DESIGNING THE RIGHT CARE TOGETHER:

EMOTIONAL WELLBEING AND MENTAL HEALTH SERVICES FOR CHILDREN AND YOUNG PEOPLE IN SURREY

February 2019

“This isn’t going to be solved in clinical settings alone. We need to shift our focus to schools, families and the community [setting].”

Direct quote from the engagement workshops highlighting the need for a different approach to emotional wellbeing and mental health.

DARTINGTON SERVICE DESIGN LAB

NHS

SURREY

We would like to thank all the participants. We are particularly grateful to those children, young people, parents and carers from across Surrey who joined workshops and spoke to us about their experiences of the mental health system and needs to support their emotional wellbeing. We are also grateful to all of the staff from a wide range of professions who gave up their time to attend the workshops and events we ran.

This report was written by Daniel Ellis and Shreya Sonthalia, supported by Rosie Allen, Vicky Baker, Leanne Freeman, Finlay Green, Keira Lowther, Jenny North, Maria Portugal and Kate Tobin: staff of the Dartington Service Design Lab. It was commissioned by Surrey County Council and associated Clinical Commissioning Groups.

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SECTION 1 Introduction

INTRODUCTION TO THE PROJECT

The project was commissioned by Surrey County Council and the six associated Clinical Commissioning Groups (CCGs) to inform the redesign of the emotional wellbeing and mental health services for children and young people in Surrey.

The aim to transform the services by 2020 is primarily driven by the heavy critique of long waiting times and inadequate support for children and young people who need it in Surrey. At the same, mental health was identified as the top priority for change in Surrey, in a survey with 18,000 young people.

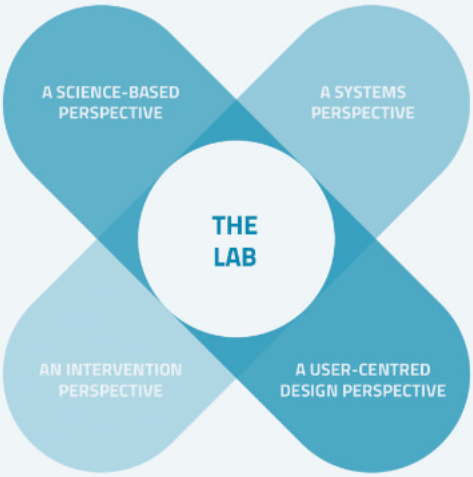
The council and the CCGs are committed to making the required changes, and to transform the experience of children and young people facing mental health difficulties. To ensure that the new services meet the needs of children and young people, the first step of the redesign was to engage with numerous stakeholders: children and young people; their parents and carers (i.e. the users of the service), as well as professionals working to support the emotional wellbeing and mental health of these users (i.e. the providers of the service).

This report outlines this engagement work carried out in January 2019 by the Dartington Service Design Lab.

About Dartington Service Design Lab

The Dartington Service Design Lab is an independent charity, committed to improving outcomes for children and young people. We improve services for children and families by applying research and best evidence to everyday practice. But we think it is really important to balance this with user and practitioner involvement. We believe it is critical to situate services in the context of the wider complex and messy systems in which services are delivered – be these public agencies or local communities.

Our system dynamics work applied mental health and social care systems seeks to identify system-level changes that may foster greater change to children's lives than a single intervention alone. It aims to identify the system conditions in which specific services could make the most difference. We work at the intersections between evidence-informed and user-centred design, and practical service delivery and wider system reform.



What is system Thinking?

Health and social care systems are complex. They tend to **self-regulate**, and changes to one part of the system will likely have knock-on effects to another part of the system. Systems thinking is a way of understanding how complex systems behave, what rules govern these behaviours, and what changes could be introduced and to what effect.

Systems thinking considers the **feedback within systems**. The feedback perspective (or endogenous view) is different to the linear cause and effect perspective (or exogenous view).

In the **linear perspective**, the focus is on causes outside the system - factors that may not be under our control, coupled with the belief that we do not contribute to the problem.

With **Feedback thinking,** we try to understand how consequences of actions in one part of the system "feed back" to influence the drivers of those actions through a series of practices, policies and decisions over time.

SECTION 1 Introduction

AIMS OF THE PROJECT

At the start of the project in November 2018, a session was conducted with senior staff from the council and the CCGs to identify the primary hopes and fears of this work. We also explored what a successful system means. In light of these, the primary aim of the workshops was to listen to the participants:

- To learn from the experiences of children and young people, and their parents and carers who have accessed mental health support and services; what was helpful, what was not helpful, what could have been helpful.
- To explore what parents who have not accessed services know about the system, and what support they would find helpful.
- To understand the challenges of the professionals providing the supports and services, what the drivers of the challenges are, with a particular focus on system structures and behaviours.

Hopes by theme

HOPES

- Clear, actionable information from workshops.
- Genuine, open engagement from attendees.
- Participants feel listened to.
- Leave feeling something will be different.
- Accessible and diverse sessions.

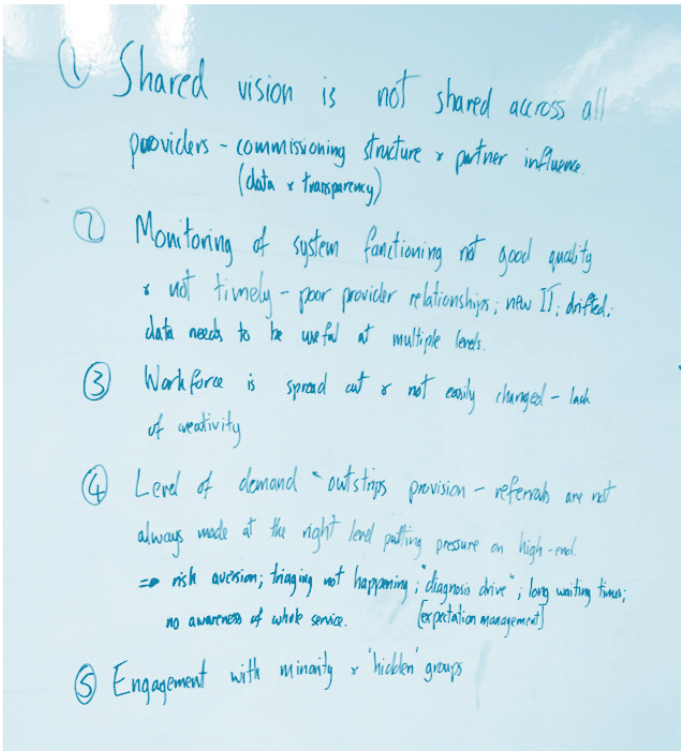
FEARS

- Anger gets in the way of meaningful engagement.
- Lack of action after the workshops.
- Won't gain insight from those unable to access services.

