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What do young people with multiple long-term conditions and carers of children with complex care needs regard as important areas of research?

Final report for DHSC

Dr Erin Walker and Professor Stuart Logan
On behalf of CPRU, PenCLAHRC and PenCRU[1]

Introduction

The National Institute of Health Research (NIHR) is seeking to understand the perspectives of people with “multimorbidity” on what research questions should be addressed. As part of this process, the then-NIHR PenCLAHRC (now the NIHR Applied Research Collaboration South West Peninsula, or PenARC) and the NIHR Policy Research Unit in Children and Families (CPRU) were approached to elicit the views of young people and carers. Early discussions with families led us to define the relevant group on the basis of having complex care needs (CCN) or multiple long-term conditions (MLTC) rather than the widely used definition of multimorbidity as having two or more physical and/or mental health conditions. Relatively few children have two or more distinct “conditions” but substantial numbers have conditions with effects on multiple systems or areas of function, often encompassing both mental and physical health, which may interact, may lead to potentially conflicting treatment recommendations and frequently require interaction with multiple clinicians and services.

These involvement activities were part of a wider set of workshops seeking the views of working-age adults, and older people with multiple long-term conditions.

The **objective** was to work with children, young people and carers to understand the issues and questions relating to their experiences of CCN/MLTC that are important to them. Our two research groups were well-placed to respond quickly to the request and to deliver these involvement activities in a short amount of time, given our experience in patient and public involvement (PPI) in research and focus on, and networks in, child health.

A larger group of stakeholders will be consulted in the future to further discuss these research questions, with the ultimate aim to put out a funding call, or series of calls, for research around what matters to people with CCN/MLTC.

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This report summarises the involvement work undertaken by PenCLAHRC, PenCRU (the Childhood Disability research unit associated with PenCLAHRC) and CPRU with young people with MLTC and carers of children with CCN.

The report, which was discussed with participants during the process, seeks to summarise what they said about how their needs, or the needs of their children, affected their interactions with services, what they wanted from services and the key areas for research which derive from their experiences. No information was sought about specific diagnoses or service use as it was sufficient for this work to understand simply that children and young people experienced CCN/MLTC.

Aims

Our aims were to identify and describe, through patient and public involvement activities, the research needs of children and young people with experience of CCN/MLTC, and carers.

Methods

A blended model of involvement activity took place, which included working with two standalone patient and public involvement (PPI) groups, facilitating a bespoke meeting in collaboration with the National Children's Bureau, and individual discussions and telephone calls.

1. The **PenCRU Family Faculty** (http://www.pencru.org/getinvolved/ourfamilyfaculty/): This is a network of families of disabled children living primarily in Devon and the south west who work with PenCRU. Eight parent carers attended a meeting to discuss potential research questions. This was supplemented by face-to-face and telephone discussions with carers unable to attend.

2. The **Young Persons Mental Health Advisory Group**: This is a national group of young people aged 16 – 25 who have lived experience of mental health conditions, and promote the young person's perspectives in mental health research.

3. The **National Children's Bureau** (NCB): The NCB has been a collaborator of the CPRU for many years. This meeting was attended by 1 Young Research Advisor (who advises on child health policy); 1 member of FLARE, an NCB group for young people with special educational needs and disabilities; 1 member of Young NCB, a more general young person's membership group; and 4 people from the Making Ourselves Heard network, which is the leading national network focusing on disabled children and young people's involvement.

4. The PenCLAHRC Evidence Synthesis Team produced a *Rapid Briefing Paper* based on a scoping review entitled "Parent experiences of health care delivery for families with children with disabilities and complex health needs" to help guide discussion (Appendix 1).

Topics and questions covered

Staff from the PenCLAHRC and CPRU developed together session plans which covered some key questions:

- What mattered to young people with MLTC and to carers of children with CCN?
- What were their positive experiences of interacting with services (including health, social care, and education)?
- What were their negative experiences of interacting with services (including health, social care, and education)?

Prompts focused around Rosenbaum's (1992) Components of Care, such as: treatment; evaluation; parental involvement; team approach; emotional support; coordination; and education/information.

Meeting summaries

Involvement activities took place in June and July 2019. Fourteen parents and 12 young people were involved in total. Summaries from group discussions, and notes transcribed from post-It notes used in meetings are presented in appendices 2 and 3.

Key issues raised

There was considerable agreement between participants about the ways in which their CCN/MLTC affect their lives and their interactions with services.

Because they have difficulties affecting multiple systems or areas of function, they deal with a wide range of clinicians and service providers who come from different disciplines and often work for different organisations. These services must then interact with primary care, which is the way through young people and families access specialist health, social care, and education services. If these services are not effectively coordinated, it leads to a huge burden on families of multiple appointments, confusion between providers (and for families) about who is responsible for what, and sometimes conflicting recommendations. It is important to them that the services involved include both education and social care as well as health. Virtually all of these conditions are lifelong (and frequently life-limiting) and periods of transition from paediatric to adult services add further layers of complexity.

A number of people raised issues related to the fact that, where more than one area of function is affected, these can interact and management of one problem may actually exacerbate difficulties in another. This is particularly the case where mental health problems are part of the clinical picture. Clinicians may not always recognise that families may have to make trade-offs about what aspects of their children's care they are able to prioritise, particularly in the context of whole families' needs.

Society in general is often not well set up for people with CCN/MLTC. The practical difficulties can significantly hinder their ability to participate in many aspects of normal life. Issues relating to stigma and sometimes even hostility can compound these difficulties. Parents of children whose conditions include a significant behavioural component were particularly vocal about this point.

Caring for a child or young person with CCN/MLTC can lead to difficulties including social isolation and place a strain on the mental and physical health of carers which is sometimes not recognised by service providers. The needs of typically developing siblings are rarely taken into account, even though they are often deeply affected by their sibling's health and additional family attention.

What makes a good or poor service?

Parents and young people were largely unanimous in their reports on experiences of accessing services. What they valued were high quality, integrated services that were coordinated, easy to access and where health, education, and social care staff communicated effectively with children, young people, carers and each other. Services and those who provide them must ensure that they listen to children and families, acknowledge the centrality of their goals in making management decisions and treat them with respect.

Frequently raised **negative** issues of interacting with services included: having to repeat the child's history with every consultation; fragmented care with poor communication between practitioners and services; disagreements between professionals about diagnostic labels and management; failure to recognise the central role that families play in management; difficulty in getting access to services and long waiting times for appointments; variability in care, with only beacons of excellence; lack of recognition for the role of parents in caring for, and supporting, a child upon transition to adult services; a lack of appropriate services for young people when they move to adult services; being labelled as "difficult" when parents challenge individuals or the system in an effort to advocate for the best care possible for their child (which was also seen as necessary for getting high quality care); the significant financial repercussions that can occur for families of children with high care needs, with parents having to reduce or terminate employment; and not being adequately cared for, and at times dismissed, by single-speciality services due to the nature of CCN/MLTC. Families also commented that navigating the system was often complex, with a lack of clarity about who was responsible for which aspects of service and a lack of simple guides for families about who does what. Staff do not always treat families with respect or even appear interested.

On the other hand, frequently mentioned **positive** experiences of care included: caring and compassionate staff; adapted treatments; staff who advocated for services in another sector for the child; understanding how conditions interact; having access to social care (e.g. a support worker) although this was also described as problematic where it was a rationed, or time-limited service; and having a personal health budget.

What should services aim to achieve

From these discussions of issues that matter to young people and families, it was clear that person-centred care that meets the needs of young people with CCN/MLTC and their carers is often not available. We identified the following specific issues relating to what they want from services.

1) **Coordination and communication**
    a. Coordination between clinicians and between services regarding appointments, to avoid multiple instances of time off work and school
    b. Effective communication between young people and families, and services, reduces CCN/MLTC treatment-burden
    c. Families need to be empowered for shared decision making based on treatment preferences and goals
    d. "Tell my story once" – having to repeatedly describe health history is incredibly frustrating, can become a barrier to therapeutic relationships, and tiresome for people whose lives are often characterised by fatigue related to services
    e. Key workers to help coordinate care and advocate for the child, especially across service areas, are very helpful but not common enough
    f. The organisation of health and social care services are opaque and ever-changing as services are commissioned and de-commissioned, and with unwanted variation. This can further compound frustration and fatigue with services. Families should be made to understand who does what, and how services interact.

2) **Behaviour of service providers**
    a. Focus on priorities for young person and the family, what they want to achieve
    b. Ask, do not assume, what a young person or carer wants to be called, for example by their first name if they are the carer, and not objectified as 'Mum'
    c. Stop considering or calling a carer difficult because they want the best for their child. Often carers have to advocate repeatedly for their child to receive good quality care.
    d. Displays of empathy and interest, and interpersonal skills, are an important component of good quality care, especially given that living with CCN/MLTC is hard
    e. Don't assume, instead ask, "what matters to you?"
    f. Do not assume another service provider is meeting a specific need of the young person or family, or pass responsibility when this is requested of you

   g. Do not assume that a person's physical appearance, in terms of how they present themselves (e.g. by wearing makeup or smart clothing) means a person is feeling well

3) **What gets missed**
   a. Burden on the family – Financial and emotional
   b. Needs of the family – Siblings as well as carers
   c. Preparing for life (e.g. "I could only have 4 therapy sessions, 10 sessions on chronic pain etc. which isn't enough to teach you how to deal with it for the rest of your life") A child or young person with CCN/MLTC will likely have life-long needs, and progress through to adulthood. Continuity of care is therefore crucial, and services should anticipate that a person with CCN/MLTC may require re-referral to services as needs vary over their lifetime.
   d. Addressing social stigma and barriers to participation in 'normal' life

4) **Understanding of the young person with CCN/MLTC as a whole**
   a. Young people with CCN/MLTC are still exactly that – young people. They have important life concerns and goals similar to those of young people without CCN/MLTC which should be respected and service providers should try to promote
   b. A better understanding of how conditions interact – particularly the intersection between physical and mental health conditions
   c. Exclusion criteria for interventions for one condition due to presence of another are nonsensical and frustrating
   d. Clinicians focussing solely on one condition or specialism without consideration of other conditions adds to frustration and increased treatment burden

5) **Intersection of service areas**
   a. The effect of health on education is significant – schools must appreciate this and make better efforts to communicate with families to understand and meet individual education needs
   b. Age is irrelevant when it comes to young people with CCN/MLTC and carers should not be rejected from facilitating and being involved in their child's care (as they currently are) when a child turns 18
   c. Health and social care services must be better integrated, and continue where clear benefit has been demonstrated, e.g. access to hydrotherapy or a personal health care budget

6) **Listening and Respect**
   a. Young people and parents are the experts on the young person's CCN/MLTC, and service providers ought to respect this and listen to them

b. Not listening can lead to incorrect assumptions or prejudice, e.g. that physical symptoms are a manifestation of mental health problems, or that a young person is limited in society
c. Feeling listened to and respected would prevent stress/anxiety and prevent the need to access further services (e.g. mental health) as a result

What research is needed?

