



Lincolnshire Parent Carer Council

Local offer event - 5th December 2013

This event was held to enable the LPCC to gather information from parent carers regarding the Local Offer which would support parent carers' representation when LPCC attends meetings to influence and participate in the implementation of the Children and Families Bill.

The format of the event was as follows:

- Introduction to the SEN reforms and background to the new Children and Families Bill by David Dickinson (Lincolnshire County Council)
- Introduction to the Local Offer as outlined in the draft SEN Code of Practice by Thérèse Lord (LPCC)
- 3 interactive sessions took place hosted by LPCC:
 - Session 1: Parents were asked, 'at the start of your journey of parenting a child with a disability/SEN what would you like to have known? What kind of information or help did you need at the time? What would have helped you?'
 - Session 2: Parents were asked 'what information do you need to know now?'
 - Session 3: Parents were asked 'what would you like to see in the future? What information do you need to know about?'

Parents were able to move freely round 5 tables set up with answer sheets categorised as follows:

- Table 1 – Education
- Table 2 – Health
- Table 3 – Social Care
- Table 4 – Leisure
- Table 5 – Other

Unadulterated responses for each session are given below:

Session 1: Parents were asked, 'at the start of your journey of parenting a child with a disability/SEN what would you like to have known? What kind of information or help did you need at the time? What would have helped you?'

Education

- ❖ Good Transition from pre-school to primary school

- ❖ Never heard of SEN
- ❖ Never heard of portage
- ❖ Inclusion in school
- ❖ Good Senco help at primary
- ❖ Choice of schools for a child with a physical disability. Is it accessible? Can it provide a one to one? What resources are available in school? Attitude of school staff?
- ❖ Found schools unwilling to make small adjustments
- ❖ How can you choose between Special school and mainstream without any help or support
- ❖ Good Senco help at primary
- ❖ The child may not have a learning difficulty but does not mean they don't have a difficulty learning if their needs of disability aren't met.
- ❖ Unaware of available schools
- ❖ Teachers not trained in Autism
- ❖ Equipment and people who knew and could show how to use it.
- ❖ Who's who in the education system
- ❖ Good Sencos, Bad Sencos
- ❖ Easier interaction with the schools
- ❖ Finding a brilliant school who could help
- ❖ Consistency from primary to secondary to post 16 education
- ❖ Teachers unaware of how much extra goes on at home (personal hygiene, eating etc)
- ❖ Straight talking from a head who admitted his school really didn't have the ability to help
- ❖ Who helps you to get a statement
- ❖ Support from teachers who really could empathise
- ❖ Exclusion in school
- ❖ If school suspect your child is struggling and has special needs, a list of services should be given to parents to see if they feel they could use a service (from school)
- ❖ Sencos are like GPs they only know the basics. Parents are experts on their kids' needs. Schools feel over protective against us.
- ❖ Experienced staff who know that sometimes things can take a very long time and don't mind/have the time to do something 30 times.

Health

- ❖ Earlier diagnosis of **obvious** disability to avoid having to go out of county for numerous consultations to return to Lincolnshire with a diagnosis.
- ❖ "Your son has Autism –we'll see you in six months" This is when parents need support.
- ❖ Need lots of disability specific information upon diagnosis and also access to organisations such as LPCC to support parents through this torrid time.
- ❖ Early diagnosis – parents know their child best.
- ❖ If your child has sensory issues sometimes they cannot access appointments because of the smell of the hospital
- ❖ Available services
- ❖ How do you find a specialist dentist?
- ❖ Camhs – why are you here?... not in crisis