Fears by theme

FIRST SYSTEM LEADER WORKSHOP (NOVEMBER)

The outcome of the first session with system leaders closed with a clear set of criteria that a successful system should adhere to.



A SUCCESSFUL SYSTEM

- Support is provided in a timely manner.
- Addresses needs and gets positive outcomes for young people.
- Early intervention, prevention and lighter-touch support is fully utilised whenever possible.
- Stakeholders have some positivity about the service.
- Meaningfully engages with stakeholders and builds a learning partnership.
- Make the best use of current skills.
- Understand system behaviours.

SECTION 1 Introduction

PROJECT LAUNCH EVENT

At the beginning of January 2019, an event was held with approximately 70 system leaders and decision-makers to launch the project and more importantly to mark the start of the journey towards transforming the outcomes for children.

The event explored the hopes and fears for the mental health services in Surrey, beginning to develop a shared vision. The themes show broad consensus amongst participants. Activities also aimed at understanding how collaborative working between various agencies including CAMHS, schools and the voluntary sector can be promoted. This was to foster a commitment to work together.

'Better collaborative working' emerged as one of the five primary themes from the engagement workshops.

HOPES

- Transformation of outcomes for children.
- Early help and support; timely support.
- Culture change.
- Collaborative working.
- Ongoing engagement and co-design.
- Support for schools.
- Listen to parents.

FEARS

- Lack of ambition and slow pace of change.
- Voluntary sector is overlooked.
- Lack of skills and losing staff we have.
- Limited resource.

SECTION 1 Introduction

LAUNCH EVENT (JANUARY)

The project launch brought together professionals from across Surrey, all of whom had a role in supporting the emotional wellbeing and mental health of children and young people. A key issue when so many different agencies and professionals are involved is effectively working together, and this was explored in detail during the day.

What follows are the main drivers of, and barriers to working collaboratively, identified by professionals during the event.

COLLABORATIVE WORKING

- Trust between services;
- Information sharing, IT and GDPR;
- Knowledge of system and constant change;
- Staff skills (right place, right skills);
- Enabling parents;
- Separate and competing budgets;
- Differing priorities;
- Personal relationships;
- Time;
- Lack of ownership for cases;
- History of things going wrong;
- Shared vision;
- Social change;
- Managing expectations of families.

Connection Circles from the launch event

EXAMPLE CONNECTION CIRCLES

Above is the first example of 'Connection Circles' drawn by participants throughout this work. These are messy looking diagrams that start with a specific issue (normally noted at the top of the circle) and then link a variety of other factors that contribute to that issue around the rest of the circle. This helps participants think about what other factors may be contributing to a particular problem and how they relate to one another. These have been used throughout this report to inform specific behavioural feedback loops that are present in the current system.

SECTION 2 The Engagement Workshops

THE WORKSHOPS

21 sessions, between 90 to 120 minutes each were run across seven regions: Godalming, Dorking, Woking, Farnham, Staines, Ewell and Caterham. Approximately 200 professionals, 50 parents and carers, and 5 young people participated in these. We would have liked to engage more parents and young people during this project, but due to the condensed timeline, this was not possible. The limitations of this method mean we did not reach a fully representative sample of parents and young people of Surrey.

Despite this we are confident in what we are presenting throughout this report for two reasons. First, because each of the themes was raised strongly in every workshop. Second, because this is only the latest piece of engagement work and these themes resonate with what has been heard before. This report is only the start of the conversation in Surrey and we'd encourage anyone reading this to contact us if they feel their views and experiences are not adequately represented here.

There are detailed recommendations on how we could improve engagement (and make the work more representative) in future work on page 31.

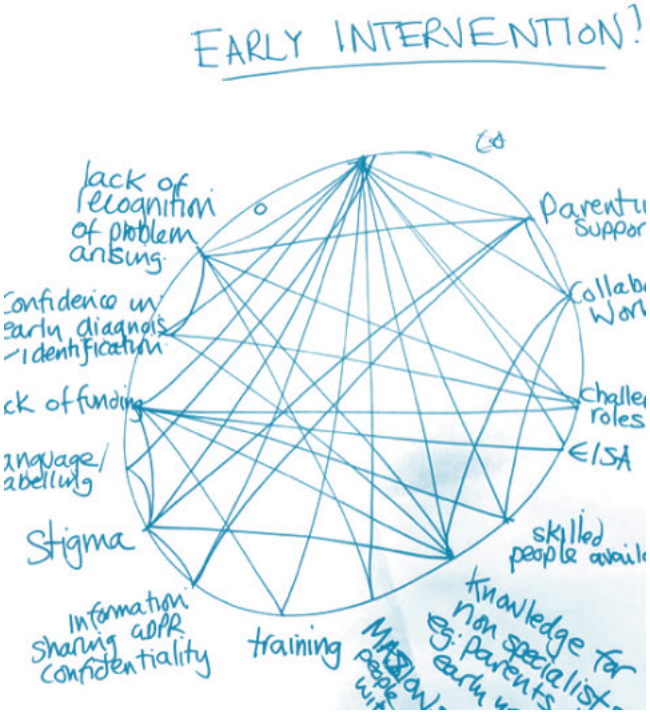
STAND OUT THEMES FROM THE SESSIONS

There are **five major themes** from the engagement workshops. These were common across parent, child, young people and practitioner workshops.

1. Early intervention and community support.
2. Collaborative Working.
3. Navigating the system.
4. Communication with parents and young people.
5. Environment design.

This section sets out the five major themes that were spoken about at every workshop in detail. Examining what participants covered under each theme, the main messages about each, any underlying feedback behaviours that we think could be contributing to the problem and recommendations for change.

"It is so much better to build a fence at the top of a cliff than run an ambulance [service] at the bottom."



