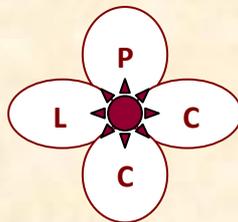


# Health Consultation Report

Re: Community Paediatrics

by



# Lincolnshire Parent Carer Council

November 2009

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The Lincolnshire Parent Carer Council (LPCC) conducted two meetings on the 23<sup>rd</sup> October 2009 which were attended by 58 parents and carers of children with a range of disabilities.

The consultations were organised as a consequence of multiple parental complaints to the LPCC regarding the service from Community Paediatrics.

## **Background**

The LPCC is a voluntary body of parents and carers with children with disabilities. As a communication medium between parent/carers and service providers, the LPCC works in partnership to enable positive outcomes for children with disabilities.

Historically, the LPCC commenced dialogue with the Primary Care Trust in March 2008 highlighting a potential gap in service once Dr Millns, Consultant Community Paediatrician, was to retire in March 2009. Parents and carers were not told of any plans for replacing Dr Millns in advance of, or subsequent to her retirement, thus resulting in support groups being inundated with calls from highly anxious parents. During the same time, other parts of the county were also affected by a shortfall in the work force. This situation is due to worsen as a result of further planned retirements.

Some parents and carers received letters about further appointments in September 2009. Others received nothing and are still waiting for some sort of communication with regard to who is looking after their child's case following on from Dr Millns' retirement.

## **The Consultation Meetings**

Two meetings were organised originally around three key professional bodies; the Primary Care Trust, the United Lincolnshire Health Trust, and Gillian Merron (MP), who was already involved in dialogue through a support group called PAACT (Parents and Autistic Children Together) based in Lincoln. Although, agreement was originally established for all parties to attend the consultation, the Primary Care Trust declined the invite shortly after advertising commenced. The United Lincolnshire Health Trust advised the LPCC the night before the consultations on the 23<sup>rd</sup> October, that the professionals would not be attending.

Parents and carers were expecting professionals to be attending and were undoubtedly disappointed with their non-attendance. Gillian Merron, however, did attend to hear what her constituents had to say regarding their experiences.

## Structure of the Meetings

After a brief introduction of the role of the LPCC, the meetings were predominantly structured around two titles; *Concerns* from parents and carers followed by *Working Towards Solutions* to meet those concerns.

*Concerns* were sub-divided into four strands relating to the most common complaints, namely:

- Availability of paediatricians (new referrals, reviews, discharged patients)
- Management of replacement of retiring paediatricians
- Communication from NHS regarding future appointments
- Receiving medication (if applicable)

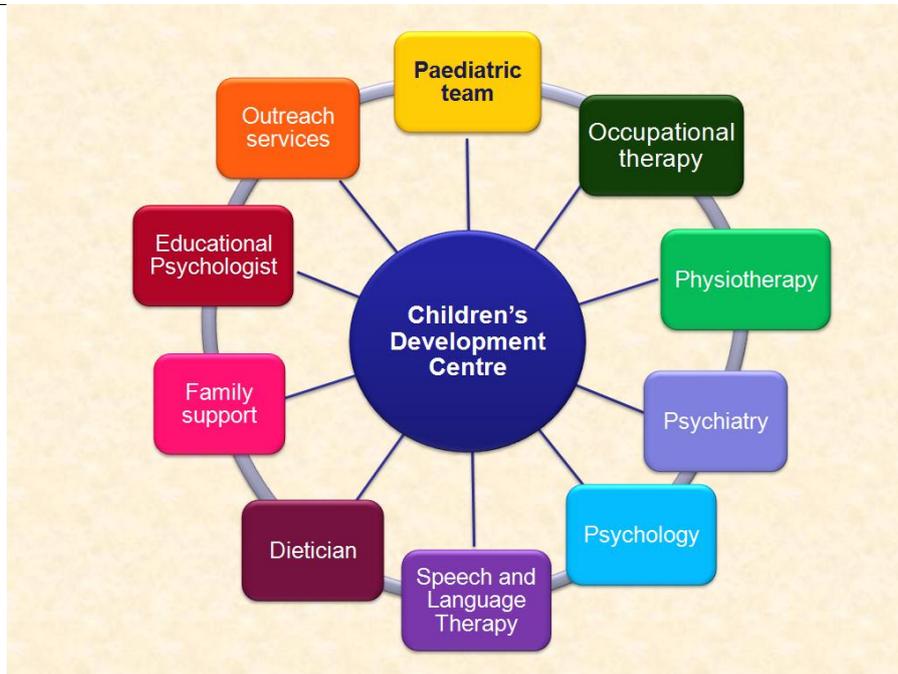
For *Working Towards Solutions*, workshops were carried out to support the way forward with regards to the following titles:

1. Diagnosis – how important is it?
2. Why would you need to see a paediatrician?
3. What support do you need with your child?
4. Accessing the paediatric team (emergency, routine, enquiry)
5. Reports for statements for educational need
6. Who can refer?

A suggested model is outlined in this document that received unanimous backing from both meetings.

## Key Findings

Parents and carers unanimously agreed the following model to represent the ideal pathway to support parents and carers with children with disabilities.



The structure is focused around a Children's Development Centre whereby all services are integrated. Multi agency initial assessments should be carried out as opposed to multiple individual ones.

Children's assessments are carried out to identify needs in priority order: short, medium and long term. An assessment is to be seen as a working document that is to be reviewed along with the child's development. Particular support should be offered around the stages known to be difficult such as transition from primary to secondary school.

This model typifies the literal sense of *Team Around the Child* whereby all connections are possible between each professional as illustrated in the diagram. Some parents suggested modifications to this model by adding the following:

- social services to be added
- paediatric team to be central
- add GP, school, and local advice groups

Family support is a new idea that would house a 24 hour helpline for general support or even crises situations. It has a multipurpose function, such as to

signpost families to appropriate support and to post out resources such as information sheets regarding specific disabilities, strategies and interventions. As well as enabling efficient support to families, it also empowers parents and carers to manage their own child's disability. Consequently this would not only mitigate the demand on appointments with professionals but also raise the quality of appointments to concentrate on areas in which families need most support.

## Concerns

The following is a list of concerns raised by parents and carers collated from both meetings.

### Availability of paediatricians (new referrals, reviews, discharged patients)

- What paediatricians?
- Absolutely diabolical. Constantly cancelling appointments, no flexibility, no consultation – expect you to drop everything
- I need a diagnosis for my son; unable to get appointment with paediatrician despite GP referral
- Parents told that a child aged 12 too old for paediatrics
- My son is not receiving regular reviews
- Parents still waiting for appointments
- Who does new diagnosis, reviews or urgent appointments?
- Criteria for services? Can't access a paediatrician due to this
- Inequality of service
- Children with preliminary diagnosis unable to get confirmed diagnosis
- 10 mins not long enough for appointments in ADHD clinic – not appropriate service
- Parents told that appointments are being used to filter out more parents from caseloads
- New referrals? How and what is happening with these?
- GP's not consistent with referrals
- Waiting 3 months for an appointment in crisis situation
- Replacement consultants out of their depth in appointments
- What can consultants do that other doctors can't (junior doctors can but daren't)
- What powers do the doctors next levels down have?
- Children waiting for diagnosis
- Have never seen one (a paediatrician) since diagnosis 4 ½ years ago
- Issue with Dr W "What are you doing here? – you are not on medication"
- Why wait until crisis point before receiving provision of service?
- Need regular appointments. A paediatrician would be nice. Melatonin would be good
- We need a diagnosis of our son's dyslexia to put support into place. Without it, the statement process is weakened. I have had to pay Dyslexia Action for report and I am on Income Support

- Not acceptable that parents are seen and treated as the lowest of the low (we don't feel we are worth anything) services are blinded to the real issues of parents and carers of children and young people with special needs. What happened about the government's legislation of "EVERY CHILD MATTERS!!!"?
- No-one is available for new diagnoses, reviews or urgent appointments. My son is now in 'no man's land' between services despite repeated efforts from a dedicated GP. Paediatrics refuse to accept a new referral. Saw school doctor so 'box was ticked' but she is unable to do anything to help.
- It is essential to be able to offer guidance and understanding of your child's needs
- I can only think that this has been driven as a cost saving