Participants clearly identified the issues that mattered to them, including about how services are delivered and about how they can be enabled to participate more effectively in society. In particular, they identified the features that constitute a “good” service and argued that services and interventions should be evaluated against these goals.

If we are to provide evidence to inform policy and practice which aims to address the issues raised by the young people and carers, our findings suggest there is a need for research in the following areas:

Better understanding the problems

1. Understanding environmental barriers and facilitators to participation in everyday life for people with complex health needs.
2. Understanding what drives stigma (and interventions to reduce it).
3. Studies which aim to understand what aspects of service delivery are associated with better outcome for children and families.

Developing and evaluating interventions to achieve the families' aims

Participants argued that there is a need for interventions which seek to achieve the outcomes they have identified above. Interventions may be aimed at making changes in systems, services and organisations or in the way in which practitioners operate.

Amongst specific areas suggested were:

1. Interventions which promote service delivery of family-centred services.
2. Methods to simplify navigation of the system for families.
3. Interventions which aim to increase opportunities for participation in everyday life for people with CCN/MLTC.
4. Interventions aimed at peer groups (e.g. in schools) or wider society which aim to reduce stigma and promote acceptance for people with disability and complex need.

Improving professionals' skills

Training, education or systems which facilitate appropriate behaviours and attitudes amongst practitioners across all disciplines and settings, including the acute sector.

Instrument for evaluation

Young people and carers suggested a need for methods and measures to effectively assess the extent to which outcomes identified here are achieved. These are needed both for research and for service evaluation.

Conclusion

The young people and carers who contributed to this report identified what was important to them about a child's experience of CCN/MLTC, which impacted the whole family. These may be significantly different to what policy makers, researchers, and clinicians consider to be important. The young people and carers identified a number of areas where service provision could better meet their needs. They also pointed to the need for increased opportunities to participate more fully in society and to reduce the stigma associated with having a disability or mental health problems. They argued that an important goal of research should be to find more effective ways of achieving these ends.

Acknowledgements

It was a pleasure and an honour to speak candidly with all young people and carers, and we are extremely grateful to all who were involved. Your stories were striking and motivating. Thank you for everything you shared.

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Appendix 1. Rapid briefing paper

UNIVERSITY OF EXETER | MEDICAL SCHOOL

ESMI Evidence Synthesis & Modelling for Health Improvement

Parent experiences of health care delivery for families with children with disabilities and complex health needs:

A rapid briefing paper

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This is a rapid briefing paper, complied in 2-3 days to address the following research questions:

In children with complex health needs what are the key difficulties that parents perceive with the way that services are delivered for their children?

What aspects of service provision do parents of these children want/value?

General context and definitions:

Children with medical complexity: In 2011, Cohen and colleagues[1] proposed the following definitional framework for children with medical complexity. The framework consists of four domains:

- Substantial family identified service needs and/or significant impact on the family (e.g. financial burden).
- Diagnosed or undiagnosed chronic condition which is severe or associated with medical fragility.
- Severe functional limitations and/or dependence on technology.
- High healthcare use and/or engagement with multiple service providers that may include non-medical providers.

Caring for a child with complex health needs: Many studies have demonstrated that parents of children with complex health needs routinely provide medical and nursing interventions alongside other parenting tasks. Parents become extremely knowledgeable about the condition and treatments, learn how to identify and respond to symptoms and seek to work in partnership with their key healthcare professionals. Parents are often keen to be involved in a shared decision making process. Families of children with complex health needs often struggle under the financial, emotional and physical burden of meeting their child's ongoing needs and navigating a health system designed to provide episodic care to individuals with singular health concerns. Accessing health care involves multiple visits to medical specialists that are unlinked and uncoordinated.

Traditional models of healthcare: In traditional models of paediatric health services, the healthcare provider plays a major role in assessing and formulating a plan of care, based upon the perceived needs of the child and/or family. In the medical or standard model of health care, the healthcare worker plans care around the child's illness and treatment needs, and the family is generally expected to comply with treatment recommendations.

Family centred care: FCC is considered the standard of paediatric health care by many clinical practices, hospitals, and health care groups. The Institute for Patient and Family Centered Care definition includes the following four core concepts: respect and dignity, information sharing, participation, and collaboration.

Numerous terms are used to describe family-centred care within the literature, including family-centred care, family-centred service and family-centred practice. For any of these, this briefing will use the term family-centred care (FCC). A comprehensive literature review conducted in 2012[2] proposed that FCC is an approach that acknowledges the importance of the family as a recipient of care, ensuring the participation of all its members in the planning of actions and revealing a new model of care, offering the opportunity for the family itself to define its own problems. Respecting the child's individuality and that of his/her family is decisive and represents a permanent challenge for health services and health workers, as well. It requires the staff to be open and attentive to the interactions and impact of experiences and also to provide knowledge concerning the dynamics, beliefs, and ways families can adapt to different situations.

NOTE; Family-centred care is also used alongside shared decision making, parent-provider partnerships, and parental empowerment (all which have their 'own' extensive literature)

What the research evidence says:

About parent experiences of care for children with complex health needs:

We were unable to identify a qualitative evidence synthesis that specifically explored parent experiences of accessing care for children with complex health needs. Whilst it is well established that parents want to be involved in decision making with professionals about their child's care and want to take an increasing role in decision making as they develop confidence in their caring role, the literature suggests that parents' experiences of involvement in decision making are mixed. Parents in some studies have reported very positive experiences and expressed satisfaction with their involvement but in other studies, parents have identified that they did not always feel listened to by professionals and their expertise was not always taken into consideration when decisions were made. The key aspects of service provision that parents appear to value are co-ordination of care across systems, effective communication with health care professionals and recognition of their knowledge and skills in caring for their child. Parents also value a stable, long term relationship with their primary health care provider building trust, understanding and mutual respect.

A rapid, structured review of the literature, published in 2015, highlights the significant role that parents of children living with a long term condition have in providing medical and nursing interventions. Parents need knowledge of the condition and treatments, to learn from illness episodes to enable them to respond appropriately to future episodes, to access relevant services and support networks and to develop effective relationships with healthcare providers. However, parents describe difficulties in obtaining information. This review also reported that parents often found communicating with health care professionals stressful and commented that relationships between parents and health care professionals were often poor when parents felt undervalued or if their decisions did not appear to conform to professionals' advice.[3]

In parental focus groups conducted during the first year of a co-ordinated care service for children with medical complexity, parents reported that communication across systems of care was often fragmented and uncoordinated and that they perceived this gap in communication as a threat to their child's health and wellbeing. In this study, parents reported trying to eliminate the gap by assuming overall responsibility for their child's care and care coordination and found many barriers and obstacles to being able to do this well. Parents reported difficulties in obtaining necessary information from health professionals and revealed a significant impact of their caring role on family life. Barriers to information sharing included a fragmented health system with poorly defined care coordination roles, lack of cross-systems accessible health information and a lack of standardised policies for sharing information. Parents in this study described how they felt they were required to take on the role of communicating across systems, regardless of their capacity or ability to fulfil this role.[4]

In a mixed methods evaluation of a tertiary care-community collaboration, focus groups with parents found that parents consistently described the benefits to themselves and their child of the co-ordination of care across settings and specialties. In particular they cited numerous examples of how they were able to communicate with their health care providers with a single call or email. The initiative also resulted in significant reductions in travel and time to attend appointments.[5]

In a discussion piece written by parents of children with complex medical needs, issues with the fragmentation of services are again highlighted. The authors describe how families of children with complex medical needs are required to navigate a complex referral pathway to access the care that they need and that this fragmentation creates gaps and challenges for families and providers. They go on to suggest the development and use of shared care plans created in partnership with the child and family and in a format that can be shared with all involved parties. The authors also highlight the importance of recognising the family as the most important constant in the child's care and supporting partnership in all aspects of that care.6

In a qualitative interview study of parents of 47 elementary school-aged children with spina bifida, Down syndrome, attention-deficit/hyperactivity disorder, Duchenne muscular dystrophy or cystic fibrosis, semi-structured interviews were conducted to examine their experiences and perceptions of continuity of care. The study found that a thorough knowledge of the child on the part of service providers was extremely important to parents and that such knowledge was underpinned by continuity of personal relationships and also by written information. Compartmentalization of services and information led to parents assuming a necessary, though at times, uncomfortable, coordinating role. Geographic factors, institutional structures and practices, provider attitudes, and, on occasion, parent preferences and judgments, were all found to create barriers to "seamless" management and provision of care continuity across providers, settings, and sectors.[7]

A survey of families with children with a range of physical, cognitive, sensory, and communication impairments [8] found that parents of disabled children continue to highlight the importance of feeling empowered and working in partnership with professionals. Although many parents reported positive relationships with professionals within the Trust and a willingness to go "over and above" the call of duty, there were also many parents who felt the need to "fight" for their child to ensure that their needs were met. This has been evidenced in numerous previous studies and was associated with a great deal of stress. Another of the areas highlighted by parents was the continuing difficulty in accessing information. Lack of information was also highlighted in a study of Icelandic parents of children with physical disability [9]. Overall, whilst the parents found the therapy services respectful, supportive, and coordinated, enabling them in their parent role and working mostly in partnership with the professionals, parents perceived they received insufficient information and wished for more cooperation, teamwork, and a key worker.