One of the many Connection Circles drawn by participants that focused on Early Intervention

EARLY INTERVENTION AND COMMUNITY SUPPORT

Workshop participants considered all of the following when talking about early intervention and community support:

- Children's Centres;
- Health Visiting;
- Community mental health teams;
- Support in schools (nurse, counsellor);
- Support for schools (to know how to best support children);
- Educational psychologists;
- Support to parents (to know how to best support children);
- Initial training for teachers, GPs and others.

There was a general consensus that there is a lack of early intervention and lower level support out in the community that focuses on mental health. Where it does exist, it is either unknown to parents and practitioners or done in small pockets (e.g. within a school or group of schools).

Parents and practitioners report that a child has to require high-end support to receive anything from CAMHS and the threshold for high-end has risen over time. As the need has increased, even lower-level supports have increased thresholds.

Children are left unsupported if they don't meet these very high thresholds or are waiting for an assessment to take place. There is a strong feeling that earlier support would mean fewer crises.

Non-specialists (e.g. teachers, youth workers, school nurses, GPs) need support to know how best to deal with children who are struggling. Largely they want to help but don't know how and are resource and time constrained in their ability to do so.

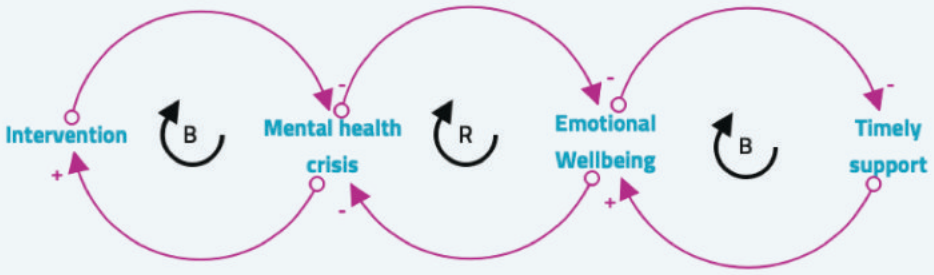
EARLY INTERVENTION AND COMMUNITY SUPPORT – SYSTEM BEHAVIOUR

Causal Loop Diagrams (CLDs) are a way of conceptualising and diagramming feedback behaviours in a system. Feedback means that an initial change has knock-on effects creating a chain of causation that ultimately feeds back i.e. influences the initial change. Understanding feedback is important because the behaviour of the system is generated through the feedback emerging from its structure.

In a CLD, each arrow represents a hypothesised causal relationship (a cause and effect relationship between two variables). The notation next to the arrowhead indicates the direction of causality: a positive sign implies that both variables move in the same direction whereas a negative sign implies that the two variables move in opposite directions.

When several variables link together, with the last connecting back to the first, this is called a 'feedback loop'. There are two types of feedback loops: reinforcing (labelled R) and balancing (labelled B). The arrow around the label denotes the direction of causality. In a balancing loop, the feedback counteracts the initial direction of change. For example, timely support is keeping emotional wellbeing in check – we start with deteriorating emotional wellbeing and going around timely support, end with improved emotional wellbeing.

In a reinforcing loop, an initial increase (or decrease) feeds back to reinforce the initial increase (or decrease). These loops denote a spiralling effect in the behaviours. In the absence of support, low emotional wellbeing will mean more crisis, and more crisis will mean poorer emotional wellbeing. We start with low emotional wellbeing and going around crisis, end with lower emotional wellbeing.

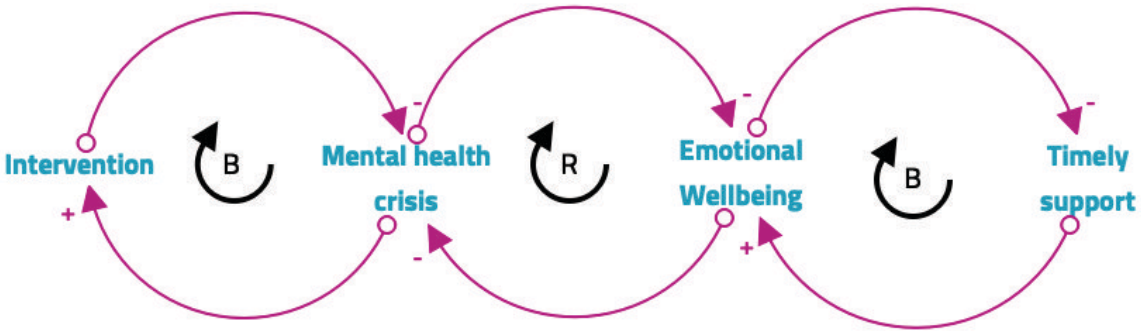


In this CLD, the negative sign from emotional wellbeing to timely support indicates that as emotional wellbeing deteriorates, there is more support. The positive sign from timely support to emotional wellbeing indicates that as there is more support, emotional wellbeing improves.

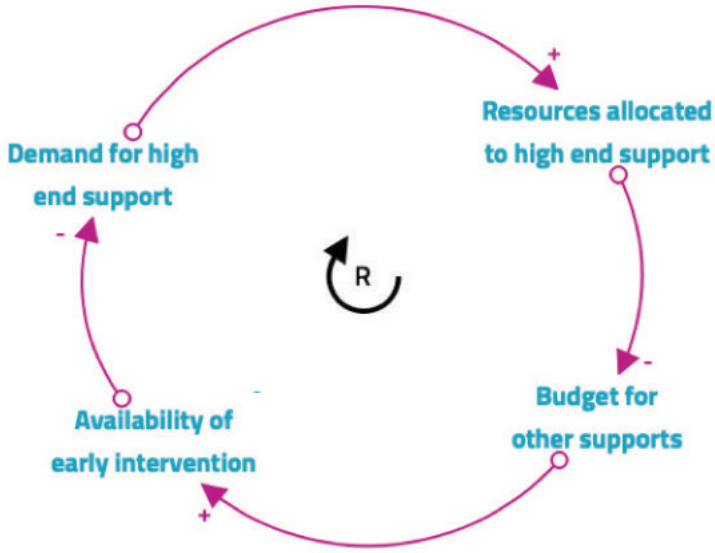
All CLD diagrams in this report have been informed by the Connection Circles drawn by participants throughout the engagement workshops.

EARLY INTERVENTION AND COMMUNITY SUPPORT – SYSTEM BEHAVIOUR

Early intervention (or timely support) and crisis intervention have different goals. Intervention at crisis point seeks to reduce the crisis. Early intervention seeks to increase and maintain good emotional wellbeing, reducing the number escalating to crisis point (over time).



