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# **Evaluation Form Feedback**





- To give feedback to shape a better service
- To share challenges and experiences and gain knowledge on voluntary offering."
- Information about who to contact, direct payment.
- The discussions around each item on the agenda
- Enjoyed the group discussions, felt those were very useful.
- Being able to contribute and have my experiences heard and listened to.
- Group discussions
- Informative as tapped into several extra websites and resources which I didn't know about. Good to talk to other parents.
- The way the first part was formal, we sat while each topic came to us.
- The questions and answers.
- Speaking to other parents and sharing experiences. Learning about progress being made.
- Feeling like I was helping, being listened to and I may be able to make a difference.
- Getting to speak to different people, who came to the tables with different questions.
- Hearing that some really good stuff is being implemented. Hopefully this will actually happen and soon.
- Fact that HCC professionals were facilitating groups and present!
- Meeting other parents, hearing and speaking to the professionals. Feedback on services provided, but will this make a difference?
- Questions, Laminated ones and given referral forms. Facilitators moving around good. Second set of questions same as first time too.
- Being able to voice concerns/raise issues
- Greater understanding of the complicities of running the 0-25 service
- Opportunity to share feedback as to what is/isn't working and what could be improved
- Opportunity to talk directly with senior leaders and get more understanding of who is who and what their remit is."
- Discussion
- Moving around/opportunity to share ideas and be listened to
- Meeting HCC managers and learning about their responsibilities"
- Sharing information, learn things from other parents.
- Very sad to know that we all are in one boat suffering and struggling to cope with things and the help being provided by the government is not enough.

#### 4. What could have made the event better?

- Bigger slot on education
- Information sent in advance
- Correct title! Email was called "Social Care" but it was a wider event today. Perhaps more parents would have come along if correctly named event.
- Might need more time next time
- Need more focused groups clear and direct
- A little more time to gather participant contribution.
- Toilets nearer. Clear about some of the words that were on the board, for a parents who is new to some of the language.
- More time would have helped to enable more views to be heard during each discussion.



- I would really have like to be able to ask specific questions, personal to me, that I am struggling with now, perhaps to Debbie Orton and Hazel Yabsley. Would this perhaps be possible in the future please?
- A "free" session maybe useful as lots of parents appeared to want to share their personal experiences but didn't really fit in within the time constraints of agenda.
- The second part The question, 1 and 2, were not right with what we wanted.
- Just not so packed with information.
- 5 discussion groups back to back quite taxing! Maybe a break in between would be helpful. One 10 minute break in 3 hours is not enough...
- More time, it felt rushed.
- Hearing that better 16 plus education is being developed in mainstream colleges but its not happening.
- More time for discussion
- More time. Petrol expenses.
- Reassurance that improvements can be made speedily!
- More structural specific i.e. for me SLD rather then broader mainstream. More targeted
- More time
- Morning too long should maybe have stopped for short lunch and then continued afterwards.
- Re-assurance that our feedback will be taken and acted upon by the relevant authority. Maybe have the county to be here so we could ask them and tell them our problems.
- 5. Please think of three words to summarise the event today:

Encouraged Insightful Co-Production Constructive Flexible Interesti Frustrating Fast-paced Social like thinking Collaborative underutilised Friendly improving Helpful Fun decision Informat Needing join part Share Interactive need parents Looks things Empathy dialogue Relaxed together ACTION making Open confusing Teaching Felt Thought Stimulating Feedback dots working Successful Useful Encouraging Thought-provoking ositive Networking Non-judgemental provoking Awareness







- 7. If your answer was yes to the above, would you like to see Education and Health included in the event?
- Yes (x24)
- No (x 1)
- Health maybe
- Yes, because it is an holistic offering, albeit a mornings conference covering all three areas could be time unrealistic.
- Yes or an event just for EHCP
- Yes definitely, especially as all services would be joined up now, so they should have been represented.
- Yes, we included these areas in discussions anyway!
- Yes they should and all the other professionals (doctors, county, GP, Social Workers and all other providers)