#### Management of replacement of retiring paediatricians

- Poor – no direct replacements for Dr Millns; struggle to get diagnosis from current so called specialists for my daughter
- Poor management – appalled at no forward thinking, planning to replace paediatrician
- Nobody to replace/cover leaving consultants
- No clarity procedures for discharge
- Inflexibility of appointments. Parents given fixed appointments with no leeway
- What happens to medical records on discharge? Some have been lost
- Who has decided that children with autism don't need specialist care?
- Is there a policy in NHS not to treat children with autism?
- Secretary deciding if a case is deemed urgent or not
- Confusion from CAMHS to GPs
- Good practice/models exists in other parts of the country; we should be looking into these; why re-invent the wheel?
- Replacements for paediatricians who have left – where are they?
- Care pathways not working
- Referrals – do we know what new criteria are being used?
- Child been discharged – told have to go back to GP for new referral – GP says he has been unable to make a successful referral
- GP's inconsistent in referrals – if poor quality, it is rejected
- How well trained are triage team?

- Parents told to come back in six months (same person diagnosed child with ASD)
- Why is there no management in replacing paediatricians?
- Consulting with parents?
- Where is their succession management?
- Child not being monitored even though on medication
- paediatrician was given no equipment to monitor child (blood pressure etc) and apologised
- Why employed a part time doctor who cannot be contacted and cannot refer out of county?
- Gap in service is deplorable. Too little, too late. Families are left in limbo with only support groups to provide advice
- Many retiring with advance notice and staying on for additional time but no provision. Patients need regular constant care
- Absolutely appalling! Carol Millns propped up the whole department on thin air. People have to be paid for the service. Isn't there a legal duty to provide?
- They come and vanish due to obvious frustration and lack of information and communication and working in partnership WITH parents. We as parents feel ISOLATED!
- Seeing the budget cuts published in the Lincolnshire Echo and the way the trust can't cope with the demands of children with special needs. Not ensuring Lincolnshire had enough cover saves them money!
- There seems to be an avoidance strategy going on here. An ambiguous letter targeting the discharge of as many cases as possible is diabolical. Are they trying to 'right size' the workforce??!!

#### Communication from NHS regarding future appointments

- Appalling!
- Discharge notification unclear – where do children's records go?
- Parent told by receptionist whether or not they were to have an appointment/discharged
- Some parents did not receive any letter
- What letters? Either lost in post or its in the system or it's on the computer
- Some told by letter/through support groups (see letter in Appendix D)
- Parents unable to get through by phone to voice concerns

- We received no notification that our son had been discharged, therefore we were left waiting for an appointment that would never arrive
- Early communication e.g. parent to parent helpline, support groups etc
- Parents not written to when Dr M retired no communication
- Very ambiguous letter
- Some parents told on the phone didn't need an appointment
- In one case received mail saying discharged from Dr who was retiring – didn't realise being discharged full stop
- Is anyone replacing Dr M – why not?
- Badly worded (re: letter to parents from NHS) – seems to be worded in way that will mislead parents. Deliberately ambiguous
- We should know what is going on:- not told after the event. We should be treated with respect i.e. cancelled appointments, not told till last minute
- They happen but not always helpful – often the number provided to ring is not correct for follow up appointments
- Impersonal, inefficient

#### Receiving medication (if applicable)

- Discharged patient – GP to prescribe melatonin but GP won't prescribe
- Associate specialist locum advised to come off medication – conflicting advice from previous consultant
- Parents being forced to buy melatonin on internet
- Parents sharing website information about how to buy melatonin on internet out of desperation
- Children on medication are not being monitored
- Incorrect medication doses
- Medication – several problems in getting it – knock on effect on whole family, child's life including schooling
- Told child doesn't need melatonin – is it just to relieve NHS of job of monitoring?
- Receiving lots of medication and regularly monitored. Fantastic support through Dr Thompson, and nobody else.
- Some GPs agreed to prescribe medication in belief consultant taking responsibility for overview, but now no consultant to do this
- Doctors can't prescribe certain medication
- Cycle of SE school doctor and our doctor in grid lock
- As patient ages, various changes will require medication

- Struggle to get medication. Some available only from hospital pharmacy. Long struggle to get medication from local GP. Pharmacy do not keep enough stock
- Obviously a GP should not be recommending psychotropic drugs to behaviourally challenged/depressed/anxiety ridden children
- Too confusing – doctors and CAMHS struggle to communicate and agree on medication. This is not consistent and frustrating to child and parent and SERIOUS concerns!