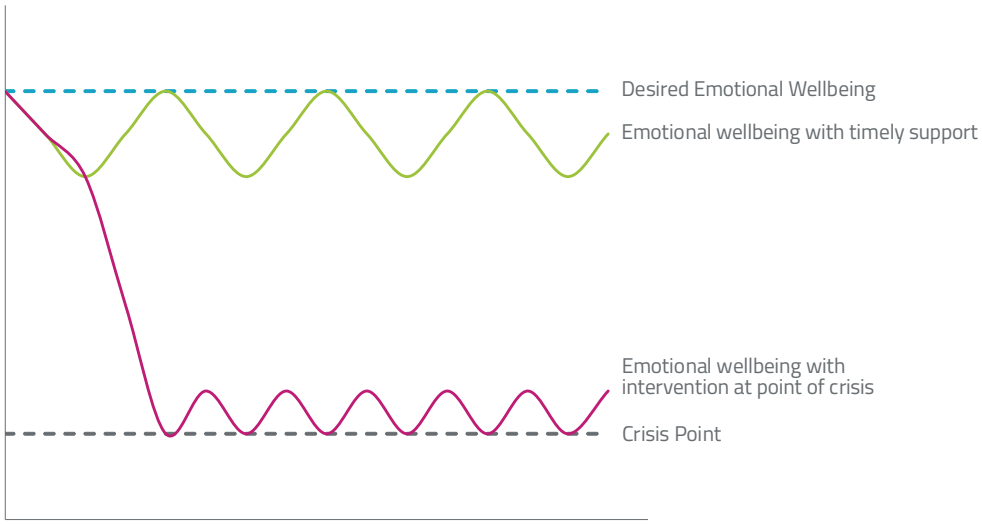
Early intervention helps to maintain good emotional wellbeing. Not investing in early intervention and lower level community support can lead to a vicious cycle of increasing demand at the high-end of the system and the further reduction in resources available for early intervention.



EARLY INTERVENTION AND COMMUNITY SUPPORT - SYSTEM BEHAVIOUR

As can be seen in the graph below, once the emotional wellbeing of a person falls below the desired level, providing timely support (early intervention) can help the person return to the desired level of emotional wellbeing. The person might fall below the desired level again, and timely support will help their emotional wellbeing return to the desired level again. Although emotional wellbeing oscillates, it is quite high. Early intervention aims to maintain the desired emotional wellbeing.

In the case of a crisis intervention approach, no support is provided until emotional wellbeing deteriorates significantly, reaching a crisis point (very poor emotional wellbeing). In the lack of support, emotional wellbeing deteriorates rapidly. The crisis intervention supports the person to come out of crisis, but does not return the person to the desired level of emotional wellbeing. The person oscillates in and out of crisis, as the aim is to keep the person out of crisis, not to return the person to the desired emotional wellbeing.



It might be possible to return the person to the desired level of emotional wellbeing, if the crisis intervention is enhanced with continued support for the required period of time. Firstly, this is not common practice within the crisis approach. Secondly, this is generally very difficult to do this and may or may not be successful. Thirdly, the person has a low emotional wellbeing for a long duration. Fourthly, according to the hypothesis illustrated in a the causal loop diagram, the more crises a person goes through, the lower the emotional wellbeing of a person.

NB: the graph is for illustrative purposes and not driven by real data.

EARLY INTERVENTION AND COMMUNITY SUPPORT - WHAT CAN WE DO?

- **Identify and commit an additional proportion of the EWMH budget for early intervention and community support as soon as possible.** To be sustainable year on year, this should come from the current budget. For example, an additional 2-5% of the total spending on EWMH could be redirected. This increase could be staged over multiple years as the system readjusts its priorities.

It is important to contextualise this:

- The current strains on the system are not allowing services to be helpful. For example, CAMHS was '6 weeks of brilliance' for some but that support was fixed and not based or extended on child needs. The result was breaking a fledgling relationship just as trust was developed and the subsequent demoralisation and feeling of rejection potentially did more harm than the 6 weeks of therapy.

- Although not a quick fix itself, a continued lack of early help and community support will further increase high-end demand in the long run, as demonstrated in the vicious reinforcing loop.

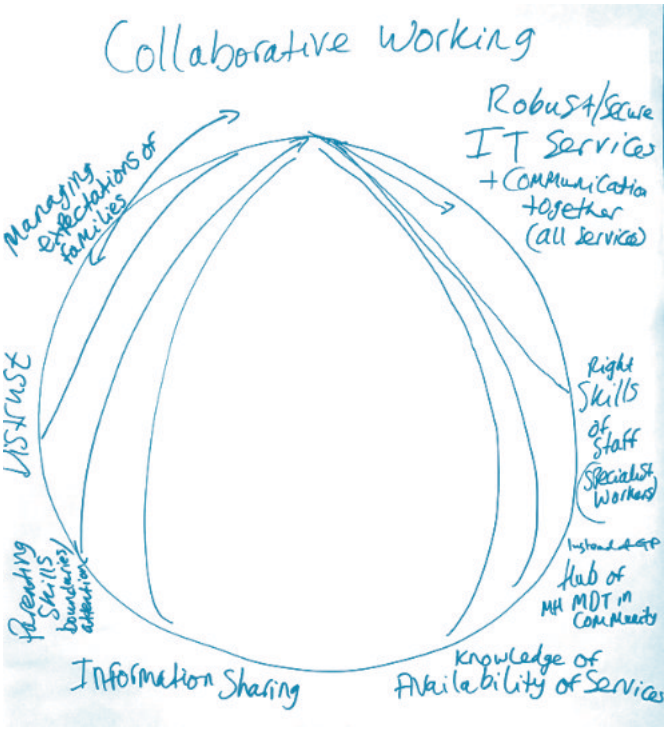
- Parents of children with very high needs who attended the workshop felt that early help is the right thing to do, and if they had received early help their journeys may have been very different.

- Only after this commitment to increased investment in early intervention, actively engage schools and the voluntary sector, some of whom are already innovating in this area but feel largely unsupported and on their own.

- Actively engage young people by going out to schools and colleges, to understand the underlying pressures driving low emotional wellbeing so that support can be built around their needs. The daily lived experience of young people should inform the supports provided.

