

ASSESSMENT AND DIAGNOSIS

- Read the file! Avoid multiple explanations
- Develop electronic information sharing mechanism
- Useful summary 'passport' (share with parents and young people)
- Nominated professional lead for movement between counties
- Communication keep parents/carers informed
- Speed up transfer of medical records via lead professional
- Improved awareness of CAF for parents and carers
- Information distribution/universal red book Health visitor, GP surgery notice boards, parent networks, hospitals, schools liaison/education entitlement services
- Explanation in Local Offer Local communication exercise for CAF, case studies from parents
- GPs need to be more informed, e.g. Local Offer, pathfinder mechanism
- Simpler pathways for parents available co-produced
- Pathways (assessment process) electronic version in Local Offer
- Too many assessments no overall responsibility, needs better communication between agencies
- More joined up education health and care providers
- 'Passport' covering all needs for each child/young person
- Stop saying 'Lets wait and see', give info on additional information or intervention in the mean time
- Professionals to listen to parents properly

- Waiting for assessments:
 - Mixed depending on condition
 - 'Toolkits'
 - Ask Normen
 - All agency communication, information sharing
 - Awareness of National signposting
 - Glossary of medical terminology (Local Offer)
- Lack of evidence base services dependent on where you live
 - Need standard model across country/same system for all
 - Sharing information

CAMHS/COMMUNITY PAEDIATRIC SERVICES

- All referrals through Referral Management Centre (3-5 working days)
- If referrals don't meet the threshold, they should explain why and what to do next
- Need to be more transparent
- Better communication between services
- Services/helplines need to be better promoted within schools
- More youth workers (linking with youth clubs)
- MINDED.ORG.UK website
- Recognising best practice
- Young-person friendly services

- Making services more accessible
- Technology solutions and community based solutions
- Different types of interventions for different needs of families
- Engage with families directly
- Therapeutic interventions
- Joined up working with GPs and repeat medication different options available
- Prescriptions need to be written out correctly to avoid delays
- More information on how medication works
- ADHD workshops/medication advice
- 'SEN friendly' workshops/learning for the community
- More preventative/Early Help services
- CAMHS linking with youth groups to promote more independent living
- Alternative therapies (LEGO therapy)
- Support community groups in setting up and running
- Transitions planning needs to start at 14 years
- Joint commissioning board for Children's Services
- Look at age ranges of different services
- Nene CCG Sue Freeman

- Common theme of services not being child-centered
- Services not appreciating the value of being child-centered
- Children get bounced between services
- Central point of contact when CAMHS/Community Paediatricians cant help that point of contact takes on responsibility for that case
- Sharing information pre-dx to stop dx being the 'be all and end all'

- Not treating co-morbid dx, e.g. 'he is depressed because of his autism', and leaving both untreated
- Info on where to get support pre-dx in the red book issued at birth direct to Local Offer
- Clinical pathway showing what to do/where to go when needs aren't being met
- Multi-disciplinary support around medicating children
- Medical professionals being easy to access so parents can understand what their child's needs do and reviewing the effects
- Frequent monitoring of medications
- Communicating parent courses at CAMHS and allowing access before crisis to manage CAMHS waiting lists
- Multi-disciplinary approach to medications and the effect they have on children, e.g. if transport issues can be fixed by medications, try it
- Lack of information for parents, empowers them to make an informed choice on what their child takes
- More power to prescribe to those at universal, accessible services when prescribing repeat prescriptions
- Clarity of pathways when being prescribed medications
- Job role at CAMHS to coordinate/collate/access to reports
- Video conferencing CAMHS/Paeds at CAFs
- Lead professionals at CAFs who do have admin support to use those roles to chase those who said they would attend or are part of the TAF for their attendance and report
- Legal duty to participate in CAFs Children and Families Act
- Identify someone in commissioning to reinforce the need for professionals to engage in the CAF process making it a 'top down' directive
- CAMHS/Community Paeds patient satisfaction feedback form (audited)
- Reassuring parents that feedback wont affect their case or their child's case everyone receives one

THERAPIES (SALT/OT/PHYSIOTHERAPY)