#### 8. Any other comments?

- Thank you
- Maybe send information in advance
- Great that it was mainly "working" getting parents views rather than a morning of endless presentations! Great to see Terri Heritage too.
- "Website Success stories and need to improve stories
- Need more focus groups
- Pathways Clear guidelines and criteria
- ""Where to go next"""
- "The importance of a good practical social worker to initially support a diagnosis of SEN is crucial. They can signpost them to the Local Offer.
- Ongoing having a named contact to refer ""new""
- Challenges is really important in maintaining an equilibrium (including key transition events and Personal Payments) "
- No
- A wide range if topics to be covered in a relatively short space of time.
- Felt this was achieving more than the last conference. Liked the format.
- The SEND system is very complicated. Would it be possible doe you to host small workshops or something so parents can get support, signposting, advice from all the service leads and providers, professionals. If they keep in touch with parents, their services will be improved.
- Too much to talk about at one meeting, need other meetings.
- I didn't see and school/college reps.
- I am keen to help, speak with professionals to make a difference with EHCP's and processes.
- Felt listened to, which is a positive change moving forward.
- As always disappointed to be hearing about segregation happening instead of inclusion i.e. Children's homes.
- Learned a lot from other parents
- Health too. PVI Private, Voluntary, Independent
- We should have a lot more help and support for disabled children, it is a shame that there is not enough given and parents are really having to struggle and the provision/budget of funds available are just too less



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# **Facilitation Feedback**

### Exercise 1 – How do we keep moving forward?

### A. 0-25 Together Service

- 1. What question should we be asking you after you have contacted or met with a member of the 0 25 Together team, to help us understand what it is like for you?
- Find appropriate method for sending questionnaire
- Rate questionnaire 'How important was this question for you?' add follow-up questions
- Do you feel the 'Officer/Worker' was working 'with you?' Remove 'us and them'.
- Ensure our target reach include all families
- Social care scares me
- Find out name of charity in Watford / & Danish guy Wood Hall Farm
- Did we understand your needs? Were you informed of what was available for your child's needs? Did we:
  - Provide an opportunity for feedback at every level?
  - Direct you call / assessment seamlessly?
  - Help you access the right support in relation to ...
- Caring, informed and listened to?
- Empathy and clarity
- Did you find the contact useful?
- Technological use telephone keypad to approve feedback (5 questions on how it was for you). If you think we were good press 1 mechanism for follow-up
- Keep things anonymous
- Text surveys are easier for parents. Email / paper (provide percentage). Simple one word response options who appropriate. Link to merit system for PMDS
- We had involvement with your child. How was it?
- How would you prefer we contact you for feedback? (Explain to parents why feedback is important)
- Provide feedback to parents 'You said we did' demonstrate what responses given / and what HCC did.
- Did you feel the officer resolved your query?
- Were you left with the 'feeling' we fully supported your child's needs?
- Demonstrate 'us' against Herts professional promise.
- Did we answer your query?
- How easy was it for you to find what you were looking for today?
- Did we provide you with the appropriate contact details to resolve your query?
- Did we support you in navigating you through the 0 25 service?
- Think about separate questions for different age groups
- Did you feel supported?
- Make questions specific to the 'person' specific (who managed family)
- Include scaled questions (& box at bottom for comments)
- If low scaled answers provided pick up the phone and call us to ask 'why'.
- Use analytics and act upon responses.
- Provide empathy training to workers / relevant experience



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- Ensure detailed conversations at the outset to understand 'what help is needed' by the family
- Tell us what it's like for you on a daily basis
- Transition service is not good.

#### **B. Information, Advice and Guidance**

- 1. List the local and national organisations that you value for information and support
- 2. The ability to sign up to HAND, SEND information updates and SBLO via the local offer is that a positive move?
- Ambitions about Autism
- Handle neuro physical approach
- Herts. MIND / Young MIND
- Nystagmus network visual impairment; advice; support group
- Crohns and Colitus IAG
- Peach applied behavioural analysis
- PDA society pathological demand avoidance
- RDA
- Papryus
- SIBS.org.uk
- PATOSS
- AFASIC
- Polish group SEN mums
- Muslim group SEN mums
- DSPL areas
- Scope, MENCAP, Leonard Cheshire Practical advice for recruitment
- Kids Hub easy to talk to; research; able to explain system; independent supporters
- Space support groups
- Parent network 'Families in Focus' support group; teaching based; parent networks; peer support
- Family lives matter
- ADD-vance
- Cebera sleep service
- Angels
- ADHD foundation
- Abbiss
- National Autistic Society
- Council for Disabled Children
- Parent Network Families in Focus
- IPSEA
- SENDIASS
- Carers in Herts
- SWAN
- Dyspraxia foundation
- Unique database of chromosome abnormalities
- Max appeal 22Q11