- Schools and existing community projects are the best mechanisms to deliver a new approach, they have the reach and are looking for support to do this kind of work.

"You do not pass the baton until there is someone to take it."



COLLABORATIVE WORKING

Workshop participants considered all of the following when talking about collaborative working:

- Professionals not knowing full details of a case, only parts;
- Lack of communication between professions;
- Having to repeat own story multiple times;
- Support between professions, especially specialists and non-specialists;
- Professionals not being updated about progress.

There is a strong perception that the system is fragmented and where gaps exist they are plugged by those outside the system (e.g. schools and voluntary sector agencies). Professionals do not necessarily work together to support the child as a whole, rather each individual need.

Parents and young people have to repeat their story multiple times to different professionals and each pass between services reduces trust and hope (as stories are distressing and no help is forthcoming).

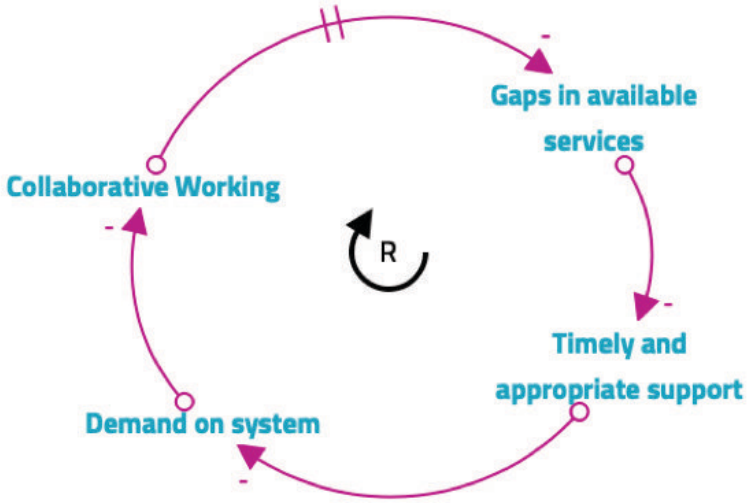
There is little information feedback in the system (e.g. referral/treatment progress). This leaves parents, young people and the initial referrer (who is often still trying to support the family) feeling in limbo.

There is no chance to build a trusting relationship with a single professional who knows the child/family.

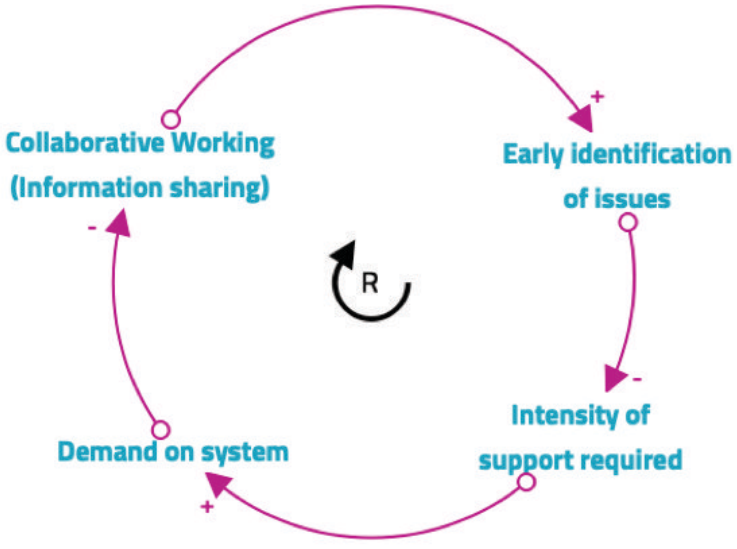
The expertise and skills available in the system are not being used to full effect due to poor collaborative working.

COLLABORATIVE WORKING – SYSTEM BEHAVIOUR

Collaborative working can help fill gaps in services over time, at least those caused by the lack of knowledge of what is available.



Collaborative working and information sharing can increase the identification of issues earlier and reduce demand at the high-end of the system if those needs can be met earlier too (e.g. when coupled with early intervention and community support services).



COLLABORATIVE WORKING - WHAT CAN WE DO?

Introduce a "passport" for the child and family so that their story follows them around the system and repetition is kept to a minimum. They can choose who to share this with and when (at least in detail).

Have a single professional hold a case as the "link worker" who builds the trusting relationship with the child and family and can coordinate the system response. This could be coupled with the suggestion of a navigator role from the next theme as these roles heavily overlap and could have multiple purposes.

Make space for professionals to come together from across the system to learn about who offers what services and what their roles consist of. This should be a structured space.

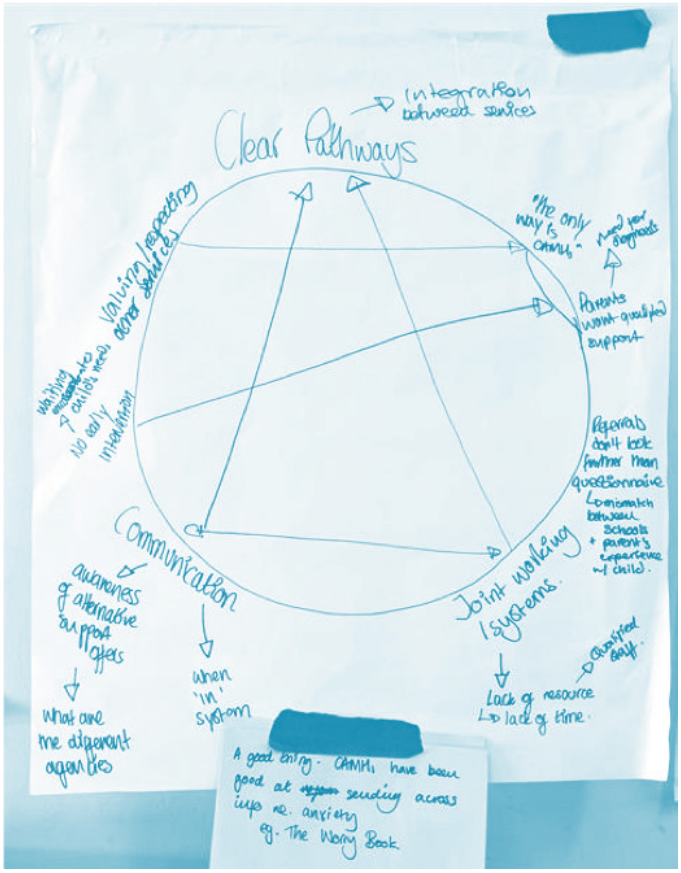
Measure how well the system meets the child/family needs rather than an individual service (e.g. evaluate the system not only a service).

