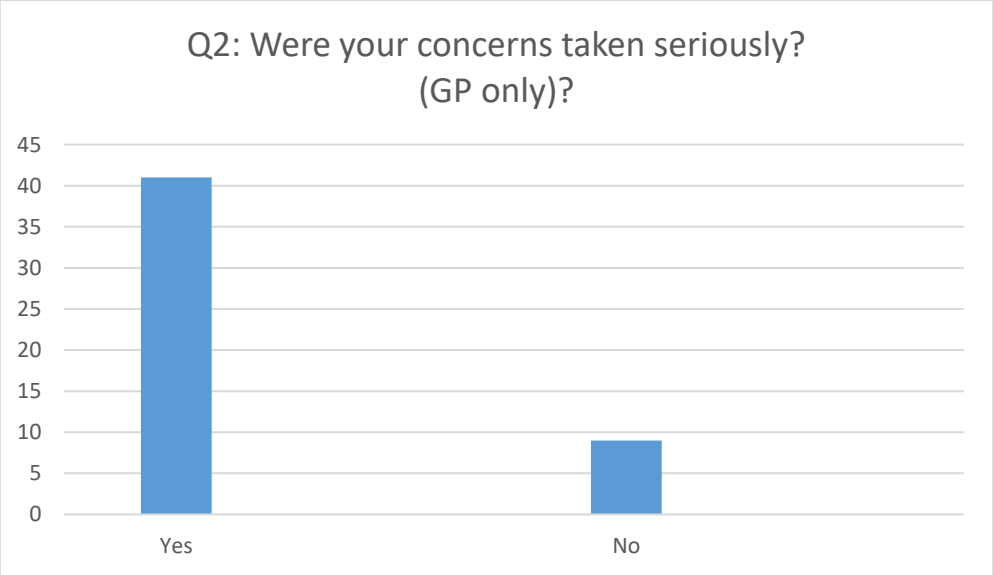
The GP has crucial role that cannot be underestimated, as the gateway to services and referrals, and the first port of call often preceding family and friends that Croydon residents turn to for support. When people had concerns about their memory, the GP was the person that they expressed these concerns to, with 70% people (48) spoke to their GP first, and 16% (11) talking to their family.

2.2 Were their concerns taken seriously?



Total=70

At the first stage of diagnosis, having your concerns taken seriously is a key part in having confidence in the health and social care system to meet your needs. Of those asked 76% felt that their concerns were taken seriously, but 16% felt they were not.



Total=50

When we focused on those 50 who consulted their GP, 82% (41) felt that the GP took their concerns seriously but 18% (9) did not. While this number is positive, over one in six still feel their concerns were not considered, so a more consistent approach is needed across GP providers.

Carers said:

"Referred to memory clinic straight away."

"Asked lots of questions, getting to know my husband. Then did a memory test. Very good. After that went for a scan at (the) Maudsley hospital."

"Immediately taken seriously."

"(The GP) Listened and dismissed me - (I) felt unsupported."

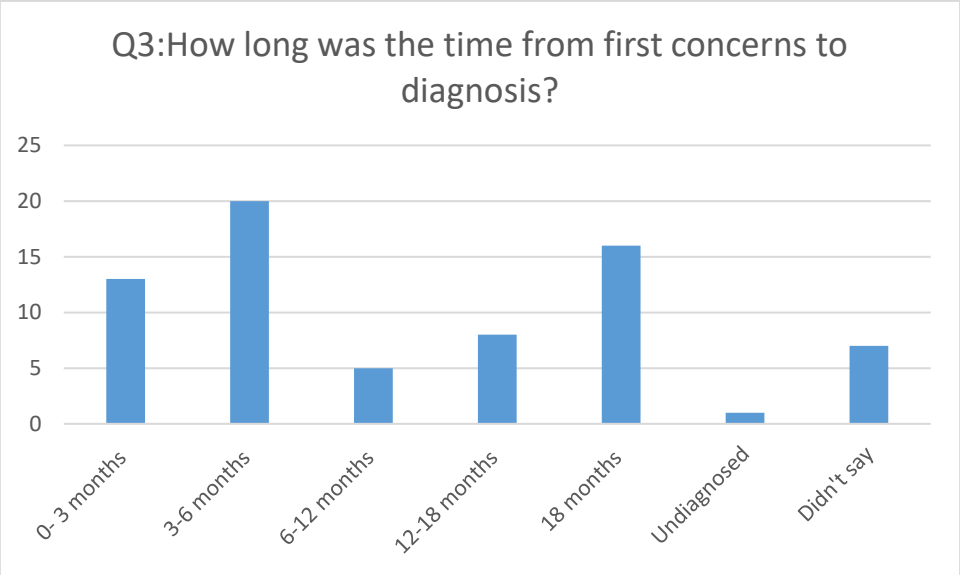
"It took a long time to get referred to the memory clinic."

"Eventually, took a while but after resistance they referred us to the memory clinic."

"(I) wonder if GP is truly aware of signs and indicators."

"Doctor did test twice but said all OK."

2.3 How long was the time from first concerns to diagnosis?



Total=70

Response times from first concern registered with health professional to diagnosis is a key part in ensuring that services can be provided effectively. Early intervention means better preparation and a more effective care plan can be put in place. This, in turn, reduces the initial concern felt by family and carers.

Where diagnosis was made it was promptly, mostly between 3-6 months, with 48% (33) gaining diagnosis at this time. However, numbers rise again from 12-18 and 18 and above with 34% (23) waiting a year of over. This may be due to them not approaching the right pathway or delays in GP referrals/diagnosis. This is something that needs further exploration.

Carers said:

"The GP asked lots of questions, getting to know my husband and then did a memory test."

She wasn't herself…got worse…took about 1 year, care for relative 9-5 paid for by me."