# Working Towards Solutions

## 1. Diagnosis – how important is it?

### Morning meeting responses:

- Every child matters – child's entitlement
- VITAL – for immediate, short term and long term
- No diagnosis – you get no power and no say
- Needed for support
- Focuses for education, health specialists
- Parental education
- Knowledge is power!!
- Ignored if not diagnosed
- Long term problems
- Cost implications
- Only way to measure
- Currently only method to get anything
- Provides common language between education and health
- Common framework needed
- Part of ongoing research
- Important – hub of wheel for all other services
- Needed to access further help/services
- To give child and family understanding
- Assumed to be bad parenting with no diagnosis
- No diagnosis harder to get statement
- Needed for headcount
- Not diagnosed as child not recognised as adult
- At transition stage not recognised
- No medication

### Evening meeting responses:

- No long term planning without diagnosis
- Affects statementing and schools know what working with
- Medical emergencies
- Impact on child's self esteem
- Affects benefits
- Vulnerable – ASBOs etc
- Support groups

- Welfare system
- Consequences could be drastic
- Access services, Occupational Therapy
- Records figures for financial planning (number of children and adults with disabilities)
- Holistic, whole family approach 'think family'
- Assists employers
- More help with further education
- Knowledge for parents
- Not going mad!
- Know what you are dealing with
- Parenting strategies
- Reason for behaviour

## 2. Why would you need to see a paediatrician?

Morning meeting response:

- To get a diagnosis
- To get referral for other help e.g. Occupational Therapy and speech and language
- To get medication from hospital or get GP to prescribe
- Continuation of care
- School (special) listens to paediatrician
- Report from paediatrician goes to mainstream school with recommendations
- Advice and strategies
- Referrals for social services
- Disability living allowance
- Recommends courses e.g. Early Bird
- Gives info on support groups
- Refers for respite and special equipment
- The hub for everything

Evening meetings responses:

- Receive a diagnosis (needed by both child and parent, families)
- Follow up the diagnosis with action plans and interventions
- Medication
- Monitoring of medication

- Add weight and credence to child's needs i.e. education
- At crisis point
- Signpost to other services
- Access to expertise

### 3. What support do you need with your child?

Morning meeting responses:

- Regular access to paediatrician
- Whole family approach
- Services working together one stop shop
- Good access to information, services and support groups
- More support at diagnosis
- Investment in support services for families – non-medical and medical
- Practical support from outside agencies
- Parents worn out
- One referral for all services
- Appropriate services tailored to the needs of the family
- Recognise that parents are the experts for their child/ren

Evening meeting responses:

- Access to Occupational Therapists (criteria for referral)
- Joined up working, education and home
- Outreach
- Wishlist:
  - communication between services
  - Support at meeting/CAF
  - Accountability and transparency
  - Support for sibling

### 4. Accessing the paediatric team (emergency, routine, enquiry)

Morning meeting responses:

- When a GP has determined paediatric referral is appropriate, there should be a means for the parent to call a number and make an appointment; waiting 6 weeks anxiously for an appointment made for you without consultation with you is inefficient and impersonal.

Secretaries making appointment ought to have knowledge or account for the parents' schedule

- For emergency calls, a number should be available for parents to have access to a qualified triage nurse (if their child has an established diagnosis the parents should have the benefit of the doubt)
- Effectiveness of therapy of autism is critically dependent on early diagnosis and specialised care. No diagnosis means no effective intervention. Behavioural therapy (ie ABA) is not given by physicians but specially trained therapists.
- Diagnosis ought to be made by psychologists with special training in autism. (Educational psychologists make autism diagnosis in America)

Evening meeting responses:

- Who are we going to access? Sibling support, behaviour/protection.
- Who is going to come in and at what level with the experience needed?
- Is there an age issue about accessing services? i.e. under 5?
- Inaccessible building (Moore House). Not disabled friendly.
- Paediatrician is key to this. Need for one is paramount.