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- Downsed
- Cacard free cinema ticket for carer
- Disability transport
- Postcard with LO links 0 25
- H2 publicise VA
- Mainstream schools
- Info pack for parents with children with SEND
- GPs don't understand the system
- Diagnosing practitioners schools, colleges and GPs, SEN hub how good are they at sharing info re local offer?
- Info re carers assessments
- Hacro
- Spectrum
- Up and downs
- Contact a family link more directly from conditions
- Carers UK
- Carers in Herts
- Family carer support service
- Family fund
- CAMHS
- CHIPS
- Include me too ethnic minority community support group
- SNAP
- Asian people's disabilities alliance
- CP sport
- Wheel power
- Whizz kidz
- Improve awareness of portal / facebook pages, particularly those who registered with HAND a while ago
- Local offer. Info to diagnostic. Professionals to share with families
- CDC
- SEND
- Families in Crisis
- Government guidance for schools re children with health, supporting schools with children with health issues
- Challenging behaviour foundation
- Leonard Cheshire Direct Payment Support service
- Skills for care (for people with direct payments employing carers)
- Anything about sleep disorders
- Sleep Scotland support for sleep problems for children with additional needs
- Disability right UK
- Foetal alcohol syndrome
- Site map
- NICE website



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#### C. Workforce Development and Communication

- 1. What top ten (or less) key things do practitioners need to understand about their customers (parents and carers)?
- 2. How could parents help improve the training we provide?
- Be part of it be in the same room
- Tell your story real listening
- Joint training
- Not just Mon Fri 9 5
- Invest in parent training staff come and go, parents are for life
- Parents are available and willing
- Prevent barriers to helping
- Role play what is like to being on the receiving end of a phone call 'we don't have what you need'
- Empathy training. How to open doors. Put those shoes on! Our perspective
- Understand we will be emotional, due to journey
- Trained to hear / respond to emotional conversation can be impactful, be prepared for difficult conversations
- Recruit parents in L&D and on the phones
- Resilience training / mental well being
- Clinical supervisional training can be safe
- Teachers need training and clinical supervision
- Already experience stigma recognise this and empathise
- We need to feel that you've got our best interests at heart.
- By the time you've got through, it may be a 'no' so provide more information up front of <u>all</u> the options including early help and what is relevant.
- Up-skilling FF to understand and condition and ask if unsure
- Parents are not just 'mum'. We are people and experts
- Parents have a fear of SIG. SIG to have knowledge / link person / specialist of condition / SEND including violence at home, checking first before referral
- 'normal' is different for SEND
- Get rid of stigma of child parent, child sibling violence
- How are voluntary sector organisations supposed to keep up to date with changes in 0 25? We need better comms "new this month".
- Please do not copy and paste (wrong names), spell-check, pronouns offensive
- Professional empathy and compassion equally as important
- Responding early to prevent escalation
- Important to signpost
- Getting services earlier, so can understand diagnosis better and support more
- What is a healthy case load? Got to be a safety net
- Need to follow through on what is on report
- S/W talking about (own issues / political views / marriage advice) etc
- SenCo being pulled in too many directions need to know COP and regular meetings
- Ed Psych not impartial enough
- ½ hour assessments not thorough / detailed enough and not adding value



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- Someone can make a huge difference. Take the time to listen
- Getting through to someone can take 20 minutes and then not necessarily the right person and no result
- GPs need to recognise carers
- Perception that S/C is about talking children away other than helping and working with families
- Recognising that some things aren't appropriate to discuss in front of children (reading between the lines) and vice versa not in front of parents!
- Don't bring computer lacks conversation
- Just say parent / carer, not customer
- Listening to P/C all different
- Role modelling excellent S/W (Barity crack?) soft, caring demeanour, empathy, listening, way of learning from / mentoring
- When do something wrong, apologise
- On-duty workers still need to take responsibility
- Too many changes of workers
- Empathy
- Not every child is the same
- Every family unit is different flexible approach (including religion)
- Shouldn't have to be a battle already under pressure
- MUST inform families when making care plan
- Understanding the pressure advice for families
- Having the worker's number so can contact any time and a back-up
- Practitioners need to know what support is available and signpost
- Length of time on hold / transfer before speaking to S/W or service appreciate / understand this
- SW NOT to be the gatekeeper of funding
- Be aware of what is happening in life
- Gaps in assessment process and EHCP
- Professionals to advocate for Ed Psych
- Some key issues cut off; parents unaware of what they need