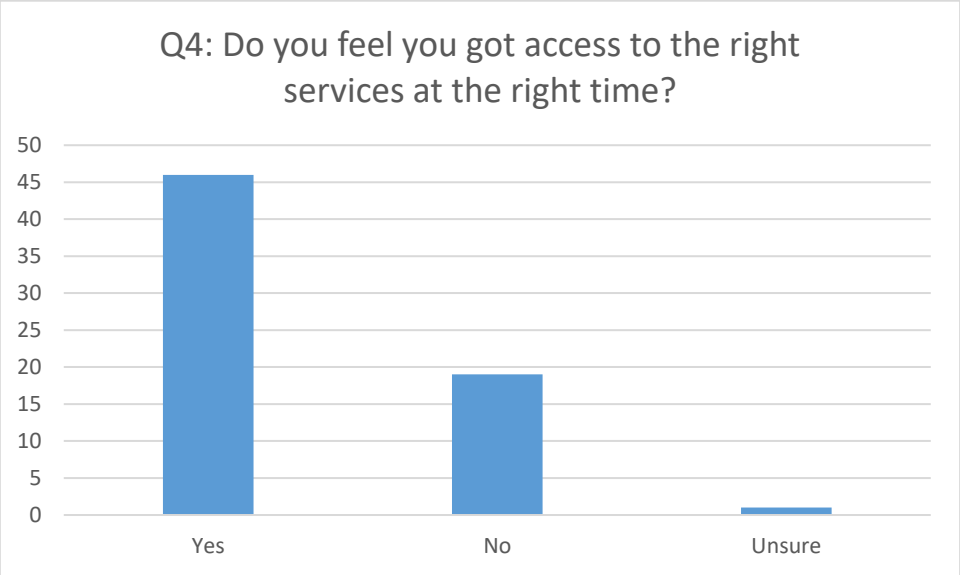
Some were not yet diagnosed, one was admitted to hospital in a serious condition before a diagnosis was made, advised by Alzheimer's Society that CUH did the diagnosis, not knowing before then, and felt they had not been given the right information.

> "Been waiting 18 months for diagnosis, in and out of hospital, not getting the right care."
>
> .'

One carer felt a misdiagnosis of dementia had been made.

> "I don't think he had dementia, but he has been diagnosed with dementia."
>
> .'

2.4 Do carers feel they got access to the right services at the right time?



Total=66

Ensuring that carers get access to the right services at the right time, reduced their anxiety about the situation. 70% (46) did feel they got the service their need but 31% (20) did not or were unsure.

It is understandable that there would be a number who did not get access at the right time, as this can vary from a person's specific circumstances to waiting time to gain access.

One carer said:

"(We) didn't know what to ask for, a lack of buy-in from the patient and not knowing what's available."

.'

Some carers requested more practical support services:

"I could have done with support, respite for me, I joined the carers community, advice there if I need it."

"Let them know what is available and for who."

"I want all my options."

"Carers need a lot of support, also help with who they are caring for. Waiting all the time."

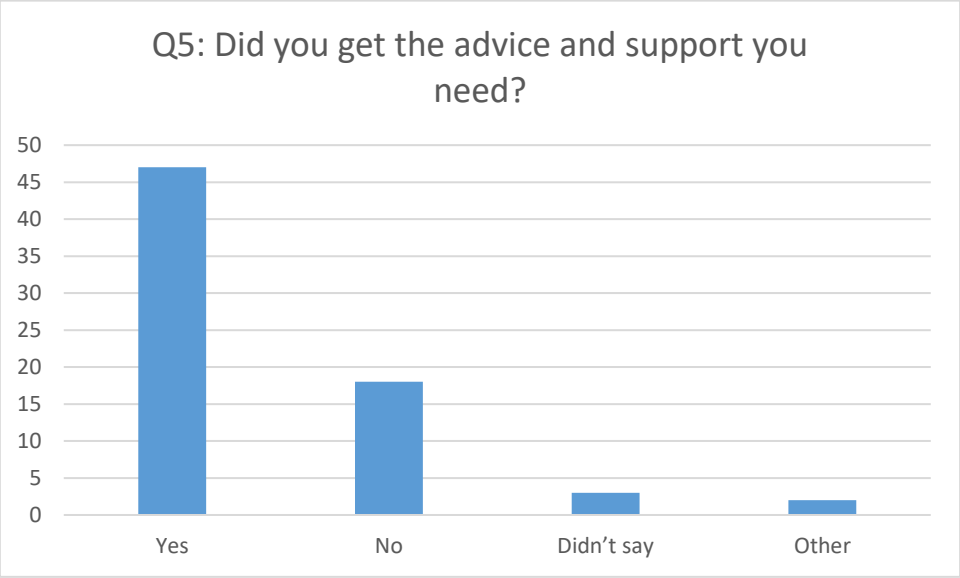
"Not just paper handouts."

"Support for carers."

Regarding the choice of residential care homes, we were told:

"CQC (reports are) not good, the ones we are offered are not the ones that we want'

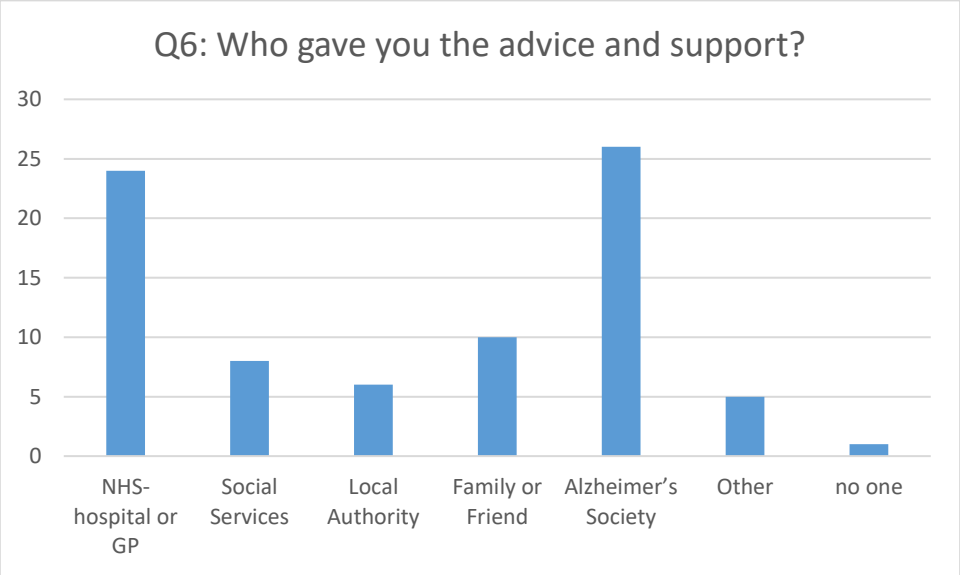
2.5 Did carers get the advice and support they needed?