- <u>Information availability</u> online/social networking sites, GP, access services directly without referral needed (GP advice no referral as child does not attend school)
- Parent networking, red book information, involve professional to engage with parent/networking groups
- Solution Information available on the LOCAL OFFER site, feedback opportunity, what is missing, listening to parental views
- <u>Identification of Need</u> step up/down system in place, easy to access, CDC (Child Development Centre) assessment only applicable in pre-school age, health visitor, system in place once need is identified
- <u>Limited resources</u> OT program in school, problem in special schools to fund for whole school, problem in mainstream schools to fund for specific child if EHC/statement
- Ring fencing funding in schools information for schools what the SEN budget is for, person dealing with child is responsible (LSA)
- Communication to parents to encourage work together (school/home/professional input)
- EHC/Statement things are not happening, what is documented complaint procedure, parent governor SEN, SENCO, LA
- Loss of specialist teacher's expertise
- Service specs from commissioners only covers certain population, no blank referral –
 SAP
- Parents would like a copy of treatment intervention plan, incl. frequency/input guidance
- IEP plans communicate with parents
- Red Book to include checklist

- Drop in centres
- Shared services OT/Physio good if locality is the same, challenging if different locations, lots of therapists work from home, small office in department
- Solution One poll record, sharing/electronically
- <u>Communication with non English speaking parents</u> difficulties with interpreters
- <u>Divide in country</u> depends on access to GP surgeries, village/city

Information:

- Hear things from other parents, charities
- Parents had to look for it, contact professionals
- Found it by chance!
- Special schools very helpful, mainstream not so well informed
- SNIX
- The Local Offer, web-based, Facebook
- Need easy access/linked up, service providers to keep information up to date
- Libraries/Sure Start/back to work

SALT:

- Swallowing/choking referral at Annual Review
- Early Interventions
- Health Visitor
- Pick up in reception at school late identification
- Waiting lists
- Schools deliver some interventions
- DSP
- Working with schools/parents to deliver some interventions

- Plans need to be very specific
- Possible problems with building relationships with professionals
- Solution SENCO training/online module/webinar
- Customise SALT training different comms problems
- Postcode lottery
- Depends on relationships with professionals
- Parents should expect to be communicated with
- Referral Management Centre should help
- KGH and NGH don't share information

ACTIVITIES & SHORT BREAKS

- A lot of information is not available will the Local Offer be a focal information point?
- Can recognise gaps when information is all in one place
- Link Local Offer and Breezy
- Short break services for deaf children will this continue? This is currently being assessed
- SNIX seriously lacking in services
- Training 'buddy' system to access mainstream activities 'mentors'
- Out of town for services difficult to access
- Wheelchair buddy
- Learning difficulties respite? Days out, nothing for more complex needs
- Resources already in place aimed at small groups, not accessible to all
- Research into unmet needs
- Forum/notice board to help families pool resources

- · Adult short breaks not enough, not publicised enough, BIG GAP
- Respite provision for ASD/challenging behaviours
- Flexifun positive feedback, take diverse range of children
- The Local Offer and Breezy has a big job to do and can have a very positive effect in getting information out there.
- · Stop changing names of services

- Communication is key
- Accessibility across the country
- · Access to clubs/activities with sibling
- Activities outside of school and home for diversity
- Mainstream school getting information
- Communication between providers
- Service for all?

SOCIAL CARE: CORE ASSESSMENTS

- Breaches remain at 35 days can be up to 60
- Social workers not skilled with specialisms or disabilities
- Need specialist social workers with a working knowledge of SEN
- Historic information can give distorted view of future needs
- Respectful of clients/not talk at people/need more engagement with service user
- Trust needs to be build/good communication
- Safeguarding professionals to have more understanding of what's going on in family, and not having pre-conceived ideas/come with fresh eyes

- Care packages involves too many forms, process too long, would like one assessment, one access, and common assessment not just CAF.
- LA Definition of disability
- Involving professionals in assessment and parents more accountability to attend conferences from professionals
- Common approach across LA's
- Social Workers inconsistent and often changes regularly, do not turn up at meetings, don't listen, not knowledgeable
- · Early intervention is required
- Review Common Assessment so it is fluid/dynamic

- Full compliment of Social Workers
- Training in all disabilities
- Engage with groups such as NPFG
- Need for stability engage with other services/departments
- No time to build up relationships with families
- Social Workers need to work on their reputation

RESPITE

- Process reviewed more regularly
- No waiting lists anymore accessing different types of respite
- Plan better provision for 18+ children having respite and short breaks now but may have nothing when they reach 18
- Respite provision for adults with Autism and complex behaviours
- More effective transitions

- Processes are CAF and core assessment both needed to access respite improve workstreams
- Extending LA respite for 18-25
- Benefit of Health and Social Care working in the same buildings