#### D. 0-25 SEND Commissioning

- 1. How we can find and keep care workers?
- 2. How could a Care worker support your child?
- University social care course
- Unemployed and older people looking for part time work
- Care worker is an old fashioned term "support worker" more appropriate
- Babysitting Website
- Tutoring websites hold worker profiles
- Herts directory care worker list to work in same way as current childminder list
- Tap into part time young people as potential care workers
- Recruit through university/college
- Leonard Cheshire to hold list of potential care workers
- In house care workers may help if wage was reasonable by it not going via 3<sup>rd</sup> party taking cut
- HCC provide a portal with screened care workers



- University leavers
- Teachers and T'A's from special needs schools
- Student nurses, consistent care required, flexible but regular
- Appropriate training for workers to retain them
- Having the right environment to allow support to take place
- Job description templates on our website
- Parents to deliver training
- Students and workers at College
- Male workers
- Database of names
- Link to 2/3 year university students
- Possible credits to particular courses
- Advertise in schools
- Specialists added to local offer
- Build resilience training in for care workers
- Matching care workers to all needs emotional, physical and cultural needs
- Community offer beyond school/college
- Inclusion project for 18 plus
- Holiday groups such as snap
- Regular contact/phone calls if family require
- Knowing what they will do
- Take child for walk/play with friends/outdoors
- MLD/SLD TA's for overnight care
- Local Offer possible creation of groups for children with similar needs all wanting t play football etc..

#### E. Education – SEN

- 1. What top tips for working with parents would you like to be included in the SEND toolkit?
- List of acronyms
- Rights and responsibilities clear roles and expectations for parents
- Clarity about statuary laws by age group
- List of what parents need to know i.e.: local offer, hand
- Care act what are the obligations
- I have a name not just "Mum", "Mrs", "Mr" ask me what I want to be referred as.
- Treat us all as equals
- Clear explanations of what prof roles are job descriptions/ explanations
- School need to navigate/ be aware of what support is available
- Recognise parents are the experts and might also be the prof
- Simple language DeProf the language e.g. setting peer groups
- Vulnerable families need to be quickly identified and signposted to independent support
- Basic organisation charts types of services in Education, Health, Social Care
- Holistic Families family approach siblings
- Benefits of getting SEN parents together



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- Case Studies expectations of being a parent
- Parents want to know what communication to expect from settings E.G How's your plan going/who to contact with an issue
- Recognise that CYP differently at home
- Do not use Mum says
- Ensure views of CYP included
- Prof no questions is too silly pick up phone be honest if you don't know but be willing to find out the answer and come back to us
- Don't make promises you can't keep
- We are representing CYP when we attend a meeting not to represent a school/service
- The meeting should focus on the good outcome for the CYP not good outcome for a school/service
- A new parent feels like we are learning a new language we didn't choose to be here
- Personalise service do not copy and paste
- Set realistic offers clear expectations
- Where do we go if EHCP'S are not happening
- Read info that we send you
- Do not tell us we have a higher priority CYP
- Don't make us feel like were being judged/assessed
- Guide to pathways know what to expect and when by prof/parent
- Explain what we expect as good practice.