- ❖ Referral to the right team at the earliest opportunity
- ❖ If your child has anxieties stopping him leaving the house, he cannot access a lot of services i.e. Camhs anxiety CBT
- ❖ Good referral to Paediatric Consultant out from across the region, Sussex to Lincolnshire
- ❖ Isolation
- ❖ Gaining a useful diagnosis
- ❖ Unaware of Physio and special shoe fitting
- ❖ Camhs – not fit the criteria
- ❖ Access to other paediatricians who understand our point of view
- ❖ Only HIV picking up
- ❖ Eye hospital referral improving
- ❖ New to the area –support groups
- ❖ Support from another parent
- ❖ Diagnosis –what!
- ❖ Health –personal care
- ❖ Referral to physiotherapy, Occupational Therapy etc
- ❖ Consistency from GP, one was great, one was useless, still is and totally unsympathetic
- ❖ Help from Mental Health
- ❖ Why do parents have to wait for a diagnosis, 15 years on or even at 32 years of age.
- ❖ Children’s ward –good support
- ❖ Point to support
- ❖ Understanding diagnosis
- ❖ Time regular to see professionals (paediatrician etc) instead of being told “not enough staff” especially if need urgent appointment
- ❖ Being able to talk to people locally
- ❖ Realising there might be light at the end of the tunnel
- ❖ Holistic approach
- ❖ Diet, we seek solution. Health sees us as fanatics and as the problem
- ❖ Some parents actually do know more about their kids than the professionals do so they distrust.
- ❖ Bad support from other departments
- ❖ Early diagnosis and guidance
- ❖ Being prepared to wait in the orthotic clinic for two hours to get splints that don’t fit with young twins!
- ❖ Not enough staff e.g. Occupational Therapist etc

Social Care

- ❖ Taboo
- ❖ Chance to have respite without a Social Worker
- ❖ Social Worker involvement
- ❖ What support available for carers
- ❖ Parents labelled as not coping
- ❖ Unaware of needing a social worker which opens up other services

- ❖ Autistic children don't come under CWD but "normal" social worker. Don't have knowledge on how to deal with them.
- ❖ Getting a social worker
- ❖ Child Social Worker promised to see us in July forgot to ask what year!
- ❖ Much speedier personal budget procedure and better guidance on how to use it
- ❖ Access to support –all sorts
- ❖ Negative from the start
- ❖ Access to support groups
- ❖ Social Workers –who?
- ❖ Not aware of sure start
- ❖ Why aren't there Social Workers for less complex severe needs (even social workers agree)
- ❖ Isolation –family support
- ❖ What am I entitled to?
- ❖ Homestart –should be extended beyond 5 years for SEN families
- ❖ More transparency surrounding the criteria to access direct payments and more support to use it for vulnerable families.

Leisure

- ❖ Learning to look after self
- ❖ Activities in Local area
- ❖ Cost
- ❖ Activities with similarly able/aged children and young people
- ❖ What is available locally
- ❖ Holiday clubs –often connected to schools and only keep connections to those who access after school clubs
- ❖ Word by mouth parent to parent
- ❖ Who can go?
- ❖ Transport
- ❖ Start time
- ❖ Short breaks for the child to allow time to be given to siblings
- ❖ What is out there?
- ❖ What clubs are available for different ages
- ❖ Distance –rural area –North/South divide
- ❖ Excluded from activities, after school clubs etc unless extra support available.
- ❖ Lack of information surrounding criteria for accessing activities

Other

- ❖ Time out!
- ❖ Parents to have time for each other
- ❖ Parent to parent experience
- ❖ A bit of patience and understanding – not dismissal
- ❖ For your child not just to be seen as an amount of funding or a disability but as a "normal" child.
- ❖ Isolation – help for siblings –families as a whole.