In studies focussing on parents of children with cerebral palsy, although fairly positive about FCC in general, all have suggested that some areas of improvement are still needed: in particular in the areas of communication and provision of information [10-12]. These studies, although acknowledging that there are some good aspects of care, suggest health professionals need to provide better communication and take more time in giving information and attention to parents [10], and that written information about the child's condition, the possibility to choose when to receive information, and contact with other families in the same situation are areas still in need of improvement [11]. One study.[12] found that parents reported a lack of information and guidance from health professionals and services, and highlighted how much parents relied on other parents for support. Furthermore although parents indicated their preference for a partnership, they did not always experience having their needs met this way. Parents frequently described experiences in which they felt that their knowledge of their child and their child's needs were disregarded. Authors went on to conclude that there is a need for better access to information and improved education of parents.

Similarly, in a qualitative study of health care providers' perceptions and experiences of working together to care for children with medical complexity, provides commonly described difficulties with communication and a lack of clarity about who should be communicating what to whom. In this study, it was observed that adolescents were particularly susceptible to service fragmentation as they transitioned from child to adult services.[13]

About parent perceptions of FCC for children with complex health needs:

In their seminal paper in 1999 King et al[14] said that care services for children with disabilities are most beneficial when they are 'delivered in a family centred manner and address parent-identified issues such as the availability of social support, family functioning and child behaviour problems'. Since then there has been much written on the need for family centred care (FCC), for children with disabilities and complex health needs, and examples of it in practice. FCC, or care focussing on family-provider partnerships has been shown to be effective[15], but has care improved for families?

A systematic review on parents' perspective of receiving FCC using quantitative measure of FCC[16] included 15 studies, mainly of parents with children with cerebral palsy. The review found that service providers tend to focus more on sharing information about children's health conditions and development rather than sharing general information about current and future services and parent support groups. The authors recommended that service providers need to engage the family in ongoing conversation to better understand the family's information needs and to share information on services, community programs, and parent groups. It is important to appreciate that family needs for information are broad and might pertain to many aspects of child's and family's life.

One of the studies included in this review was a cross-sectional survey that aimed to examine the factors that are most important in determining parent perceptions of the family centred-ness of care and parent satisfaction with service[17]. The survey, which was completed by 494 parents, 324 service providers, and 15 CEOs from 16 organizations delivering children's rehabilitation services concluded that parent satisfaction with services was strongly influenced by family-centred culture at the organization and parent perceptions that services were more family centred. Perceptions of family centred-ness were more positive when there were fewer places where services were received and fewer health and development problems for their child.

A review of FCC for children with intellectual disability in hospital[18] found that for parents, when health care staff get to know their child, negotiate care roles and work in partnership with parents, it lessens the parental burden of responsibility, and keeps the child and their individual needs at the centre of the care experience, acknowledging the child has intrinsic value. The authors concluded that health care models still need to be better at focussing on the child and their health care needs and this will inherently involve negotiating care roles and partnerships with parents, while maintaining focus on the child. The review highlighted that shifting beliefs about the optimal models of paediatric health care will necessitate a systems-wide approach to improvements such as health policy and enhanced undergraduate education, expedited though changes to broader social and cultural perceptions of the value of people with intellectual disability.

Similar findings were concluded in a review of support systems for families of children with disabilities[19]. These authors suggested that although the research on supports available to families suggest that there are local and regional mechanisms that provide educational, instrumental, and emotional/advocacy supports to families with some benefits, there still needs to be system-wide policy changes to have the most significant impact on improving the quality of life and long-term outcomes of families of children with disabilities.

Guidelines and government strategies relating to this area:

2019 Scottish Government; Supporting disabled children, young people and their families: guidance. https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/

2015 NICE; Challenging behaviour and learning disabilities: prevention and interventions for people

with learning disabilities whose behaviour challenges. NG11.
https://www.nice.org.uk/guidance/ng11

2017 NICE; Cerebral palsy in under 25s: assessment and management. NG62.
https://www.nice.org.uk/guidance/ng62

2018 NICE; Learning disabilities and behaviour that challenges: service design and delivery. NG93.
https://www.nice.org.uk/guidance/ng93

2010 World Health Organisation; European declaration on the health of children and young people with intellectual disabilities and their families . Better health, better lives: children and young people with intellectual disabilities and their families Bucharest, Romania, 26–27 November 2010. 15pp

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Appendix 2. Notes from PenCRU Family Faculty and PenPIG

Multimorbidity workshop: PenCRU Family Faculty + PenPIG

Thursday 13th June 2019

Attendees: Hannah, Julia, Kirsty, Jane, Mary, Mark, Heather, Chris, Katharine, Emma, Chris.

What works well?

- **Teams working together**
    - **Clinics within education (Education and healthcare):** Having healthcare clinics in special schools (Paediatrician, optician, dietician, wheel chair clinic). Makes life easier for all. Parents don't always have to be there. Decreases stress for child and have less impact on day (10 minute appointment ONLY as opposed to an hour of driving, parking etc.). Works well on both sides, it's good for the services as well. They are in school anyway so less no shows.
    - **Residential schools (Education and social care):** Monday – Friday spent in residential school. Taught things that couldn't at home. Strong and supportive teams.
    - **Multipurpose Appointments:** Having lots of things done at the same time. e.g in for a general anaesthetic, so use opportunity to have brain response hearing test, and teeth examined. This required a team of willing people. Plus persistence and politeness to get people to help.
    - **Disability services in the hospital:** Were able to meet at entrance of A&E to avoid waiting in waiting room, and get treatment that would have otherwise been refused.

- **Common thread of support / Co-ordinated care.**
    - **Tailored care:** Understanding the individual's needs and abilities and adapting care accordingly. For example hearing test: Worked with multi-sensory worker and the teacher for deaf, in practice for preparing for the test. Found a way to do the test that was unique to the child. Ignoring how things are meant to go, and what will work for the child. This was because the person who is with her daily was able to advise the audiologist.
    - **Direct contact**: When working with a clinician being able to contact them directly and not go through "the secretary of the secretary to organise them".
    - **Key named person**: whether this in school or hospital – someone who takes overall responsibility if have a problem or needs something doing. This gives consistency of knowledge about the child.

In the 0-5 years you might get allocated a key worker who co-ordinates everything. The key worker is there "as a shoulder to cry on" "someone that just really guides you through, co-ordinates it all.
  - **Early years support model:**
  - **Consistency:**
    - Staff knowledge about child which means that care is appropriate.
    - **Institutional memory:** The same place, same rhythm, same secretary, same room set up. All of these things really help. Often have the same routine e.g. "when we've seen the doctor we will go to the café and have a milkshake" "if the café then changes milkshake – it's the end of the world". If you can keep the things around the experience the same.

- **Understanding the system**
  - **Kit box for 0-5s:** Depending on the issues your child had you would get inserts with information about physio therapy, visual impairment, occupation therapy – explanation of who professional were and what they could do for child. **"Blue book"** where pages where you can write about diagnosis, conditions, medications. Page for professionals – put photographs of those involved with care (plus telephone number and email) When your head is exploding with information it really helps to group thoughts and the "team" involved in child's care.
  - **Being given a sense of how services are organised amongst themselves:** When you've been using them for 10 years you understand how they relate, but when you are new to services, understanding who you can use for what. "if you are new to it all you have never heard of the services, you haven't heard of half the names" "absolute double Dutch"

- **Communication**
  - **Being listened to:** Parent carer Input is understood to be helpful and not difficult. How you and your voice is perceived in the system is really important.

- **Culture:** where people believe that a person has the right to develop and be supported that is really powerful. It's not a "thing" it's an approach or way of thinking and when that happens it's really powerful

What are the difficulties?

- **Communication and coordinated care**
    - **18+:** After 18, parents then not informed or involved in care. "I'm really scared about that, because when my son turns 18 he is not suddenly going to become competent, but I'm going to be officially pushed out of that table of care, but still expected to do the donkey work". They might assume understanding, prior knowledge of a young person. "He presents really well and he will look at you like he takes it in, but he's come home and I've asked him, and he doesn't understand anything about the process"
    - **Reading notes / personal understanding:** doctors etc. don't read notes or know background and so might follow routine practice rather than adapting for the situation. Or they might ask things that are inappropriate or have been answered before.
    - **Between hospital / NHS trusts:** Trying to organise co-ordination between hospitals can be difficult. Often have to go to different hospitals for different treatments. What is difficult is when communication breaks down when trying to co-ordinate treatment between hospitals (e.g. teeth clean whilst under general anaesthetic – request by one hospital dentist but didn't happen in hospital two as requested)
    - **Lack of information:** Not knowing what services are out there, and how the "system" works. It can be hard to get help for children from other services.

    A Parent's experience – "in my experience if you want to help your child effectively it is absolutely fundamental that you keep every single scrap of paper regarding your child's treatment filed and organised. Whilst it's not complicated, this vital process is easier said than done. I think along with all the other brilliant suggestions regarding blue books and kit boxes it would be good if prominence was given to this issue for new parents. I think a few prompts and guidance to help parents physically manage the mass of documents that accumulate could save a lot of heartache".