## 5. Reports for statements for educational need

Morning meeting responses:

- Diagnosis is key to trying to obtain a statement – is it true that they need to have '5' diagnoses (SENCo 12.10.09) to fit criteria? I.e. do they have to have five things wrong e.g. dyslexia, ASD, auditory processing, etc, etc?
- Surely initial 'report/diagnosis' from paediatrician should stand instead of requiring to go through it all again – (Obviously if things have changed a lot - then necessary)
- Why is it such a lengthy process? This in itself must be costly.

Evening meeting responses:

- It is vital to get a statement to understand the child's needs and progress from there. To review and to monitor additional changes. A statement is most important
- Helpline – 24 hours/7 days a week for advice, support, someone to talk to
- Having a central point would help

- Experience is that school was main source of help. Education and health don't talk – they need to
- Why duplicate reports when already been done before?
- Well trained health visitors can spot things early and give guidance

## 6. Who can refer?

Morning meeting responses:

- GPs and Health visitors, schools, SENCos, parent referral
- Paediatricians to be able to refer to all relevant services
- Need open links between services

Evening meeting responses:

- GPs
- School
- Health visitor
- Parents?
- Other health specialists
- Educational psychologists
- Independent health professionals
- Social services
- Child self referral
- Children's development centre
- Should be able to access children's development centre on basis of proven need with or without a diagnosis. You shouldn't have to wait for a diagnosis before you can get help.

## APPENDIX A

### **Minutes of the Health Service Consultation**

**Held at Bishop Grosseteste College, Lincoln on**

**Friday 23<sup>rd</sup> October 2009, 10.30 -12.30**

**Organised by the Lincolnshire Parent Carer Council**

The meeting was opened by the chair of the Lincolnshire Parent Carer Council, Thérèse Lord.

Thérèse thanked everyone for coming and explained that it was organised to be a joint consultation with the PCT and ULHT but unfortunately the PCT professionals could not make it and the LPCC were informed subsequently that they were on holiday. ULHT had cancelled by email the night before.

As the report is to be informed by parent/carers' opinions, the consultation would still carry on and views would be heard.

Thérèse briefly introduced the LPCC and explained that they were all parents of children with disabilities and they were volunteers.

Thérèse then explained that the LPCC facilitates two way communication between parent/carers and service providers such as LCC Children's Services.

Thérèse then went on to explain that the PowerPoint presentation would facilitate and cover the main crux of the discussions and that parents would be able to air their concerns verbally or on the feedback form.

She emphasised the need for parents to use this opportunity to not only present their concerns but work on solutions so the LPCC could feedback their views in the form of a report. Further, she suggested that there is no point in just voicing concerns, but invited parents to say how those concerns could be met. All models of good practice were welcomed.

#### Agenda

#### **Structure of NHS**

Thérèse explained the roles of the Health Service:-

PCT –commissions services  
ULHT –buys and provides the service  
Families –use the service.

## **Concerns**

### **1. Availability of paediatricians**

The situation regarding the availability of paediatricians and the retirement of Dr Millns and other consultants who have also left or in the process of leaving was explained and Thérèse asked whether anyone would like to comment.

**Parent** –There appears to be conflicting advice between the locum and Dr Millns regarding medication. Locum said that parent’s daughter was too old to be seen by a paediatrician now that she started secondary school.

**Question** –How many parents have seen the locum -3 had and agreed that advice was inconsistent.

**Parent** –Clinics in the South of the county had been cancelled due to lack of staff.

**Parent**-What is the protocol for discharging children as parent had nothing in writing, email or phone call? What procedure is in place as parent had no evidence of child being discharged? Is it up to the receptionist?

**Parent** – had a letter discharging child so parent went to see MP who wrote a letter (Edward Lee). Parent received letter of apology from hospital where eldest son was reinstated, but youngest son wasn’t as **only** had autism. What is the criteria for discharging children?