#### **Exercise 2 – Personal Budgets**

#### Group 1 – I want to talk to...

- 1. Which professionals would you wxpect to have a conversation about personal budgets with?
- 2. Please can you explain why?
- Speech Therapist
- SEN Officer EHC they don't know and refer to social care
- Continuing Care Manager/Community Nurse
- Must have appropriate level of knowledge
- Sign poster / champion for personal budgets in all key service areas
- Right info for parents Local Offer
- Not wanting to talk to SEN officer about personal issues

#### Group 2 – Language and process

- 1. Feedback on the draft infographic and supporting information
- Process takes too long (One parent reported that it had taken over 2 years to set up a direct payment)
- Not kept informed
- Guidance is unclear (particularly what next once agreed i.e. how to access)
- Outcomes only meaningful if know about them
- Pictures are random, don't add value



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- Do we need another set of terms
- Summary circle plus detailed circle on same page
- Clearer difference between elements 2 and 3, titles too similar
- Too many Chinese whispers about when you can access PB and diagram EHC only?
- Too complex re: how to access different types of support and whether funding available to families
- Why are VCS not represented in these discussions
- Doesn't tell us about personal budget, more about holistic assessment
- Assumes that have basic understanding of what PB is needs to explain

#### Group 3 – Pre paid cards

- 1. What are your views about introducing pre-paid cards for children and young people which parents/carers can manage and which give older young people, from 16 upwards greater opportunities to develop independence skills if they become more involved in using their cards.
- Can you do BACS payment with a pre-paid card?
- Need more clarity around card usage
  - How do we pay a carer using the card?
  - How does the card work?
  - I wouldn't trust my child/young person with the card
  - What is the purpose of the card?
  - What can we spend it on?
- Provide clarity at the outset
  - Make it clear to parents what we can/cannot use card for?
  - What's the most you can have on the card How long can it stay on the card, before it stops? And does it get lost? (as a result of no usage in a set period)
  - Where can we use the card?
  - Can we take cash out?

If we pay carers like this - how will it be monitored from audit trail perspective?

- How do you pay the carer with the card?

Who is the card for? - Parents? Or Young person?

- Provide guidelines for DP or pre-paid cards

#### Group 4 – Practical experience

#### 1. For those who have a personal budget, do things look different now to a few years ago and if so how?

- Change of terminology previously called "direct payments"
- Level of paperwork
- Process works well simplified by recent changes to adult services
- Reduction in amount with agreement
- New legislation has caused confusion around terms and existing families on direct payments.
- Quarterly returns are a lot of work



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• Inconsistency in info submitted to county – bank statements vs quarterly returns – how is the quarterly return relevant?

QA: Who is responsible for direct payments?

- Don't know what it is or who to go to, to find out if it is useful
- Professional who spoke to No follow Hot Potato
- Clear criteria and timelines for process clear expectations
- If not eligible refer to other places for support
- SEND parent support worker allocated to each school could they be champions for IAG?
- KIDS Hub buddy system went nowhere

#### <u>Group 5 – Barriers</u>

- 1. What are some of the current barriers to using a personal budget, or having a conversation about personal budgets?
- Inconsistency of info received. Some received booklet, some great social worker, some nothing.
- Have we got a right for PB for education? (eg: Tutors, speech and language therapy) Not encouraged
- Got told it wasn't suitable to ask for PB due to budget cuts made me feel guilty.
- Didn't return calls! Just ignored when asked
- PB is in EHCP but not talked about
- Get email assuming don't want it (opt-out) but not discussed
- Should be flexibility or choice but in reality HCC can refuse due to eligibility
- More info needed on Local Offer/Websites
- Cuts! Not as much available.
- Don't know who to contact re PB eg: What does it mean? How/What?
- Not actively encouraged to discuss or use.
- Very formulaic approach
- Thresholds/eligibility
- Money advice are brilliant (PIP)
- Criteria: some services purchased in bulk so no choice about provision
- Keep being told it is up to P/C to bring it up but tired and don't always want a fight someone to advocate on our behalf and appeal
- Getting EHCP is first barrier!
- Cost of going to tribunal! Unnecessary barrier!
- Costly

#### Group 6

- 1. What service would you most like to receive a cash equivalent for and why?
- Orthotics NHS provided service only provider or expensive private. No shared working between hospitals.
- Physio/speech therapy to suit specific need
- Counselling



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- Transport/taxis
- Flexible use of direct payments
- Alternative therapies
- PA support
- Mentoring/inclusion project for younger age range.
- Tutoring for English/maths etc.
- Consistent approach required
- Equipment for home
- Siblings
- Holiday towards cost or support costs
- Activities
- Job coaches/life skills
- Brokerage