- **Ownership / responsibility of care**
    - **Funding:** funding always seems to come from different pots, with organisations / services "passing the buck" to someone else to try and cut their own costs.
    - **Services assuming another service is doing something and therefore no one does it:** There is sometimes a feeling that no one is taking ownership of child's need, with child "too complex" to fit the mould of a normal service.
    - **Split across different hospitals:**

- **Treatment**
    - **Priority setting:** Not taking into account what is important for the child / parent. Dismissing some of the "normal" treatments e.g. orthodontics, optometrist, because it's not seen as a priority.
        - E.g. buck teeth, doctor questioned why would want to consider braces "I would do it for his twin, why wouldn't I do it for him". "Just because they have got a lot of other conditions shouldn't mean he can't have straight teeth."
        - Too much writing off of children from certain services because they have got complex needs. "perception, well she's too difficult, and no expectation of what she is going to achieve, for all the wrong reasons because they are looking at a broad-brush disabled child from birth view"
    - **Strategic oversight:** Not understanding the bigger picture.
    - **Prevention over treatment:** Providing counselling for parents is all well and good, but focus should be on making the environment less stressful so it's not needed. "We are going to have a really stressful, inappropriate provision and then send the parent to counselling to fix it. Have a service that is emotionally aware of the way in which it works, and the stress that it provides, and then don't be stressful. And then the parent isn't stressed and doesn't need the counselling". **Services are often only triggered at crisis point.**
    - **Financial costs:** Although treatment itself doesn't cost family, there is still a huge financial burden. If treatment away from home, only 1 parent allowed to stay on ward with child. Hotel needed for the other. Cost of eating away from home / having to buy new cloths as no access to washing facilities.
    - **The system understanding the needs of the child:** It's important that people doing the testing understand the complex needs. That they might not be able to do the straightforward test like other children. Lack of understanding from the health care providers about the specifics of that child and their needs.

- **Being labelled as "difficult" / "anxious"**
    - **Not being taken seriously:** Parent carers are meant to be taken seriously, as equal member of the team working with the child – often this is not the case. "There for lip service but actually the professionals know the right thing"
    - You have to be pushy to get stuff done.
    - "we, more than anyone, know the potential of our child"

What services are missing?

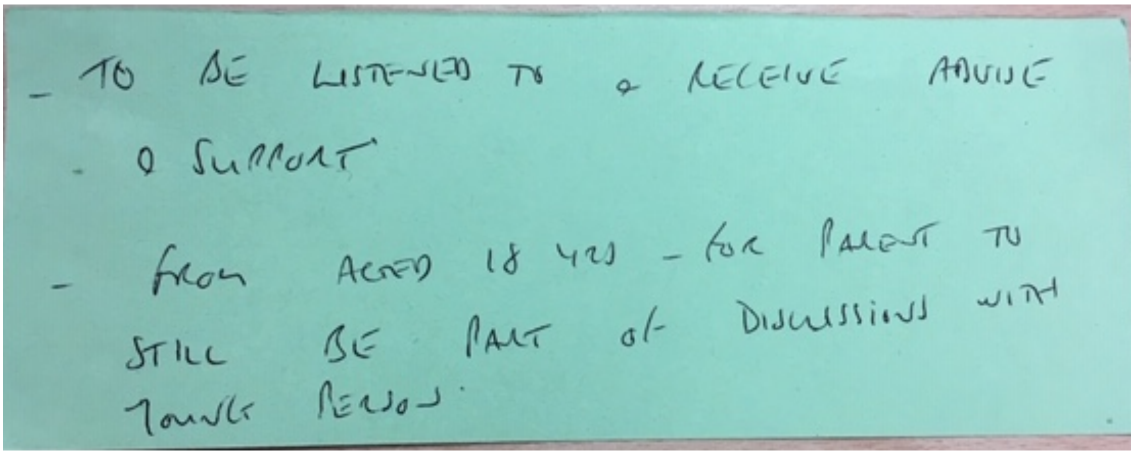
"You are not just your illness, what can you do with that illness for the rest of your lives"

"Being supported with your disability in the outside world not just in the hospital, and across the lifespan."

" listen to me, understand what I'm saying and take it on board and action it"

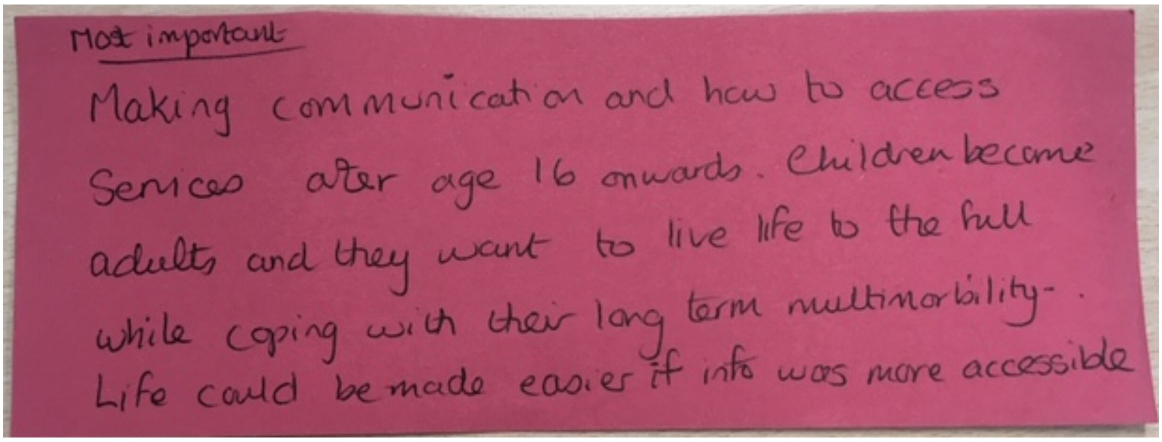
- **Employment support:** Often just think about the support as a child, but also important to think about the future of that child. Things like employment support would help to support this.
- **Life skills / preparing for adulthood:** This is especially important if in mainstream school, as this can be missed. E.g. making a cup of tea if you are visually impaired, make-up lessons.
- **Parent career skill development / recognition / supervision:** The skills and attributes of parent carers are unique. Skills gained with experience are valuable for ensure the services work as in the "what works well" section. If some of these skills could be taught early on it would have impact on both the child's care and the carer's wellbeing.
- **Services after 18:** Continued support after 18 which also encompasses the involvement of the parent.
- Programme for children to help them accept who they are, and their disabilities and have value and worth in the world.

What is the most important thing to you when interacting with services?



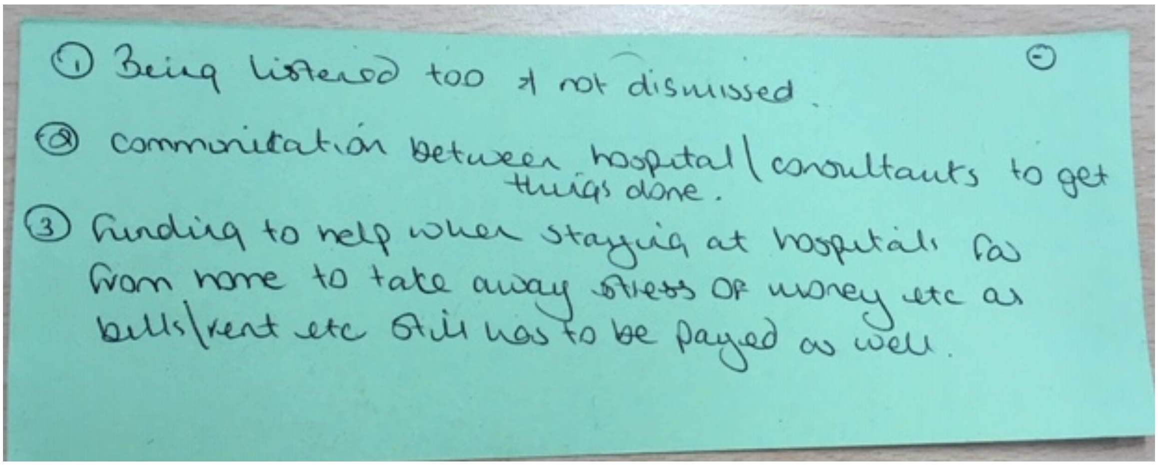
- TO BE LISTENED TO & RECEIVE ADVICE & SUPPORT

- FROM AGED 18 YRS - FOR PARENT TO STILL BE PART OF DISCUSSIONS WITH YOUNG PERSON.



Most important

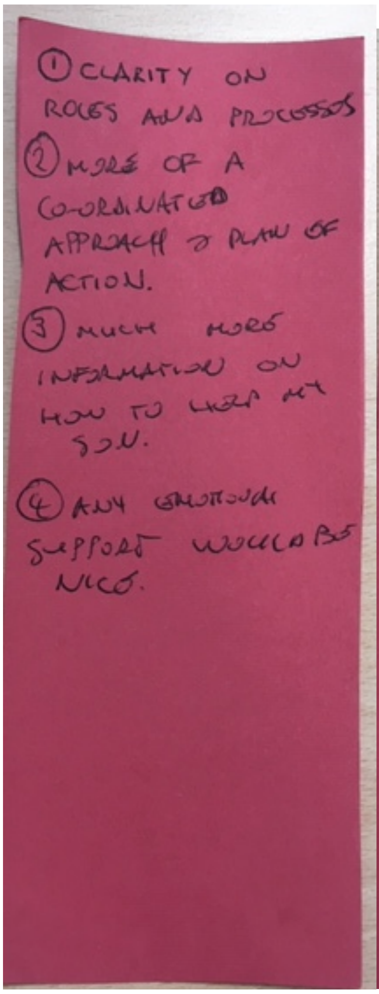
Making communication and how to access Services after age 16 onwards. Children become adults and they want to live life to the full while coping with their long term multimorbidity. Life could be made easier if info was more accessible



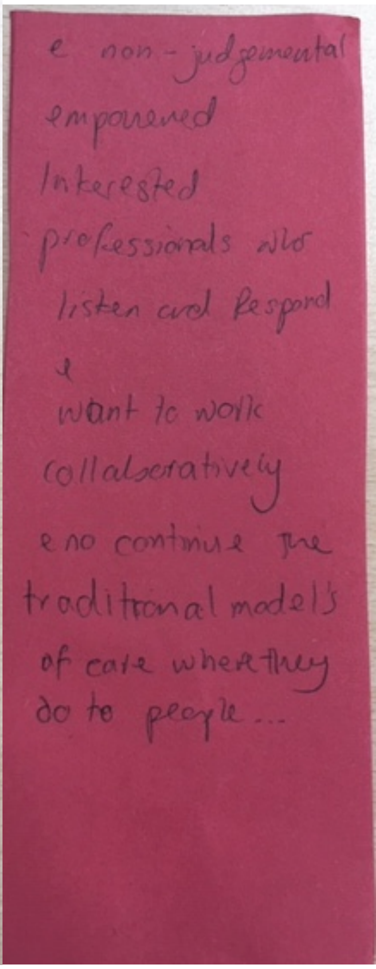
① Being listened too + not dismissed. ☺

② communication between hospital | consultants to get things done.