Total=70

Getting relevant advice and support is important to ensure that patients and carers can make the right decisions and create care packages that work for all. Of those surveyed, 67% (47) felt that they did get the advice and support that they needed, with 26% (18) not receiving enough. Of 'other' responses, one reported that they sometimes had the right advice and support, and one felt the GP was the only source of advice and support.

2.6 Who gave carers the advice and support they needed?

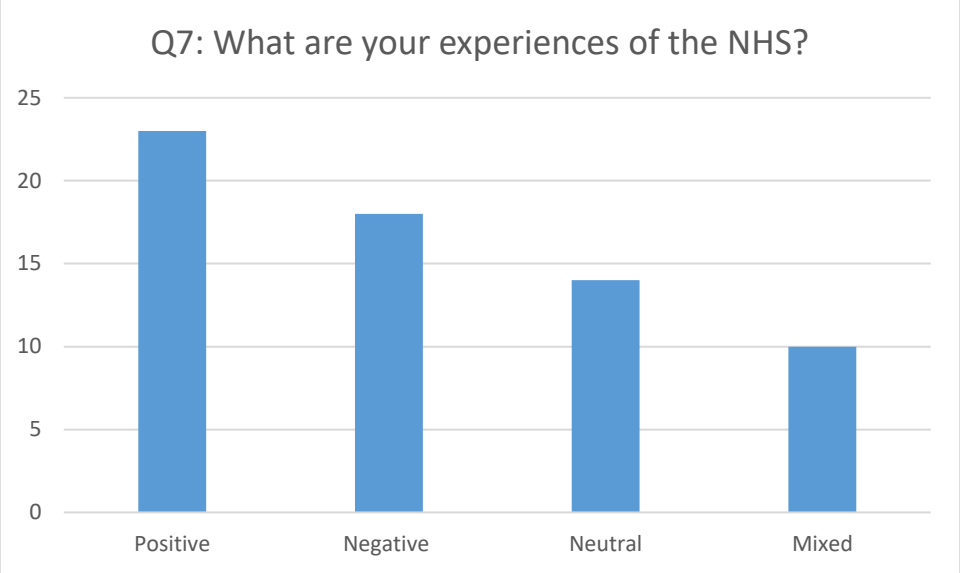


Total=80

When it came to providers of information, the NHS scored highly with 30% (24), although since 42% or 30 of those surveyed had been taken at Croydon University Hospital may contribute to this figure. That said, this reflects the quality. The Alzheimer's Society was highly regarded as providers of advice and information, even topping the NHS with 30% (24). Croydon Council advice services and Croydon Council Social services scored very low, whose duty it is to provide information, scored 10% (8) and 7% (6) respectively.

However, the Alzheimer's Society is commissioned by the CCG to provide information on dementia and provide a chance to talk to a Dementia Adviser at the Alzheimer's Society. Additionally, anyone with a diagnosis of dementia can be referred including self-referrals / GPs. This may reflect the high uptake of advice and support from Alzheimer's Society.

2.7 What were the carers' experiences of using the NHS?



Total= 64

Carers experiences of the NHS rated highest with 35% (23), but 28% (18) had a negative experience, 22% (14) was neutral and 15% (10) had a mixed experience. This question was very general of the whole NHS reflecting GP, hospital and community services, and so may reflect different services at different times, see the detail reflected below.

Carers said generally:

"Very mixed, depends on who you get at the time, across the board."

"The NHS services a have been mixed. Some have been first call an at other times I feel they failed my Mum's best interests."

"Overworked, long days- depends who you get."

Views of those carers using hospital services:

"CUH – brilliant."

"Very good."

"Neurologist diagnosed my sister while looking for something else."

"Well supported."

"They work well and are helpful with my husband's issues."

"Some nurses not supportive or well trained, not understanding. Not treating underlying existing conditions. Relative had a brain scan but they are denying their condition."

"Well supported. Were going to get discharged (on Queens) but I noticed medical issue, they questioned me (I've been caring for 2 years) but A&E listened and were brilliant."

Carers experiences about consistent support:

"Slow, 7-8 months to get assessed, at memory service, from where mother was discharged when medication was seen to be ineffective and stopped, no continuity, no course on practicalities on how to deal with dementia suffer (from how to get her out of bath to faecal contamination)."

" For dementia, so so, remember we are a medical family and pushed hard for my father's care. One later hospital assessment week, in patient on phyc (psychiatric) ward was awful. My father, 78, had become too violent for my blind mother 68, to manage him alone over nights. He was in the wrong place for a week's assessment even more violent in unfamiliar surroundings and hospitals stays were unknown to him. We were forced to agree to a quick medical quash. It took four weeks at home to get the Meds (medications) right for him. With SS (social security) fees for social care on the first PIP (personal independence payments) paid for social care, we <I alone> could then manage him at home.

"The GP was very concerned and helpful and also the Alzheimer's dr (doctor) was very helpful. System is slack, M had a blood test - getting result was difficult, results suggested a new test, frustrating, I am in another country! Medication (caused her to be) zombied, lost so much weight, not eating, within a week of removal (of meds) back to normal. Brigstock medical, no call back, frustrating. called 111 as protein in urine, Mum couldn't walk - all linked to blood test."

"The doctor has been of help going on home visits. She has been under the MH team."

"Very good, GP. Respectful, well looked after."

"Been asking 18 months for diagnosis. Get referrals but no proper treatment. In and out of hospital not getting right care."