- ❖ Sibling support –who to turn to
- ❖ Baby sitting services for children with SEN
- ❖ What's out there?
- ❖ If you get a late diagnosis your child is then too old for a lot of services
- ❖ What happens when your child reaches adult services?
- ❖ What can you expect for your child in the future –it worries parents what will happen to their children when they die?
- ❖ Why does a family have to crash before anything is done
- ❖ Enjoy your child!
- ❖ Spend your child's childhood fighting for services.
- ❖ Does not meet the criteria for any agencies –so is fine to be just left.
- ❖ Childminders who can support a child's Special need.
- ❖ After access to one parent group!! Why told not sure what help is available to you to then find out several years later ESCO (do help)
- ❖ If a family has needed so many professionals involved does that not state there is a problem and to support parent with what they need (not pass buck)
- ❖ Kids want friends but other kids are told to stay clear as our kids are unsafe, volatile etc. So self esteem just gets lower.
- ❖ Acceptance by other people that sometimes we have to do things differently and what works for them might not work for us.
- ❖ Unable to join in normal social events, seen as just weird.
- ❖ Not treated as equals by professionals
- ❖ If away at school no services available in holiday from Local Authority
- ❖ Young Carers
- ❖ Easy accessible self research
- ❖ Tolerance and understanding from others
- ❖ “social” made to feel we are just takers of money
- ❖ Unappreciated by teachers, other parents etc for amount of work behind the scenes
- ❖ Combatting isolation
- ❖ Inflexibility of normal social situations
- ❖ Increased pressure on marriage
- ❖ Help with house improvement –where to go
- ❖ What benefits?
- ❖ Information about DFG grants
- ❖ Accepting that this is going to change your life completely.

Session 2: Parents were then asked what do you need to know now.

Education

- ❖ Special Schools for Aspergers/High Functioning children who cannot manage mainstream in Lincolnshire instead of having to board in another county
- ❖ Why does a child have to fail before their needs are recognised in Education
- ❖ Getting new college courses sorted early to avoid delays later
- ❖ Will Colleges meet the child's needs

- ❖ Support to enable children with complex needs to access higher courses at the Local College (high aspirations)
- ❖ Transitions into work – work experience in the holidays i.e. once a week
- ❖ 16 plus – What happened to Transition?
- ❖ Good career advice
- ❖ All the professionals involved with child attending the Annual Review
- ❖ Parents need copies of reports for Annual Review to read before the meeting – not during the meeting.
- ❖ Parents need to know who the school have invited to the Annual Review BEFORE the meeting
- ❖ Where were the professionals at TAC meetings?
- ❖ College event needed – who can provide what?
- ❖ Training for parents to improve i.e. Learning courses
- ❖ Specialist provision for high functioning ASD children NOT in with behavioural units EBS. Lincolnshire doesn't do them or my son wouldn't be in Cambridge.
- ❖ Social Skills
- ❖ Statementing – clearer can pursue independent schools
- ❖ Schools using potential changes as a barrier
- ❖ Sencos better trained – staff/schools/pre-schools/Nursery etc
- ❖ Jargon busting
- ❖ School recognising/admitting child's difficulties
- ❖ Transport issues – cross border collaboration

Health

- ❖ Camhs input
- ❖ Need good consistent access to therapy services
- ❖ Personal issues (hygiene)
- ❖ A lot of pressure on parents and sibling to cope with needs, behaviours, demands and emotional stress of child
- ❖ Continuity of care post 18 when changing to adult care
- ❖ Who else have the same diagnosis problems
- ❖ Someone who deals with attachment disorder
- ❖ Your child has reached their potential? What's that about disabilities continue for life?
- ❖ GP to realise that he is treating your child not treating you as a hypochondriac parent
- ❖ Day centres –what's available
- ❖ A list of good dentist specialising in disability.
- ❖ Cross border –keep doctor in Lincs who knows child's family but access CAMHS in Cambridgeshire as near border and in school near Cambridge
- ❖ Jargon
- ❖ Diagnose still
- ❖ Are parents allowed to stay with a child on the ward once they are 18 but has Mental Age of a 5 year old?
- ❖ CAMHS for children without SEN –siblings who are impacted.
- ❖ First Aid Courses
- ❖ Who are the liaison nurses we need more?