"You have to put time and energy into working out the system. What happens when parents can't do that?"

NAVIGATING THE SYSTEM

Workshop participants considered all of the following when talking about being able to navigate the system:

- What support is available and who it is for;
- What the thresholds for support are;
- Who can refer to which services;
- Who is best placed to provide support based on particular needs;
- Where you can find reliable information about support and services.



There is no map of the system or accessible information hub available to families or professionals. This hampers everyone in being able to understand the system and provide the right support to a child, young person or family.

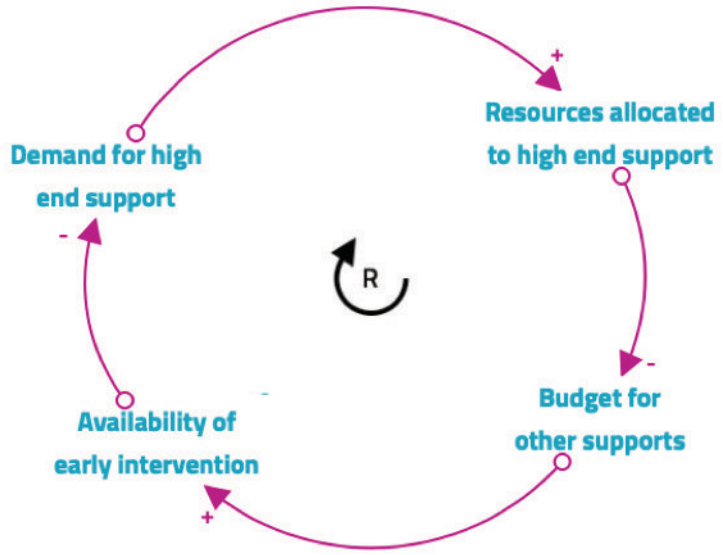
Parents must become "system experts" in order to be able to push for a specific service or support for their child. Some parents have the time and resources to do this; many others do not.

CAMHS thresholds and services are opaque, and knowledge of services beyond CAMHS is low, driving high CAMHS referrals.

Service restrictions can be due to commissioning rather than clinical reasons, making it more challenging to find support, especially for rare diagnosis or those at certain age boundaries.

Gaps in provision are likely unclear to system leaders.

NAVIGATING THE SYSTEM – SYSTEM BEHAVIOUR



Lack of knowledge about what CAMHS can and can't do hampers referrals. Improved quality of referrals means CAMHS can focus on treatment rather than processing. Training and support here could cover knowledge of CAMHS but also what else might be appropriate for the child outside of CAMHS.

Getting another service earlier (rather than waiting on a CAMHS processing list) could also reduce the escalation of need in a child, further reducing the pressure on CAMHS.

Ideally, this should be combined with the earlier identification of issues through better collaborative working and a bolstered early intervention and community support offer. This would allow the system to respond in a timely way much earlier to a child or families need.

NAVIGATING THE SYSTEM – WHAT CAN WE DO?

Publish clear guidelines on what can be provided, what can't be provided and what support or strategies could be put in place instead, making CAMHS a fully transparent service and it clear where other support is available.

Map the services currently providing emotional wellbeing and mental health support from across the sectors and make this publicly available.

- A quick first step will be to send details of existing registries of the services available (local offer and the Family Information Service);
- Longer-term, an interactive online database, that can be kept up-to-date and powers a map of services.

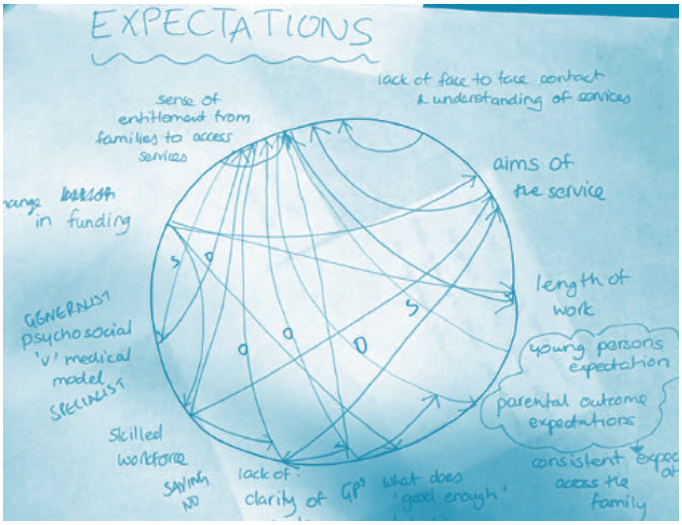
Create a helpline with an expert mental health worker who can talk through a case and guide professionals about how best they might proceed (in a similar manner to on-duty social workers with safeguarding concerns).

"They do what they have to do to us, not with us."

COMMUNICATION WITH PARENTS AND CHILDREN

Workshop participants considered all of the following when talking about communication directed towards parent and young people:

- Parents are not listened to or believed;
- Parity with physical illness;
- Parents are not given support (e.g. strategies and advice) to support their children;
- Information given to parents is not clear or consistent:
    - Waiting times;
    - What to expect at appointments;
    - What a service or support will consist of;
    - Diagnosis and what it means for their child;
- The child is not at the centre of treatment.



Parents and young people are highly frustrated with the communication they get from CAMHS and related services. Sometimes this starts earlier than CAMHS with not being believed or listened to about what their child's needs are and what they are like at home vs what they are like at school or college.

Waiting times are problematic, but what increases frustration is not knowing what the wait is for. The expectation this builds is that at the end of a long wait someone will provide help and often the first wait is for assessment, which may or may not lead to help. This drives distrust, disillusionment and frustration.

Children are not always spoken to as the patient and practitioners child friendliness is inconsistent. When a rapport is not made quickly, children are discharged or moved back to a waiting list.

Parents are not believed if there is a discrepancy between what the school says and what parents say, due to a lack of appreciation that children behave differently at home and at school.