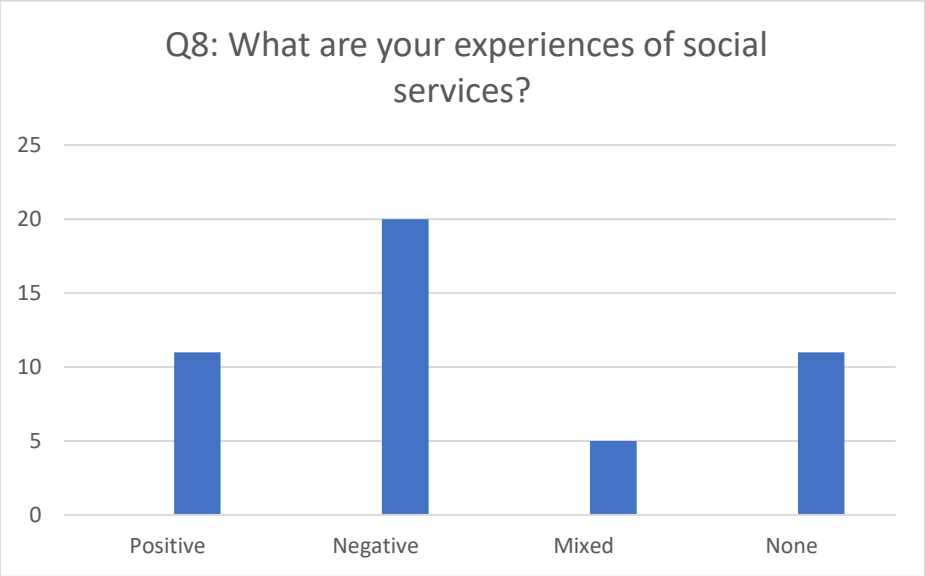
"NHS services not brilliant, GP not proactive at all regarding Alzheimer's, Heavers (Alzheimer's Society centre) however was very good."

"Change GP, then got the right support eventually, I am named carer, should get a priority appointment, GP not aware of this. I'm having to tell them - I don't want to have to be keep repeating myself about the same stuff."

"The Heaver Centre prescribed donepezil for dad and I have a letter they sent him saying a joint care plan was in place with the GP, but there was never evidence of this."

"GP slowing at taking my husband seriously. When my husband was saying to me he felt he had a problem with his memory for years."

2.8 What was the carers' experiences of using social services?



Total=47

For carers, it is essential that they have an effective service which integrates the NHS services with council-run social services. For the carer and patient, the shift between one service provider and another should be smooth, to reduce unnecessary concern

Of those who did respond just 23% (11) had a positive experience and this was outweighed by the 42% (20), who had a negative experience. What is of interest is that 23% (11) had no contact with social services, suggesting either they were at an early stage of caring and did not need to call on social services, or did not want to disclose their involvement. A further 23 of those surveyed did not record a response, which suggests no involvement at all.

Carers experiences of services, process and approach:

Some had a positive experience, even expecting that is was going to take a little time, others felt it took a long time to access information or support. There may be a link to understanding the process and then managing expectations of what could be done and when.

"I had to contact the local Social Services, very good, when I phone up they are excellent, but it does depend who you get, I had a social worker before who was not good."

Social worker- difficult to say. Met once, first impression 'efficient'."

"Social services have been very good according to my sister who deals with her wellbeing as lives nearer."

"Slow but acceptable, have had carers assessment and assessment for diagnosed person brokerage have been very good to secure care staff."

"Social services been ok. Reasonably responsive. Feel they have a big caseload, no continuity."

"Social Worker was good but hard to get hold of. Leaving messages. Frustrating though when you need help."

"Effective referral to day centre for my husband with dementia initially was able to book restbit (respite) and get it confirmed months in advance, that was not possible last year which was disappointing."

"Trying to get my husband into a home, have been on a ward for two months."

"Incredibly difficult to contact relevant department, very frustrating for carers."

"Social Services are diabolical. Waiting three weeks so far for an assessment. We were told 7 days."

"We have had a diagnosis for several years, had our first social services appointment next week."

"Very difficult to contact, very slow to deal with anything, administration extremely poor, not at all what one needs as a carer for someone with Alzheimer's adds to the already considerable stress – very disappointing."

"Not helpful once the social worker found out that we were self paying we were turned down for CNC because I was looking after him too well."

"They became involved later on but were not helpful."

Carers experiences of funding challenges:

The national funding policy is, of course, a constraint beyond that of Croydon Social Services, but it is this service that bears the frustration of those seeking financial support. Again, more clarity on the care process, ways and limits of accessing funding would help manage expectations.

"Relying on family, social services have offered us a day centre, 1 day a week, nothing else, £60 a day, a whole week's money, Access memory clinic October 2014, diagnosis 2015, Social Services 1st appointment last Monday. Social services: 1st visit mention of money, she did say she hated doing it."

"Selling house how much money we have. Social services need to be interested in mum's welfare not costs so we haven't bothered."

"Non-existent. We are self funding as we are not eligible due to mothers savings."

"Awful. No support/ feel alone. Pressure to cope with relative. What's easier for them. Sell the house. Pressure."

"Paying for out own care. Very expensive (£)100,000."

"Huge social services appeals and tribunal etc. PIP for social care on top of all other fees, enabled me to give up my career teaching and retrained as care home manager/social worker L5, around my father and blind mother, and friends when visiting."

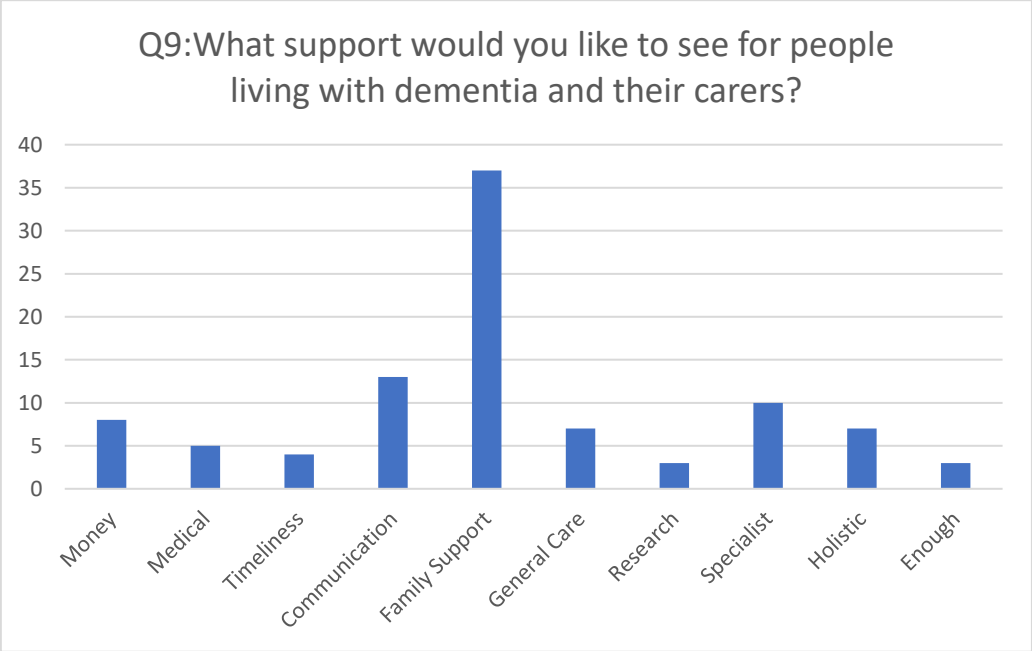
Carers detailed experiences:

These are two full recorded experiences of managing through the system.

"Absolutely useless. When a social worker was first assigned to my mum she made loads of comments that she can do this and that for my mum, didn't hear anything for a month, called and chased her, finally got her and had the same again, another month passed then received a call from her saying she was no longer the case worker, and that was the last we heard from them for over 2 years."

"Because of his age, they said they wouldn't consider providing the 6-week care package because the expense might serve no purpose as he could die within days/weeks. I had to be firm with them, refusing to take him home when he came to be discharged. Unfortunately, he fell, fractured his hip. Four weeks later and was operated upon at CUH. On discharge, social services declined to consider resuming the 6-week package and we have been paying for his care ourselves since. I am pleased to report that a year later he's still very much alive and in his own home."

2.8 What support would you like to see for people living with dementia and their carers?



Total=97

The graph above shows what Carers would like to see based on an analysis of their responses. We found the following themes

Money

"I am paying for care myself at £600 a week."

"Paying for everything."

"Government to contribute in the same way as they do for NHS."

"Carers allowance is a pittance, caring is a full time job, £62.70 for 35 hours

"I would like to appoint a care worker for a few hours a day but I can't afford to pay, I understand I have to go online and fill a lengthy form and wait for assessment."

Medical responses were anywhere medicines and diagnosis were mentioned, such as:

"Training for GPs and receptionist, I don't want to hear excuses."

"Care package, medications."

"Regular check ups."

Timeliness refers to the speed of assessments and access to services:

"I have been doing the night shift for five years."

"Make it simpler when applying for help and respite care."

Communication related to provision of general information, knowing where to go and who to speak to:

> "Want all my options."
>
> "I need to know how to employ a (paid) carer' 'let them know what is available and for whom. It is sometimes a very difficult existence."

Family support included emotional and respite care for families and carers of people living with Dementia. This reflected 38% of the total responses.

> ''Look at the whole family approach it is a full-time job to care."
>
> "more time for the Carer to go to the various events available by means of providing alternative care for the patients.' 'more stress relieving sessions, singing, dancing, yoga, lunch clubs."

General care was in response to activities of daily living such as help with general care needs of the person who was being cared for:

'

> "Someone to provide stimulation, Dementia walks."

Research into Dementia:

"'advice on research, plus any type of information on possible cures (doubtful)."

Specialist was where a social worker or specialist was requested such as access to a Specialist at every stage, as well as specific groups for younger people living with Dementia and Men's groups:

"a visit now and then from somebody qualified in this area.'

Holistic was interpreted as treating the whole person, not the condition, and services working together to treat the whole person:

"The whole family approach."

"Support in the form of specific advice about the person living with dementia and their carer."

"More support than being treated as a number."

"Working together, SS (Social Services), Alzheimer's, forward planning and advice, what type of homes are available and recognise it is the condition, not the person."

"I want carers to be listened to and not feel like they are wasting time."

Three respondents felt that they had enough support:

‘(want to be left alone to) get on with it’,

‘All the support they required since finding the Carers Information Centre’,

‘We have all the support we need, thank you’

2.9 Further comments from questions 7 to 9 about experiences of services and what they would like to see.

Support

There seemed to be a difference in comments between those who knew there was support and used it, and those would like to use it if they could get their caring duties covered so they could attend support groups. A further group did not seem to have awareness or access to the kind of support services they needed to meet their specific circumstances. This may need a consideration of how support services are delivered and prioritised across a network of providers.

"There is plenty of good support already, just visit the carers centre."

"I would like to appoint a carer or carers at least a few hours a day but I cant afford to pay I understand I have to go online and fill a lengthy form and wait for assessment it maybe takes a long time "

"Need more support some days I am on my own carers café good, family are busy/ far. Work and family. Need groups."

"Support needs to be met for the carers, and support for the individual. Medical check ups need to be more regular."

"I could have done with support for me, respite. Fortunately friends helped."

" (I) want all my options, GP to take me seriously, CUH to diagnose us, going to be discharged without tests. Getting worse not better.

"More practical courses (not just handouts / fact sheets) at locations and times of day that don't clash with school run. More stress relieving sessions (singing/ dancing /yoga/ etc) my lunch clubs. More carers allowance as caring is usually a full time job, £62.70 for 35h is a pittance."

"More home visits from specialists to support the carer, support in the form of specific advice about the person with dementia and emotional support for the carer."

"Time to take more time for carer to go to the various events available by means of providing alternative care for the patient."

"I would like to appoint a carer or carers at least a few hours a day but I can't afford to pay I understand I have to go online and fill a lengthy form and wait for assessment it maybe takes a long time."

"Power of attorney…Age UK provided information on a donation basis, why isn't this information publicly/easily available?"

Service provision

Continuity and closer relationship between providers and clients are considered important to maintain. There is also a sense that some services are doing a good job such as the memory service but they need to be better financed. Conversely care homes need to be more affordable for carers and families.

"Names (named) SW (social worker) continuity throughout someone provide stimulation, befriending type, social interaction go out walking."

"The memory service could have supported us better and been more flexible about visiting us at home, despite knowing how difficult I found it to get to their premises."