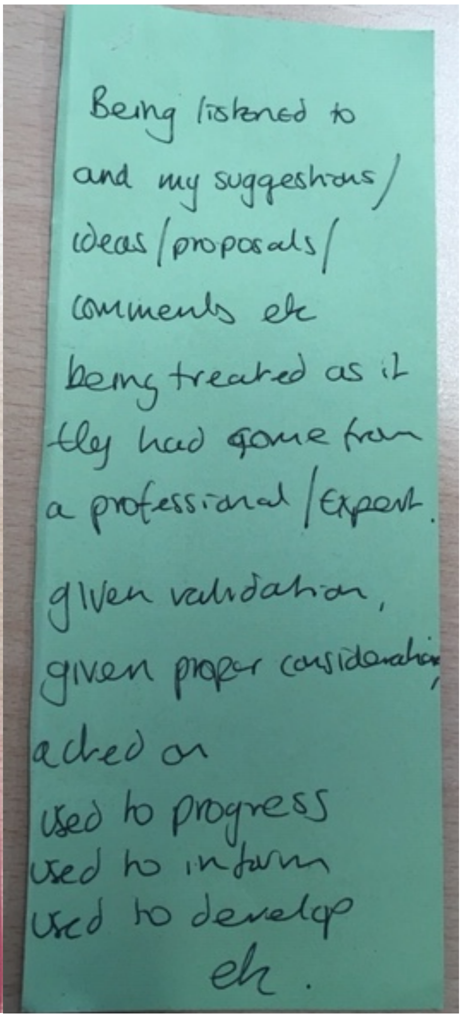
③ funding to help when staying at hospitals far from home to take away stress of money etc as bills\rent etc still has to be payed as well.



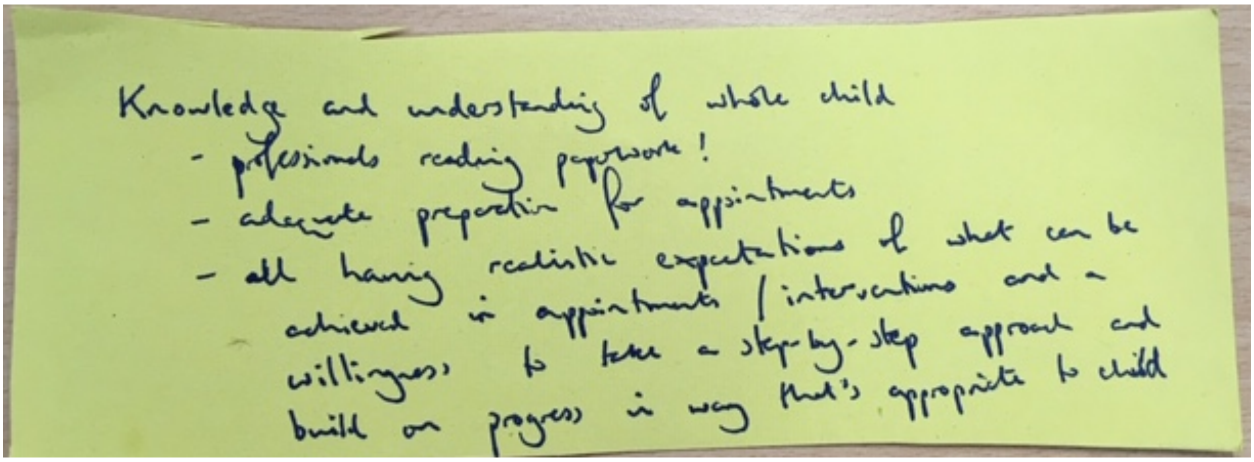
① CLARITY ON ROLES AND PROCESSES
② MORE OF A CO-ORDINATED APPROACH & PLAN OF ACTION.
③ MUCH MORE INFORMATION ON HOW TO HELP MY SON.
④ ANY EMOTIONAL SUPPORT WOULD BE NICE.



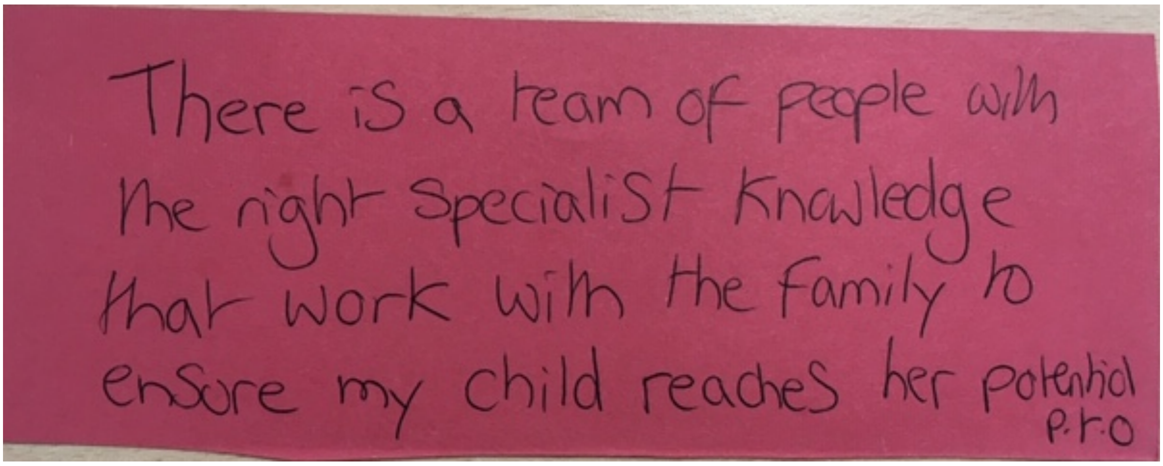
- non-judgemental
- empowered
- Interested
- professionals who listen and respond & want to work collaboratively
- no continue the traditional model's of care where they do to people...



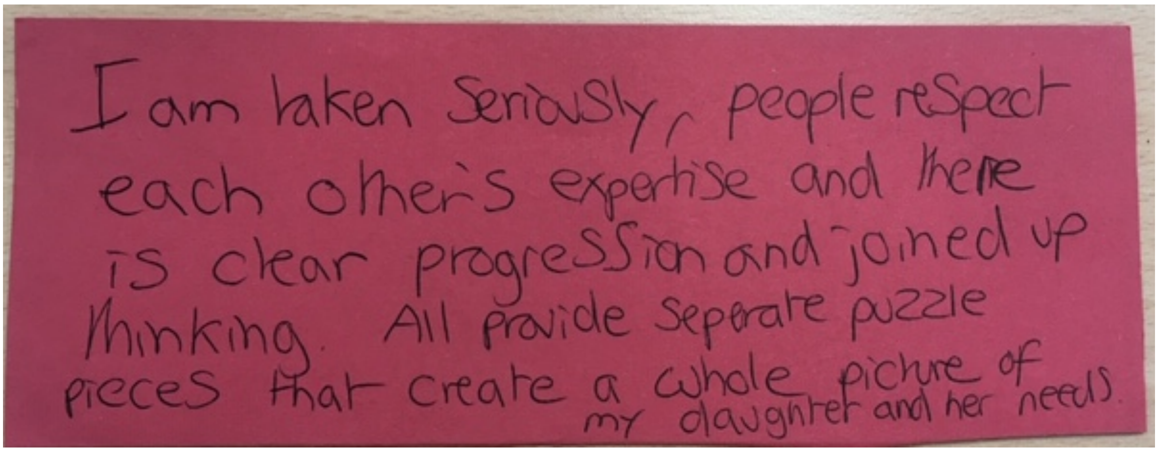
Being listened to and my suggestions/ideas/proposals/comments etc
being treated as if they had come from a professional/Expert.
given validation,
given proper consideration,
acted on
used to progress
used to inform
used to develop
etc.



Knowledge and understanding of whole child
- professionals reading paperwork!
- adequate preparation for appointments
- all having realistic expectations of what can be achieved in appointments / interventions and a willingness to take a step-by-step approach and build on progress in way that's appropriate to child



There is a team of people with the right specialist knowledge that work with the family to ensure my child reaches her potential
P.T.O



I am taken seriously, people respect each other's expertise and there is clear progression and joined up thinking. All provide seperate puzzle pieces that create a whole picture of my daughter and her needs.

NOTE: A list of outside agencies who help in long term conditions with children and their carers.

1. Housing departments within councils, housing societies
2. Adaptive suppliers for special needs for equipment - Age Concern believe it not supplied my high stool so when I was huge in pregnancy with my son, so I could sit instead of having a wheelchair!
3. Citizens advice bureau
4. Pharmacists suppliers and delivery schemes
5. Designated co-ordinator person at nursing agencies who organise care needs for carers and the child
6. Transport - disabled access on trains and buses or in taxis. transport to school,
7. Garages - disabled car supply or where makers supply adaptions to cars to get the whole family in
8. Homestart - organisations who offer help, respite or advice to parents who struggle with little or no extended family or need help generally,
9. Charities - Lions, round table, buffs who supply money (unnamed donations or gifts) to help struggling families

Appendix 3. Notes from CPRU-organised workshops

Workshop 1: The Young People's Mental Health Advisory Group 15 June 2019

6 CYP

What matters to you about multimorbidity?