CAMHS is not flexible and does not listen to parents concerns. For example, appointments are frequently changed and parents not being able to attend an appointment or being late with a highly distressed child are discharged for non-attendance (likely due to high pressure on CAMHS).

The language of letters can be unhelpful and mistakes are hard to correct.

Cannot communicate with CAMHS between appointments or prior to them. There is no provided email address and direct calls often go unanswered.

There is no communication on what to expect at the appointment, which makes it very challenging to prepare an anxious child. This is counterproductive to improving mental health and wellbeing.

COMMUNICATION WITH PARENTS AND CHILDREN - WHAT CAN WE DO?

Treat parents as partners in improving the emotional wellbeing and mental health of their children. Have straight forward conversations with parents, focusing on the child's needs. Support parents to support their child's recovery.

Set up an 'expert by experience panel' for those with experience of the CAMHS services (parents and children) to meaningfully engage in system-level changes and act as a sense check for users.

Make the referral process to CAMHS and the stages of CAMHS transparent so parents and children know what to expect right from the start. This could be as part of making the whole system transparent (see recommendation relating to navigating the system pg. 22).

Treat emotional wellbeing and mental health issues in the same way as physical ailments – listen to what children and parents are saying check back that information has been recorded and understood correctly.

Where support cannot be provided, give clear information about what the parent can do to support their child and where else they can turn (linked to better navigation pg.22).

"As a system we are reactive, not proactive."

ENVIRONMENTAL DESIGN

Workshop participants considered all of the following when talking about the environments CAMHS delivers services in:

- Where CAMHS is located;
- Timing of the sessions;
- Parking and transport;
- Waiting rooms;
- Making the child feel comfortable.

CAMHS, and associated services, are not easily accessible physically once you have gained access through referrals.

Buildings are not located on transport routes or do not have parking close by.

Waiting rooms and consultation rooms are not child or young person friendly. Waiting rooms and consultation rooms are grey and "dingy". Often there is no secluded area for a highly anxious person to wait in and in many cases, there is nothing for a child or young person to do whilst they are waiting.

The timing of the sessions are not flexible and sessions are not always at a suitable time. For example, sessions during school hours require children to explain to friends where they are going.

ENVIRONMENTAL DESIGN - WHAT CAN WE DO?

Make sure there is always a waiting room. Redecorate waiting rooms and offices where children and young people are seen for appointments in a way that is age appropriate.

Provide toys, books, games, wi-fi or other age-appropriate things to do whilst a child or young person is available. Arrange the area so that people will be as comfortable as possible (e.g. café style). This is to reduce their anxiety at their appointment and improve engagement with the services.

If a building is awkwardly located make sure good directions and information about transport options are available online or with the appointment letter, including where to park.

Consider making the timings and location of sessions more flexible.

FURTHER DETAILED FEEDBACK

The five themes presented in this section cover all the major areas spoken about during the workshops. However, participants also shared some specific feedback on various aspects of the system. For example, CAMHS referral processes, CAMHS support, Autism services, causes of mental health, examples of good practice and a range of ideas for system leaders to consider. These valuable insights are detailed in Section 5.

SECTION 3 Recommendations

QUICK WINS

These are recommendations we believe can be implemented quickly and with relative ease but will still improve the experience of the system for parents, children, young people and practitioners.

1. Improve communication with parents by mental health services about what a referral means and what to expect from the system. This will help increase trust and decrease frustration.

2. Make CAMHS consultation areas child and young person friendly.

3. Map the current system and publish it so that everyone knows what is available, for whom and how to access it.

BIG WINS

These are recommendations we believe would have the biggest impact on the system as a whole. They may be longer term or harder to achieve but should be built into any strategy seeking to improve child and adolescent mental health and emotional wellbeing.

4. Identify and set aside an additional proportion of the current year-on-year budget to focus on early intervention and community support (e.g. 2-5%). This is to help deal with lower level issues earlier and reduce the strain on CAMHS in the long-term, which should remain a high-need service.

5. Consult with schools and voluntary services who are already providing this on their own, learn from them and support them going forward. **This should be fully dependent on fulfilling (4).**

6. Foster a culture of collaborative working where the child is at the centre and the professionals involved can all share information vital to that child's recovery.

7. Continue to engage with parents and young people – but go to them.

SECTION 4 Conclusions

LEADERSHIP SESSION ON 29th JANUARY

A final session was held with senior leaders from the council and CCGs to share the five main themes from the workshop and consider what can be done.

There were meaningful discussions regarding the impact on the system for the various recommendations (both magnitude and time frame) as well as the difficulty in making the change and ability to control it. In particular, the discussion focused on early intervention. There was a strong level of agreement that more needs to be invested in early intervention and community supports, although where the money came from needed to be considered. The impact on the system would be high, and it would impact positively in the short, medium and long term. The consensus was that this will be hard to do right, but not impossible. People in the room actually would have more control than they initially might consider. They could influence other parts of the system as well, in addition to deciding how to spend the budget they hold.

This momentum and enthusiasm should not be lost and the new strategy should reflect the above.

REFLECTIONS ON THE PROJECT

The main aim of clear actionable inputs has been achieved. Although the engagement period has been intensive and brief, and the reporting rapid, there is plenty of information to guide a new strategy and start making changes.

Most parents were very reflective and had clarity on what would have been helpful earlier in their journeys. Anger didn't seem to get in the way as was feared. Parents were largely motivated to contribute so that the system can be better for others.

In terms of leaving the sessions feeling something will be different, there could have been more clarity on next steps. Some people have already experienced a lack of any significant change in experience after engagement work done a few years ago. It will be important for all participants to be kept informed. Highlighting the next steps while sharing the report will be crucial. It might be helpful to restate that this initial engagement was to listen to current challenges, and later in the process, we will seek to engage in genuine co-design.

We had some representation from young people and minority groups, but a lot more needs to be done to reach these groups and those who are not able to access services.

Further engagement work should actively go to parents and young people.


Sharpie

SECTION 5 Further feedback

This section covers some of the very specific insights that may not be fully covered in the main themes presented in Section 2. Many of these insights do relate to those themes and should be considered when drawing up a detailed strategy for system reform. This section ends with recommendations for conducting further engagement work with parents, young people and children.