"Closer relationship to GP, same GP 47 years, relationship, confidence/trust/contact not just a number."

"I would like carers to be listened to and not feel like they are wasting time."

"More day centres and more places like forget me not café, cheaper care homes."

"Make it simpler when applying for help and respite care."

"There is nothing my husband can attend for his age group. Day centres seem to be for people in their late seventies/eighties. The government have got to look at people getting early onset Alzheimer's .They never mention the ones in there sixties or younger .They need to wake up .And get there heads out of the sand."

Process

"Nightmare time getting the 25 per cent discount on the council tax. Too many forms to fill in one for the attendance allowance one for the carers allowance, which you can't apply for until you know about the attendance allowance. Council tax rebate was ridiculous had to get a certificate from the GP. The fact that we were already claiming the attendance allowance wasn't relevant. Took months before Croydon Council finally agreed to give the discount. More needs to be done offering a basic respite care system for the carer. Just being able to phone a number and ask for someone to come and sit with the person for 2-3 hours would help. Friends and neighbours make promises they will help the reality is most carers are on their own. Or a neighbour will do it once realise what is involved and then never offer to help again. Not pleasant for the carer who is left feeling embarrassed.

"Advice on research plus any type of info on possible cures (doubtful) much more accessible information and help for carers also more respite needed."

"A one stop shop at the point of diagnoses where all necessary info and directions of how to access help is available."

"To get help and advice at an early stage and put in contact with the right bodies that can offer help."

"Power of attorney this info isn't out there, it needs to be out their early."

Respite

Respite care is important to give carers a break and also time to gain more information and support. If it not available for moderate care, this should be considered. If it is available then it needs to be promoted better.

"Respite opportunities, more readily available when the condition is maybe only moderate."

"More centres to attend to give carers respite. Have had good care by private. Very draining."

"More day care and respite. I am stuck at home every day except Friday when my husband goes to day care for which I have to pay £40. Cannot go to see friends or support groups as he will wander or do something dangerous in the house."

Integration

It clear that a more integrated service between providers would make a real difference, particularly in the switch between NHS and social care.

"More joined-up services, more clear sign posting, easier access and information, more empathy and clarity."

"I'd like unified approach NHS. Social services falls down there."

"Training for GP and receptionists, I don't want to hear excuses, my one priority is continuity of care for my husband, if you can't help me tell me, be dealt with on a case by case basis, why should we be put in a box. Care home issue needs addressing, none run by council, all private/ money making."

Quality

There is a concern that some nursing and care homes do not meet the quality expected.

> “Having seen how residents in nursing homes needing assistance are ignored, I am determined never to let my husband be left in similar straits. Apparently carers (care workers) in nursing homes are assigned certain residents for whom to provide care. If a resident outside that group needs a cup of tea, or assistance to the toilet the carer going past the individual declines to assist. It would appear nursing homes, despite charging extortionate fees are invariably short-staffed. Individual carers are often responsible for 10 or more residents, irrespective of their mobility / feeding problems. That is no good for the carer, or the resident whose family need assurance that their loved one is being cared for well and is happy. After all they are paying for the individual to be stimulated and cared for."

3 Findings & Recommendations

3.1 Findings

Based on what we have heard these are our findings:

GPs are crucial to the experience: GPs have a critical role in being a gateway to services, so confidence in them diagnosing early and referring patients and carers effectively needs be good. Nearly 1 in 6 did not feel they had had this experience in Croydon.

There is confusion about pathways for support: Having an understanding of a clear pathway for support is significant in helping patients and carers cope with their situation. Many patients in Croydon were confused about how they accessed the right sources of information and support.

Right support at the right time: Getting the appropriate support at the right time is also crucial to the experience that carers and patients experience. A third of those surveyed in Croydon felt they did not get what they needed, when they needed it.

NHS service experience is mostly positive, but good practice needs to be shared: The experience of using NHS services was mostly positive, but there can be a variety of experiences of different parts of the service from GPs to hospital care. Sharing best practice on how to support carers of those with dementia, would help bring a more consistent service experience for carers and cared for.

Social care advice and support seems to focus on finances first before care options: While some found social services supported them, many service users stated that there was a lack of useful information or help. There seemed to be too much emphasis on financial aspects of providing care and process issues, instead of focusing on the caring and support needs that carers and patient need. While we understand the significant issues in both personal finance and resources, much of this is linked to the need for effective information and communication.

3.2 Recommendations

These are our recommendations linked to provider and commissioner:

Based on our findings we make the following recommendations for the Croydon Dementia Action Alliance (CDAA), Croydon Clinical Commissioning Group (CCG), GP Collaborative (GPC), Croydon Health Services (CHS), South London and Maudsley NHS Foundation Trust (SLAM), Croydon Council Social Services (CCSS) and voluntary organisations such as Age UK and Alzheimer's Society.

Ensure all GPs are fully compliant with national guidelines in diagnosis and response times for referrals. (For CCG,GPC): Since GPs are the gateway to services it is important that they all are providing the same quality of service irrespective of provider. Surgeries providing best practice could share their knowledge and experience across the network to ensure consistency.

Ensure suitable and easy to access signposting for support is available from GP and community level. (For CCG, GPC, CHS): One of the challenges for carers is in finding suitable and easy to access signposting from the GP. Croydon has both the Carer Information Service and specialist support from Alzheimer's Society and Age UK, it just needs to link together for clearly when GPs refer patients for diagnosis and support services and be there for all access points on their journey.

Present the appropriate pathways of support and information in clear way which can be easily understood by carers, perhaps as a leaflet and online material. (For All): For carers, clarity on the journey they must take would help their experiences significantly. While it is a complex process of different providers and options, a simple and easy to understand guide to the journey, available across all providers would help manage expectations and support effective decision-making.

Each NHS service to review their service delivery where patients with dementia are involved to ensure they meet patient and carer needs at each stage in the customer journey (For CHS, SLAM, CCG): Patients with dementia and their carers, need the NHS to provide a service that meets their specific needs. Becoming

Dementia Friends as well as training staff and reviewing processes will help ensure their needs are met.