- Cliff edge – Parent very active in accessing services + transition. Appointments so spaced out. No reminders.
- Adapted treatments that acknowledge intersecting needs
- Better information sharing between specialists
- Interconnectedness of conditions + looking at the whole picture + nature of interaction
- Self-determined hierarchy of conditions
- Adaptable treatment techniques
- Informed professionals
- Allocated resources i.e. not going to be prematurely discharged because case is 'too complex'
- Transparency, regarding options for treatment (waiting times etc… allows you to make your own informed decisions)
- Rapport – caring, empathetic
- Communication between services
- An understanding of the links between the multimorbidities
- Patience, a calming approach amongst the personal complexities
- If your primary condition is mental, reassurance or clarification physical symptoms are, or not, problematic. It's difficult to know the extent to which address physical problems if unsure they're psychosomatic
- Having all your conditions respected equally
- Having an understanding and kind clinician – I was able to gain a really good relationship with the clinician to work with. It was often the actual system that let me down, not the people within the system (often?)
- Knowing how they (your conditions) relate to an affect each other
- Being judgement free – Having an environment without the feeling of judgement, no matter what the disorders
- Treating each illness on its own and not as side effects of one illness.
- Neglecting treating one illness over the other/better understanding of one over the other
- Understanding how conditions can affect each other
- Seeking quality treatment for each illness
- Willingness to listen – People usually know what's wrong, what's normal and not normal for them. (We may not be professionals but we're not idiots.)

- Compounding effects
- Reassurance of belief by practitioners
- Adapted intervention services
- Identification of more than a singular ‘root cause’
- Acknowledgement of how conditions intersect
- Strategising for each condition
- People not making judgements/assumptions about my health/life because of my age
- Understanding my limits + getting support
- Getting support that encompasses all elements of my health issues as much as possible
- Being challenged to try things I think will be difficult but understanding if I have to rest of stop
- Being able to live as normal a life as possible
- Trying to balance my mental + physical health
- My chronic pain nurse has chronic pain so completely understands where I’m coming from

What are the bad things/difficulties you’ve experienced with services?

- Other conditions = exclusion criteria!
- Dismissing symptoms as psychosomatic without investigation
- Comorbidity cancelling out effectiveness of interventions even if you are not explicitly excluded for them e.g. ASD + CBT for anxiety, gastric problem + anorexia treatment, CFS or chronic pain + exercise for depression, social anxiety + group therapy for bulimia
- Ignoring one or more diagnoses for simplification or recognition of immediate risk – however diagnoses are interlinked + inextricable
- Being asked to prioritise health conditions
- Being referred to one-size-fits-all treatments, no alternatives even if I know (and there is corroborating scientific evidence) that due to multimorbidity the method will be less/ineffective for me
- Difficulty meeting criteria for needed diagnoses because of unacknowledged comorbidity
- Being ‘too complex’ for services to accept you as a patient/offer you appropriate treatment
- MH service access dependent on YOUR RESPONSE to treatment – if you don’t get better, you’ll be discharged. Comorbidity needs <u>long-term</u>, <u>adaptive</u>, <u>personalised</u> care
- Condition excluding access to treatment for another [condition]
- Difficulties fitting multiple appointments in to your schedule
- Poor communication
- Lack of focus on your wide picture (your complex health needs)

- Priority of physical health
- Having multiple conditions often excludes from taking part in research
- Doctors/GPs being uncomfortable with mental health issues. I had the flu very badly because my immune system was down due to being underweight. Once the doctor was told I had an eating disorder he recoiled and was clearly uncomfortable. It doesn't make you feel great…
- Problems with waiting lists and miscommunication – I had to wait 16 months to get help. And due to multiple problems I had a lot of miscommunication happen between services, family, school and my own information.
- Never being given a clear diagnosis – Diagnosis isn't needed, but it was never very clear as to what was wrong so what I needed to work on out of sessions, e.g. is it family? Mentally? Physically? Myself? How do I work on it?
- Doctors making assumptions about my physical health because of my mental health.
- Physical specialists not helpful with the mental health side. Psychiatrist does not understand physical conditions and their implications.
- An intervention for one condition worsens another condition. Feel very 'stuck' which worsens mental health which worsens physical health.
- Limited amount of treatments. I could only have 4 therapy sessions, 10 sessions on chronic pain etc. which isn't enough to teach you how to deal for the rest of your life.
- Getting a diagnosis was hard because I was 'too young' to have that condition
- Having multiple specialists in multiple places means a lot of time is spent on travelling/appointments and is difficult to juggle with full-time work/education
- Having to spend ages thinking and planning social invitations e.g. mobility, rest space, who there, what if. When should just be simple yes or no (want vs. feasibility).
- Medication is expensive!
- Not understanding my needs
- Not getting the right support
- Finding time to seek treatment for each condition without it taking over your life
- Cost of services (transport costs)
- Waiting lists for SLaM/Early intervention
- Managing day-to-day activities
- Emergency support
- Stigmatisation of personality disorders. Inaccurate diagnoses. Waiting times. Too many doctors involved. Lack of specialists, i.e. adapted therapies. Education discrepancies of coinciding conditions. Lack of sign interpreters. Inherent, systematic bias against BME service users.

What are the good things/positives you’ve experienced with services?

- Early Intervention (COAST) Croyden - Holistic care, care co-ordinator who I could text for any issues. Psychologist for CBT weekly, helped massively. Careful review of medication. I was able to recover quickly from 1st episode psychosis
- Allowing expression in ways other than forms e.g. visual comms. Not being penalised for missing lectures. Lecturers being able to sign. Expense coverage.

Workshop 2: NCB 6 July 2019

6 CYP, 3 parents

What matters to you about multimorbidity?

- Schools need to be more accommodating for your condition. I am allowed to breaks but it’s hard for me to access it. Right now I am in hospital for longer because they need to find independent accommodation for me but it’s taking long. Hard to receive financial funding whilst I am at hospital. Having all your healthcare professionals involved in your care knowing about other illnesses. A lot of times you have to explain all your illnesses to healthcare professionals a lot of times. Having a log of all illnesses would help. Being able to access the support you need more targeted to your condition. Often you end up in a long queue in A&E even though it is long-term. Learning to manage all your illnesses by knowing and getting help to understand how one might trigger another. People in the community often think your less capable because you have more illnesses which can sometimes not feel good. Being in hospital moving from adolescent unit, it can be daunting since it’s 18+. There should be a 18-25 ward maybe.
- Having a responsive administration at school/university/in the workplace. Aid promised by VM [*slightly illegible*] mental health suppliers never comes/delayed by months. No support (virtually none) at secondary school, only 25% extra time for exams (instead of 50% normally) meant I never fully completed exams so grades suffered.
- Frustrations at the lack of treatment available.
- Can gradually wear someone down due to the inability to do what he wants
- Understanding communication
- Training
- Normal part of life
- Togetherness
- Anxiety. Worry they don’t understand me. I get tired easy. I want people to understand me. ME. I would like recognition of my efforts to communicate.
- Not something I really thought about.
- Preventative care. Community provision. Encourage people to maintain health for good quality of life and feel supported.

Additional points:

- Lack of hydrotherapy provision. Not enough hydro pools OR lack of access. Essential to strengthen muscles – cannot do on land easily (presence of gravity). RNIB Pears Centre (for the blind) Hydro pool – built new hydro pool on their school site. Opened in 2016 (September). Funding from council (Coventry) given on condition opened to public (have access). Had regular sessions with physio from RNIB Pears until about December 2017.

Promised continuous access with Mum supporting in water but change in RNIB Pears management meant denied access/entry. Site now closed/shut down due to poor management inc. hydro pool. Waste of resources. Should not be the case. NEED more hydro pools plus access across country.

What are the bad things/difficulties and good things/positives you've experienced with services?

Health

Bad things/difficulties	***Good things/Positives***
My physical health conditions were triggered a lot by mental health. But doctors never considered that as a factor until I noticed. Cyclic vomiting is triggered by mental health a lot but doctors too 2 years to do physical tests.	All my psychologists have been supportive and provided CBT
When discharged from mental health service, there isn't follow up treatment so I relapsed really badly.	Our GP always happy to refer us
Specialists fit people in to boxes	Speech and language therapy since 4 years old
Waiting lists for appointments	When it works, mental health services can really help
Lack of transition period	Once at appointments, specialists were helpful and kind, worked to reassure me that the diagnoses were not harmful or shameful
Appointments are repetitive	
Lack of communication	
Waiting times too long for all health services	
Lack of any real initiative	
Getting through to the right specialist	
Conditions treated separately rather than holistically	
No understanding between specialists	
Trying to get the diagnosis made in the first place (arranging the appointment, meeting the specialist etc.)	
Not enough diversity of therapy treatment (psychoanalysis)	
The most understanding people have no powers	
Not person centered	
Not using the systems in place	
Education, Health and Care Plan (EHCP) – Still in the works. 2 years since initial assessment. 2nd time round were addressing education side of things but not health side of things (most important), without support with health, e.g. funding towards specialist powerchair with different functions to change position and	

posture, helps relieve pressure sores – so can attend school for longer time – limit time taken off school. Address health support (lack of) given to access education. Essential. Could not agree on support required – went to tribunal	

Education

Negative/bad	***Positive/good***
Many reports needed to create strong EHCP document	The right teaching methods in the secondary school
Lack of support in sixth form – more regarding mental health but also physical	Good if school is good – teacher. Also comes from understanding of pupils
Infrequent and inconvenient appointments	A teacher in secondary really helped to encourage and provide support for my needs
Sixth form told me to not do A-levels due to having panic attacks in lessons and missing school for CVS	The EHCP – the fact that we got it!
Difficult to receive support for exams, and accessing the support	In-house University Staff at Disability services friendly (don't brush off concerns, listen to problems)
School thinking that you are faking your illness just because you don't have a diagnosis	
No EHCP at uni level	
Teachers can be VERY contrasting when it comes to support	
Mental health personnel in educational establishment are shocking	
Other staff aren't trained about conditions	
Support is woefully lacking without understanding	
Private contractors assigned by University not delivering aid that had been promised	
Not enough sports/physical activities at school for children who cannot do group sports	
TA's not always prepared to support children with disabilities	
Bullying widespread	
Understanding the different needs of physical and mental health conditions	
Lack of trained staff in mental health and other conditions. Lot of blame put on young people.	