Social Care

- ❖ Help to leave the house, not given respite where he plays on his xbox so won't go because he can do that at home so won't go
- ❖ Respite for the child to allow time with siblings
- ❖ Get rid of the bureaucracy surrounding direct payments
- ❖ Criteria on crisis
- ❖ Respite
- ❖ Care after 25 years old –what is available?
- ❖ How do you get hold of a Social worker before the child is 18?
- ❖ No market to purchase services e.g one to ones for personal care
- ❖ New position for social workers who specialise in special needs/Disability - not just for complex/severe needs.
- ❖ Support for carers
- ❖ Jargon
- ❖ Social Skills
- ❖ If older person gets in trouble with police etc, due to social problems is someone available to speak to parents for advice.
- ❖ Adult respite (not 65+) in a nursing home
- ❖ Clarity on post 25 – feel pressured to use “social housing and live independently”
- ❖ A list of service providers that provide independent living

Leisure

- ❖ Respite for high functioning and families - access to funding for it – direct payments
- ❖ Concessions
- ❖ More activities in the certain parts of the county e.g. south
- ❖ Sports and leisure activities for children and young people over 18
- ❖ Transport issues
- ❖ Buddying
- ❖ Help to involve all family to get active by fetching or supporting in activities, not just the child or young person
- ❖ Post 16 activities locally

Other

- ❖ Scary future for when parents are not around
- ❖ Recognition of mobility issues – not just about lack of mobility but safe movement e.g. children/ASD/ADHD can't cope sibling in car – larger car to separate. Movement round car parks so access to blue badge – have middle rate mobility issues (DLA)
- ❖ Social events for carers – isolation still issue
- ❖ Social events for all family – isolation still an issue
- ❖ Sibling groups
- ❖ To help siblings understand the diagnosis
- ❖ More training to all professionals in all disabilities – not just some
- ❖ Employment for the future
- ❖ Respite

- ❖ Fed up with all of it being about budgets and funds
- ❖ Still isolated, misunderstood, underfunded, not trusted, ignored
- ❖ The co production between the LPCC and LCC will make a real positive difference to the county as a whole
- ❖ Still fighting for basic services that should be a right as it is for “normal” families
- ❖ People being consistent in the help given, not just a quick fix or short term help
- ❖ Parent Carers are for life – carers come and go
- ❖ Friendships for young person
- ❖ Benefits
- ❖ Residential respite and where
- ❖ Local friends
- ❖ Wills and trusts
- ❖ Lack of integration between services
- ❖ Access to more for siblings – young carers exist but nothing being offered.
- ❖ Since 2006/7 the LPCC has helped raise the awareness of families with children who have special needs
- ❖ Support offered post 25
- ❖ EHC only goes up to 25 if in education still need support if not in education.
- ❖ Isolation
- ❖ Nothing much has changed
- ❖ Home start extension beyond families 0-5 yrs to those with Special Needs children. Volunteers to support –good inexpensive support.
- ❖ If move out of the area will the EHC still go with the young person.

Session 3: Parents were then asked ‘What would you like to see in the future?’

Education

- ❖ System in schools
 - ID problem
 - Stages of support
 - Pathway
 - Criteria
 - Policies
 - Personnel e.g. SENco
- ❖ Accessibility – open door
- ❖ Transparency of school processes e.g. exclusion
- ❖ Accountability of schools
- ❖ Types of provision e.g. School for HFA or Physical Dis etc

Health

- ❖ CAMHS –signposting to the right person first time
- ❖ Criteria –transparent
- ❖ Accessible – email/not just face to face/waste time
- ❖ Across borders co-operation

- ❖ Specialised paediatricians
- ❖ Local accessible health practitioners
- ❖ What paediatricians can do and signpost
- ❖ Referral process transparent and access to it
- ❖ Specialism and paediatricians' credentials and what they can do

Social Care

- ❖ When are you entitled to a social worker?
- ❖ Who makes that decision
- ❖ Specific training for Social Workers
- ❖ Eligibility criteria – what they can do
- ❖ Transparency – what can others do e.g. external agencies
- ❖ Complaint system
- ❖ Process to assessment – different pathways - consequences of decision
- ❖ Direct payments info
- ❖ Who do you talk to, to get social worker
- ❖ Stigma issues/overcome
- ❖ Contact details
- ❖ Non- interfering social care
- ❖ Trained staff
- ❖ Openness with families (correct minutes)

Due to time constraints and the vast of information generated by the parents, the event came to an end at this point, with parents feeling valued for helping to influence future provision for Lincolnshire families.

We thank everyone involved in this event.

The LPCC team.