Review social service information and support to focus on care options before considering finances and explore further service experience by carers. (For CCG and CCSS with the involvement of the CDAA): While we understand the limits that social services can do in respect for carers based on their financial situation, this does not hinder delivering effective advice and information needs to focus on care and support separate to the discussion on with financial aspects. When you usually buy a service, you would expect to see some of the range of options before the seller asks you how much you have. This is not that different for social services. By presenting all the options, showing the difference between those on different funding streams, carers can see all the relevant pathways and then effectively decide based on their financial situation. We understand that a number of changes are taking place so suggest that the experience of carers using social services be further explored at a later date.

Continued monitoring of patient and carer experience by all service providers to see how service experience has changed in previous 12 months. (CHS, GPs, CCDA and Healthwatch Croydon): This insight report has presented carer experiences, but should be seen as a beginning rather than an end. By continuing monitoring patient and carer responses going forward we can measure how changes in services have impacted patient experience and help resolve issues when they occur rather than months or years later.

Apply the power of the One Croydon Alliance (All): The opportunity of the OCA to bring all key parties together to find solutions, as they are doing in so many health and social care areas, could also be applied to meeting the needs of dementia patients and their carers and make a more integrated service.

4 Responses to our research

Before publication, we shared this report and its full data with the relevant providers and commissioners of services to give a response to our recommendations and findings. This is their responses:

Rachel Carse, Dementia Action Alliance lead & Social Inclusion Coordinator, Croydon Council

Listening to the views of carers and people living with dementia is something that the Croydon Dementia Action Alliance (CDAA) takes very seriously. We would like to thank Healthwatch for this report and we appreciate the contributions from the carers and family members who have shared their views.

In the past year, the membership of the CDAA has grown substantially due to Croydon Council funding a full-time post to increase its reach and impact.

All organisations mentioned in this report are members of the CDAA. We are already working collectively and individually to make improvements for people living with dementia and their carers.

Every Practice Manager in the borough has recently attended a 'Making your GP practice Dementia Friendly' session. The Council, Clinical Commissioning Group, Croydon Health Services and South London and Maudsley NHS Foundation Trust are working together to make the journey seamless from diagnosis to support with health and social care needs.

CDAA will continue building on the extensive work achieved so far locally this year including the improvements highlighted in the report.

- **Funding of advice and support services structure:** Both the council and CCG fund dementia services across the borough. The Council has excellent day services supporting people living with dementia and their carers. The CCG provides the Memory Assessment Service, which formally diagnoses if someone has dementia. After diagnosis, the Alzheimer's Society, also

funded by the CCG, provides everyone with information on dementia and offers the chance for people to talk to a Dementia Adviser. Importantly, anyone with a diagnosis of dementia can be referred to the Alzheimer's Society including self-referrals or referral from a GP.

- **Information on how residents contact adult social care and its services:** Following in-depth analysis of the way residents contact the council, it became apparent that a different approach was needed for this to work better. From March 2019, the Council is moving to a model where there is greater provision of information, advice and guidance and earlier intervention to prevent, reduce or delay peoples need to receive social care. It will be a multi-agency, multi-disciplinary approach, working together with the safeguarding team, mental health service, Croydon police, the FJC anti-domestic abuse service and communities in the borough.

- **Clearly presented pathways:** The path of a person living with dementia and how they and their family negotiate services can be extremely complex and that is borne out by the comments in the report. The Council and other stakeholders are starting to work on how to create clear information about dementia, identifying what is available around the borough in a bid to make things easier to understand.

Croydon Clinical Commissioning Group

NHS Croydon CCG welcomes Healthwatch's report and their interest in this important area that affects so many of our residents. Alongside our partners in the Croydon Dementia Action Alliance, we are working hard to make improvements for people living with dementia, their carers and families. This report will help us further focus our efforts for local people. In particular our current work during 2019/20 includes:

- Introduction of a new, national diagnosis dementia assessment framework - the CCG and Dementia Service providers are expected to adopt a more nuanced approach to diagnosis taking into account age and gender differences. This will lead to improved diagnosis rates, earlier detection and treatment, and better outcomes. The CCG will work alongside GPs and Primary Care to ensure implementation of the framework.
- Information for patients and carers - the CCG will ensure that leaflets and posters are available for patients and carers in all GP surgeries. Primary Care information systems alert GPs to relevant referral forms on the dementia pathway. The CCG will review the possibility of introducing IT carer assessment alerts to ensure comprehensive cover and onward referral to local voluntary bodies.
- Carers Registers, including dementia carers - GP surgeries maintain these registers which alert GPs and primary care health workers about an individual's carer status. Surgeries can then provide help with the carer's own physical, mental and emotional health plus signposting to support groups. Multidisciplinary "Huddles", including Dementia Huddles, are meetings of relevant professionals involved in delivering health and social care. They are being embedded in all General Practices across Croydon, and will have a positive impact on timely access to services.
- Dementia Pathway - the CCG is facilitating a workshop in February 2019 with local stakeholders including the South London and Maudsley NHS Foundation Trust, GPs and voluntary bodies. The outcomes of the CCG facilitated

Dementia Pathway Workshop will inform the ongoing work of the One Croydon Alliance.

- The Healthwatch report findings and recommendations will inform the workshop agenda. The need to develop information about the various services delivered in the pathway that is user friendly could be one of the outcomes of the meeting. The CCG will work with partners and communication professionals to develop user-friendly promotional material.
- The new NICE Dementia guidelines include provisions for care co-ordination and care planning and psycho-education for carers. This will give them skills and strategies for dealing with the challenges of caring for people with dementia. The CCG will work with our partners to make sure that these new standards become part of dementia pathway ways of working.
- The CCG will continue its 'Dementia Friendly' staff training programme.
- The CCG will monitor all the health services we commission for dementia, including the local mental health trust and the Alzheimer Society, to make sure that quality standards are continuously improved including services that directly impact on carer experience.

Croydon Health Services NHS Trust

We welcome this report by Healthwatch Croydon looking at the experience of carers of people with dementia in our borough. With our ageing population, rates of dementia are rising and more people are finding themselves caring for their loved ones.