Social care
Note: Several people reported they had not accessed social care

Negative/bad	***Positive/good***
Complete lack of social care in EHCP	Activity groups organised by MENCAP
Lack of flexibility in hours	Personal budgets work if no care agency
Lack of understanding that life isn't rigid	Listened to my concerns and made sure they acted in a safe way
Short breaks are quite scarce and are withdrawn after 19 years	
Having the space to be able to move about freely – giving independence – limiting costs on social care limit amount of support required in long run.	
Lots of new build homes being built as new government initiative – need accessible homes built – people living longer	
Be able to get around home without space restriction. Effective – long run. Looking at whole picture. Property too small to adapt. Waiting list for housing comparing to someone worse off – apparently able to navigate space without constant obstacles.	
Not reasonable for Mum to do all of caring	
Going in to adulthood – no support given	
Hospital are looking for independent accommodation for me through social services. But there seems to not be much on offer. I have been told I might be referred to adult homelessness place but I don't think that would be a great place coming out of hospital	
The social worker did not tell her views and understanding with the doctor which made it difficult. Did not have regular meeting with my social worker.	
Better consistency	
Having to repeat my stories	
Better communication, both between department and service user, and also departments themselves	
Social inclusion. Not enough awareness and education in the society about disabilities, and special needs, especially invisible disabilities	
Lack of social care available at secondary level education (only becomes professional at tertiary level of education), stunts potential development at secondary and at A-level education.	

Components of Care

Education/information

- Ensure information is relevantly shared
- Information of how to stay healthy. Information how to manage my condition
- Providing relevant person-centered info
- Preparation for living and transforming lives

- Developing roadmaps of what needs to be done and making political and economic changes
- Inform. Awareness.

Parental involvement
- Help them understand how to support child and what helps and what doesn't
- Education. Family support.
- A doctor speaking in an office to two (possibly one figures) explaining the condition and course (if possible) of action.

Team approach
- Togetherness. Communication.
- Parents and teachers working together.
- Working together, supporting with same end goal.

Evaluation
- Assess the symptoms of illnesses and understand what helps and doesn't help.
- Evaluating the treatment after and also during to ensure effectiveness.

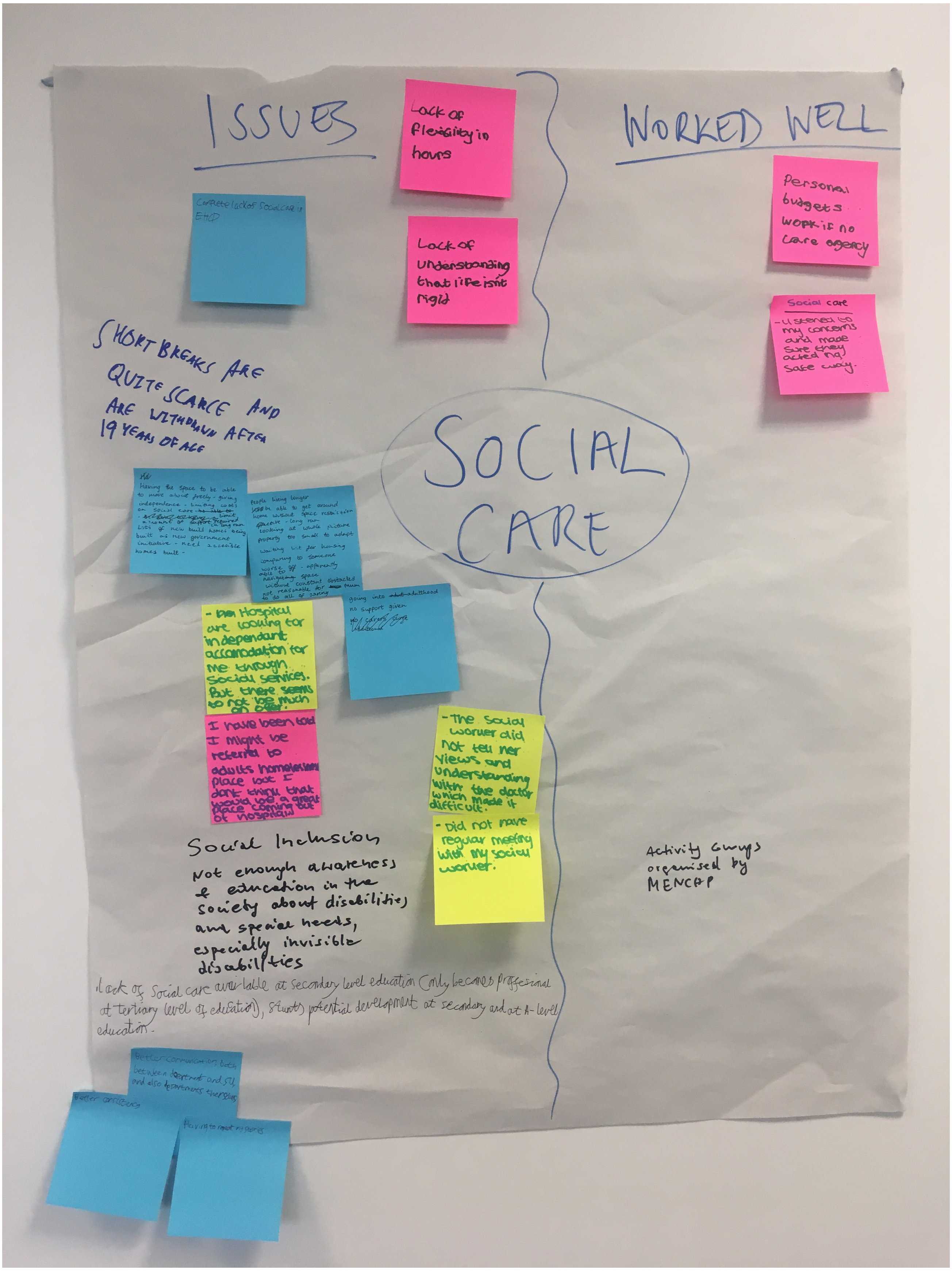
Treatment
- Knowing ways to manage or reduce symptoms to help the patient feel better.
- Person-centered. Not just box-ticking.
- Use of diverse forms of therapy (i.e. not just CBT).
- Implementation of resources, strategies and/or equipment.

Emotional support
- Counselling, mental health, understanding
- Understanding, signposting
- Ensuring that both carers and SU'S have adequate support during treatment
- A kindly (probably maternal) figure allowing you to cry on their shoulder or offer you a hug when receiving bad news.

Coordination
- Easy way needed to accumulate data about needs of child without copious bureaucracy
- Coordinating between multiple professionals.
- Links. Helping to create smooth transition.
- Continuous care. Families.

Other ideas
- Budget constraints
- Invest to save – Prevention, rather than reaction-led
- How to foster independence?
- Understanding and sharing of best practice
- NICE-equipment for social care? Underpinned by rigorous evidence.

- Replacement of equipment – Specifically walking aids, to retain function ‘walker’. Need for transfers and to stretch legs – prevent tightness and pressure sores.
    - NHS – OT and physio department recognise need for walker but not willing to cover costs for replacement. Essential to ensure good health. NOT ACCEPTABLE/OKAY. Needs to be addressed. There is reasoning – goes through the commissioners – do not see use. Commissioners do not have clinical background and are the decision makers. Current walker had for 3.5 years – worn out and unstable. Not very safe. Average life of a walker is 2 years.
        - It should fall under a budget – need to provide then.



ISSUES

Complete lack of Social care in EHCP

Lack of flexibility in hours

Lack of understanding that life isn't rigid

SHORT BREAKS ARE QUITE SCARCE AND ARE WITHDRAWN AFTER 19 YEARS OF AGE

~~Ha~~
Having the space to be able to move about freely - giving independence - limiting costs on social care ~~to be able to~~ - ~~[illegible]~~ limit amount of support required in long run
Lots of new build homes being built as new government initiative - need accesible homes built -

People living longer
~~less~~ be able to get around home without space restriction
effective - long run
looking at whole picture
property too small to adapt
waiting list for housing
comparing to someone worse off - apparently able to navigat~~ing~~ space without constant obstacles
not reasonable for ~~[illegible]~~ Mum to do all of caring

going into ~~adult~~ adulthood
no support given
~~no carers~~ ~~[illegible]~~
~~additional~~

- ~~Dan~~ Hospital are looking for independant accomodation for me through social services. But there seems to not be much on offer.

I have been told I might be referred to adults homelessness place but I dont think that would be a great place coming out of hospital

- The social worker did not tell her views and understanding with the doctor which made it difficult.

- Did not have regular meeting with my social worker.

Social Inclusion
Not enough awareness & education in the society about disabilities and special needs, especially invisible disabilities

Lack of Social care available at secondary level education (only becomes professional at tertiary level of education), stunts potential development at secondary and at A-level education.