FEEDBACK SPECIFICALLY ON CAMHS REFERRALS

- Confusion about whether parents can self-refer or not, among GPs and parents.
- Confusion about when to refer (how bad is bad enough) among professionals and parents.
- Difficulty in getting referrals to CAMHS - parents are not believed if behaviour is not problematic in schools.
- Some arbitrary restrictions – form needs to completed by one teacher only; can't access if you are seeking private help.
- System restrictions as the system isn't built around need but around the services commissioned. Children can't be on multiple waiting lists even when they would benefit from multiple supports.
- Very high thresholds; suicidal children not a priority if not left unintended; implied to parents they should exaggerate concerns to get access.
- Lack of clarity that the referral is for an assessment, not necessarily treatment or support.
- Frustration that waiting times are not clear and are different for different areas in Surrey. No updates offered on progress in the queue.
- Referral doesn't contain information and support regarding what to do whilst waiting.
- No alternate support, re-directing, sign-posting (needs to be appropriate) or feedback when a referral is rejected.
- Phone assessments are not helpful, felt as though the person was reading from a flowchart and disinterested; no opportunity for parents to discuss with their children.

FEEDBACK SPECIFICALLY ON CAMHS SUPPORT

- Focused on assessment, not support; discharged after diagnosis.
- Inconsistency in quality; dependent on individual CAMHS worker; Not all practitioners are good with children, although some are excellent.
- Play Therapy from Learning Space seemed to help just after the session, but effects would disappear by evening.
- No option to change treatment option (e.g. From group to individual therapy) or therapist if it is not working.
- Support is offered on an arbitrary timeline ("6 weeks of brilliance") this can be actively damaging as help is quickly taken away.
- The inflexibility of re-scheduling appointments when clients are too ill to attend.
- Discharged if the child or young person does not engage, no alternative methods considered; no support provided for those with communication difficulties.
- Diagnosis paradox – sometimes support is not forthcoming until a diagnosis is made for a child so parents will push for one. Other times a diagnosis actively gets in the way of support (e.g. child has ASD and anxiety is seen as part of this so no additional support is given).
- There is a perception (within CAMHS) that CAMHS has only been commissioned to diagnose ASD and not support the treatment. This may or may not be correct, but needs to be addressed, especially because it corresponded with the experience of most parents attending the workshops whose children had been diagnosed with ASD. In most cases, the only support was signposting to the National Autistic Society. A professional stated that St Peter's Hospital used to provide diagnostic and other services for ADD an ADHD. They stopped offering this service, stating that CAMHS would do it. CAMHS was not resourced to do this and there was an immediate bottleneck in the system. Either a service gap or a communication issue.

SECTION 5 Further feedback

FEEDBACK SPECIFICALLY RELATED TO SCHOOLS

- Inconsistency between schools in support provided and focus on emotional wellbeing. Dependent on headteacher and staff focus.
- Bullying cited by those who would go to access mental health - it's not socially acceptable amongst peers within the school.
- Children said that it was more difficult for adolescent boys to step forward and share how they were feeling.
- In special schools you adapt to fit the child, this does not happen in mainstream.
- In most schools, there isn't enough done to help children with the transition from primary to secondary school.
- Schools feel under-supported and are struggling alone. They require guidance on what to do regarding school-wide emotional wellbeing and mental health. They also need support to know what to do with children who are actively struggling with poor mental health and wellbeing.
- Services need to be accessible to all, including independent schools.
- EHCP's are a constant fight for parents and don't always provide the support their child needs as purely education focused. They are used by parents as a means of getting extra support, but it may not be the right support.

EXAMPLES OF GOOD PRACTICE IN SCHOOLS

- Eikon and ELSA, though not all schools have one.
- Essen Dean lodge - an emotional wellbeing programme that works well.
- Eastwick School in Bookham - staff are trained and the ethos is good, mainstream students are encouraged to support those with additional needs.
- Oxted school – has school counsellors; attitude of the school is more positive; different in their learning approach; Good integration with down syndrome / blind.
- Wellness weeks in some schools – everything offered to the child, also offered to parents.
- Half term review of all vulnerable families in school with a staff group.
- Pre-visits in secondary schools for vulnerable children to support the transition.
- Parent sessions in Magna Carta; immediately after drop-off, positioned as chat.
- Creative solutions to addressing the need. Gardening club for children who were being bullied, so they had something to do in break time and also make new friends. Cold rooms as a way of identifying children who need more help.
- Mindfulness and yoga sessions, resilience workshops.
- Breakout rooms, regular movement breaks to reduce restlessness.
- Parent: "What will you do when my child starts kicking off?" School: "We start by asking ourselves, what have we done wrong". Parent: "It was music to my ears".

SECTION 5 Further feedback

OTHER IMPORTANT CONCERNS RAISED BY PROFESSIONALS AND PARENTS

- Autism and other severe disabilities are not well provided for and rely on the parent battling for provisions to be made. Often this goes hand in hand with mental health difficulties and there is a huge overlap between the two. This is not necessarily recognised (e.g. anxiety is part of ASD so no mental health support).
- Transitions to adult services are not always well managed. The young person does not get a staggered handover, the approach is inconsistent depending on the service and there is no flexibility for young adults with additional needs.
- There is no provision to transfer CAMHS support between different areas.
- There is a lack of support and professional supervision for professionals, the mental health and wellbeing of teachers and providers is important. Need own good health to support others.
- Causes of poor mental health and emotional wellbeing need to be considered. Ideal opportunity to listen to young people about what concerns them and what support would be most helpful. Consider related issues such as communication.
- BME communities, young carers, LGBT and those not accessing services need to be represented. This can only be done by going to them rather than expecting them to come forward.

RECOMMENDATIONS FOR FUTURE ENGAGEMENT

Better parent and child engagement, more frequently should be part of the ongoing system reform.

- Reflections from some parents that they've never shared their story in an engagement event like this before.
- Parents felt the peer support from this workshop had been helpful, some said they felt renewed to fight on.
- Make a purposeful effort to invite parents involved (or previously involved) in CAMHS to a session (rather than an open invitation).
- Frustration that some of the parents involved/ experience with health systems, only found out about the events by chance.
- Frustration that a conscious effort hadn't been made to explicitly invite parents from CAMHS. 'Obviously the parents involved with CAMHS haven't been invited'.
- We also likely had a skewed sample. Those turning up were probably more likely to be motivated by poor experiences with CAMHS, rather than positive.
- Parents expressed disappointment that parent sessions were not well attended although advertisement didn't always get through to parents.

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