There are a number of measures we already have in place for patients with dementia including:

- Annual participation in the National Audit of Dementia which benchmarks us against other trusts and suggests actions for improvement.
- Identifying people with cognitive impairment or delirium and signposting them to their GP for further follow up care and support.
- Telephone contact with all carers of any patients with delirium to assess people's experiences of our care.
- Ongoing monitoring of our services through the Friends and Family Test and our PALS team.
- Participation in the Croydon Dementia Action Alliance and more than 370 staff trained as dementia friends.
- Support for John's Campaign, to ensure flexible visiting hours for carers on our wards, and the Herbert Protocol to protect vulnerable people in the community.

However, we know there is more than can be done to ensure services are fully joined up between health and social care. We will study the recommendations closely to look at whether there is more we should be doing to support carers of those living with dementia. We will also work closely with our partners across health and social care to see what additional actions are needed to create truly integrated services.

South London and the Maudsley NHS Foundation Trust

The report will be used to inform discussions we will be having with our Service User and Careers Action Group (SUCAG), to ensure we continue providing high standards of care, including a new care pathway for people with dementia in Croydon.

Carer's Support Centre

We're pleased to see Healthwatch Croydon highlighting issues faced by carers of someone with dementia in Croydon. It is positive to note examples of good practice, including carers using the Carers Support Centre for information and advice.

However, it is concerning that many carers are not being identified early enough and signposted to the help they need. Our 2017 *Not Just a Patient* report found that 82% of carers had not been informed by their GP of carer support available in the community.

There is clearly still work to be done to ensure every carer of someone with dementia has clear pathway to appropriate support and advice. We invite Croydon Council and Croydon CCG to liaise with us on this issue, to ensure all carers are aware of the services we offer.

5 Quality assurance

Design

Does the research ask questions that:

Are pertinent? This research asks carers of those with dementia in Croydon their experiences of obtaining a diagnosis for the person they care for, and their experience of services. As one of largest boroughs of over 65s in London and with 3250 people registered as diagnosed with dementia, and a prediction of an increase in the coming years, this research is very pertinent.

Increase knowledge about health and social care service delivery? This research helps both commissioners and providers of services both in the health and social care sectors. Real experiences of carers using the services now, will help inform knowledge for the future delivery of services.

Is the research design appropriate for the question being asked?

a) Proportionate: We know there are around 2339 diagnosed with dementia and over 3000 project it to have the condition but are undiagnosed. It would suggest that there may be a similar number of carers, but we do not know for sure, since numbers are counted on those who register for services. In seeking to ask for view from a group that is seldom-heard and hard-to-reach, and in some cases may not access services, or only use them as a last resort. The 70 carers we have heard from is proportionate number from those we have access to via our network of community organisations and the health services.

b) Appropriate sample size: Has any potential bias been addressed? We have spoken to carers while in hospital with their cared for in elderly wards, as well as those accessing service via Alzheimer's Society in Croydon and the Carers Information Service, as well as promoting an online survey for those who may not be able to access services directly. We extended the time for the survey to gain

experiences from a three month to six-month window so we could access more experiences. We accept the limits of this research, but state any bias has been addressed. We refer to the fact that 25% (18/70) came from elderly wards in the hospital and so may have leant heavily to experiences within the NHS and particularly hospitals.

Have ethical considerations been assessed and addressed appropriately? Carers were always given the opportunity to refuse our request for their views. We understand the pressure and concerns they had and worked closely with relevant organisations such as Croydon University Hospital, Alzheimer's Society and Carers Information Service.

Has risk been assessed where relevant and does it include?

a) **Risk to well-being:** None.

b) **Reputational risk:** That the data published is incorrect and not of a high-quality standard. Careful checking and referring to relevant organisations has been undertaken before publication.

c) **Legal risk:** Have appropriate resources been accessed and used to conduct the research? There was no need to refer to legal resources for this research.

Where relevant have all contractual and funding arrangements been adhered to? This did not relate to any specific contractual or funding arrangement. It was referred to by the draft business plan agreed with the commissioner.

Data Collection and Retention

Is the collection, analysis and management of data clearly articulated within the research design? Yes.

Has good practice guidance been followed? Yes.

Has data retention and security been addressed appropriately? Yes.

Have the GDPR and FOIA been considered and requirements met? Yes.

Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? ie the Mental Capacity Act. None required for this research.

Has appropriate care and consideration been given to the dignity, rights and safety of participants? Yes, particularly on hospital wards and with support groups where we worked closely with relevant staff

Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity? Yes.

Collaborative Working

Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement? There was not contractual agreement for this research, but our working with partners was clearly agreed in advance of research taking place. The Croydon Dementia Action Alliance gave advice in the drafting of the questions.

Have any potential issues or risks that could arise been mitigated? These are shown below:

Risk factors	Level of risk	Contingency
Cannot access key people to research	low	Going on to hospital ward / captive audience
Organisations let you down	medium	Use social media
Question set does not work with group	low	Co-written by CW at frontline of service delivery
Data is seen as being out of date	low	See above
Not enough respondents	medium	Extend survey time

Has Healthwatch independence been maintained? Yes, this research is shared with partner organisations before publication for their comment, but only factual inaccuracy would be reviewed. This does not affect the comments of experiences we receive.

Quality Controls

Has a quality assurance process been incorporated into the design? There was a proper process of scoping.

Has quality assurance occurred prior to publication? Data collection was checked and re-checked.

Has peer review been undertaken? No peer review was undertaken. It was not required for this research project.

Conflicts of Interest

Have any conflicts of interest been accounted for? The Croydon Dementia Action Alliance gave advice in designing the questions. We mention their role in the recommendations since they have a key role to play in influencing change in services. This research does not state a view on the work we do. Likewise, the Alzheimer's Society and Carers Information Centre, helped us promote the survey and gain access to carers, but their own work is not the focus of this study. References to their services have come directly from the carers.

Does the research consider intellectual property rights, authorship and acknowledgements as per organisational requirements? The research is owned by Healthwatch Croydon, who are managed by Help and Care. Other organisations support has been recognised and suitably referenced.

Is the research accessible to the general public? It appears on our website as of 11 February 2019

Are the research findings clearly articulated and accurate? To the best of our knowledge, we believe they are.

6 References

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https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18

Projecting Older People Population Information System (POPPI) (2019)
http://www.poppi.org.uk/

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