Better communication both between department and SU and also departments themselves

Better consistency

Having to repeat my stories

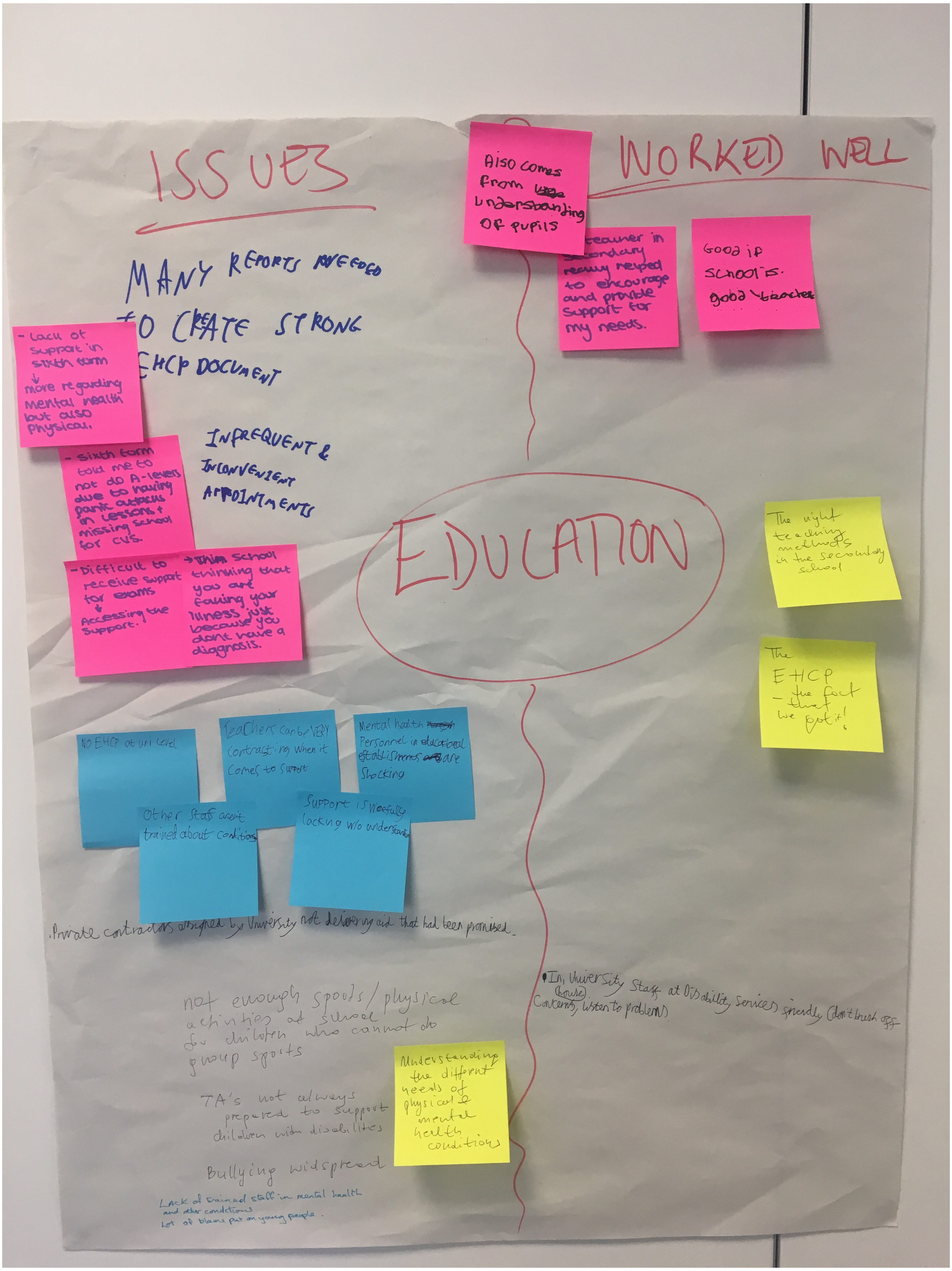
SOCIAL CARE

WORKED WELL

Personal budgets work if no care agency

Social care
- listened to my concerns and made sure they acted in a safe way.

Activity Groups organised by MENCAP



MANY REPORTS NEEDED TO CREATE STRONG EHCP DOCUMENT

INFREQUENT & INCONVENIENT APPOINTMENTS

- Lack of support in sixth form
↓
more regarding mental health but also physical.

- sixth form told me to not do A-levels due to having panic attacks in lessons + missing school for CVS.

- Difficult to receive support for exams
↓
Accessing the support.

→ the school thinking that you are faking your illness just because you dont have a diagnosis.

NO EHCP at uni level

Teachers can be VERY contrasting when it comes to support

Mental health ~~person~~ Personnel in educational establishments are shocking

Other staff aren't trained about conditions

Support is woefully lacking w/o understanding

.Private contractors assigned by University not delivering aid that had been promised.

not enough sports/physical activities at school for children who cannot do group sports

TA's not always prepared to support children with disabilities

Bullying widespread

Lack of trained staff in mental health and other conditions
Lot of blame put on young people.

Also comes from understanding of pupils

teacher in secondary really helped to encourage and provide support for my needs.

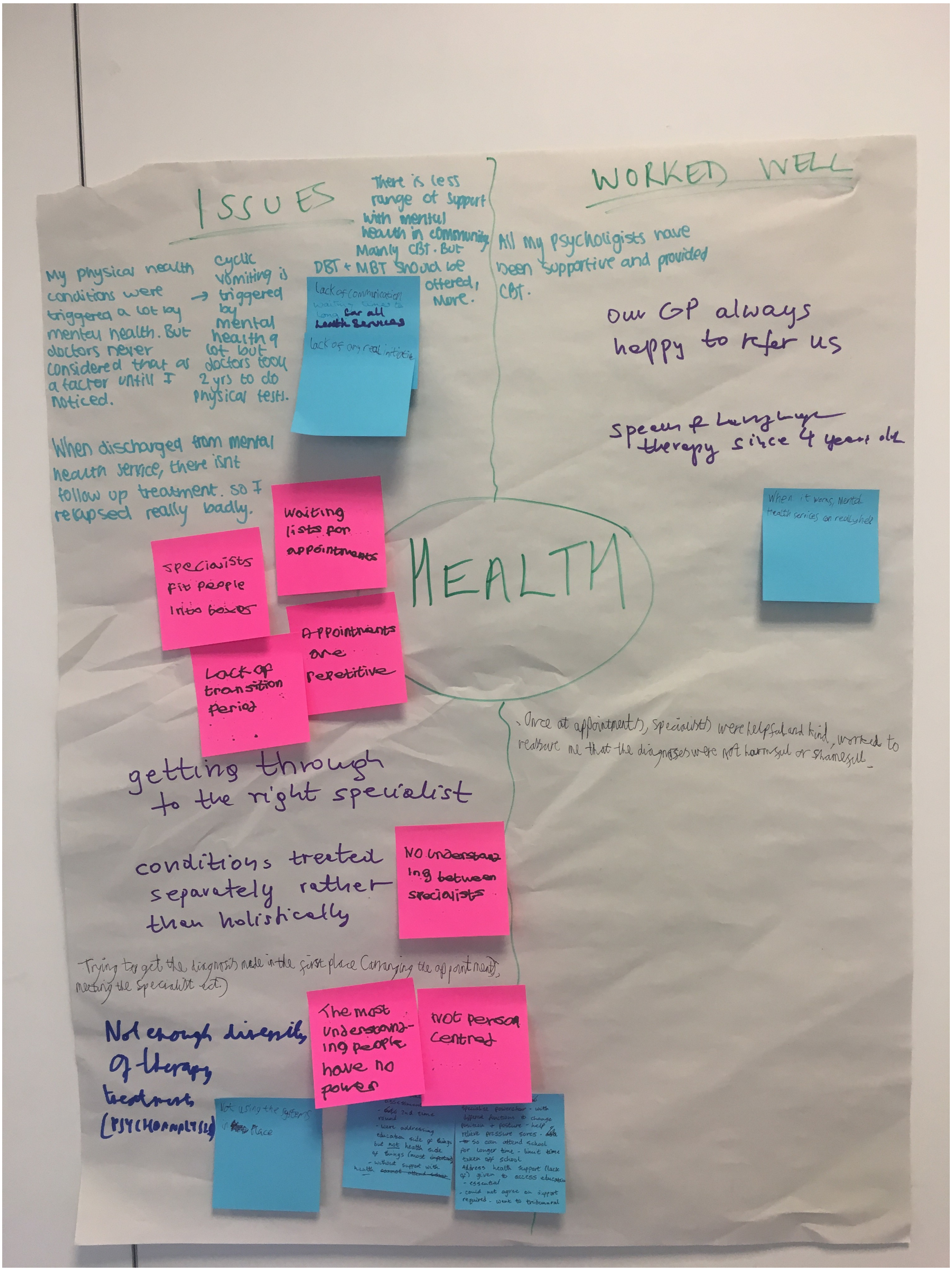
Good if schools. good teacher

The right teaching methods in the secondary school

The EHCP – the fact that we got it!

Understanding the different needs of physical & mental health conditions

• In University (house) Staff at Disability Services friendly (don't brush off concerns, listen to problems)



HEALTH

ISSUES

My physical health conditions were triggered a lot by mental health. But doctors never considered that as a factor until I noticed. → cyclic vomiting is triggered by mental health a lot but doctors took 2 yrs to do physical tests.

There is less range of support with mental health in community. Mainly CBT. But DBT + MBT should be offered, More.

lack of communication
waiting times to long for all health services

lack of any real initiative

When discharged from mental health service, there isnt follow up treatment. so I relapsed really badly.

Waiting lists for appointments

Specialists fit people into boxes

Appointments are repetitive

Lack of transition period

getting through to the right specialist

conditions treated separately rather than holistically

No understanding between specialists

Trying to get the diagnosis made in the first place (arranging the appointment, meeting the specialist ect.)

Not enough diversity of therapy treatments (PSYCHOANALYSIS)

The most understanding people have no power

not person centred

Not using the systems in place

assessment
- 2nd time round
- were addressing education side of things but not health side of things (most important)
- without support with health ~~cannot attend school~~

Specialist powerchair - with different functions to change position + posture - help relieve pressure sores - so can attend school for longer time - limit time taken off school
Address health support (lack of) given to access education - essential
- could not agree on support required - went to tribunal

WORKED WELL

All my psychologists have been supportive and provided CBT.

our GP always happy to refer us

Speech & Language therapy since 4 years old

When it works, Mental Health services can really help

Once at appointments, specialists were helpful and kind, worked to reassure me that the diagnoses were not harmful or shamefull.