**Parent** – child discharged without me being aware of it –received copy of letter from PAACT. Child was discharged in April although Dr Millns had stated she needed to see him. GP tried to reinstate him but issues weren’t significant enough (although there are many). School Doctor agreed to see him but there was nothing she could do. Looks as though if does not attend a special school, child discharged.

**Question** –How many parents have complained to PALS? One person put their hand up.

PALS are aware of the situation but are not able to come today as may not be allowed.

**Parent** – I have been told that child cannot be seen because they don't meet the criteria. Had a letter saying criteria is: No long term care, obsessional behaviour, aggressive behaviour, suicidal, depression or self harming.

**Parent** –believes there are communication issues and clinics are inflexible. Children could not be fitted in together. ADHD clinic diabolical service.

**Chair** –How many parents have had an appointment since March when Dr Millns retired?

3 people only.

**Chair** – Triage criteria has tightened a lot?

**Parent** –Her child had been discharged; some parents have received a letter some haven't. Appears to be inconsistent.

**Chair** –How many have received a letter? As out of 352/4 cases there were 4 days worth of clinics allocated and the maths does not add up. Dr Millns went through her caseload and discharged patients and kept the ones that needed to be seen again.

**Parent** – Concerned about what happens to the medical records?

**Parent**- Did everyone know Dr Germer is not coming back?

**Chair** –Dr Julie Clarke replaced Dr Germer and stretched between clinics covering the area. Dr Clarke will be covering Lincoln as a locum too.

**Parent** –Stated children at Queens Park received a letter that if they did not contact appointments by 3pm, they would be discharged. Lady would let us see a copy of letter. I tried ringing the number but no-one answered the phone and tried phoning for 45 minutes.

**Parent** –Looks as those that are seeing Dr W are being filtered out. All given short appointment. People are buying medication from the internet. Parent felt as though consultant was querying diagnosis. Other parents agreed. Another excuse given was the age of the child (not seen at 11); another thing was genetic background and parenting techniques.

**Parent** – I got my melatonin off a website.

**Parent who was a medical specialist** was alarmed that the NHS decided that Autism was not specialist care. Outrageous to think GP's can manage it. Is there a policy that NHS is abandoning these children to GPs?

**Community Health Visitor** –Aiming High for Disabled Children means service should be tailored to meet the needs of the child.

The community is serviced by the PCT and ULHT. Should be commissioning services for it.

Her concerns were echoed around the room.

**Parent** –Asked what paediatricians there were?

**Chair** –Dr Crawford, Dr Johnson, Clarke and Ikena (part time)

**Parent** –Concerned there must be a list of children who have been discharged.

**Chair** –reassured parents that if they had problems getting an appointment we would email parents with Joanna Fawcus' contact details.

**Parent** –thought there might be new referral criteria, as only GP can refer.

**Chair** –Education setting is writing to GP but GP's are not consistent with referrals. If case doesn't fit criteria it is bounced back.

**LINK** - At this point LINK explained their role in that they were here in support, to talk to local communities about the gaps in Health.

**Chair** – It is the LPCC's intention to provide a report.

LPCC agreed to send out an Email to network with PALS details.

## **2. Management of replacement of paediatricians**

**Chair** –Emailed Alan Kitt, Bronwyn Whitaker and Hilary Barrett regarding the situation in March 2008. She has been in constant dialogue since to get situation sorted. No long term solution offered.

Tribal consultants were called in to host a paediatric review on 14<sup>th</sup> October and parents have not yet been consulted directly. They have asked that we submit our report to them by first week in November.

## **3. Communication – letter regarding appointments**

The LPCC and PAACT emailed the letter to its members to let them know of the situation.

The letter was presented on the PowerPoint and everyone agreed it was down to interpretation as to whether you classed your child as an 'urgent priority case' when it was just a review. It was agreed that the letter was misleading.

**Parent** – Had a crisis situation and had to wait 3 months and then only saw a junior doctor who couldn't deal with the child's medication and had no equipment to do the tests. The child ended up distressed.

#### **4. Receiving medication**

**Parent** –when phoned for appointment the receptionist told her it wasn't urgent. The secretary is making clinical decisions.

**Parent** - If CAMHS is writing to Dr please ask for a copy of the letter as could be a mix up over medication e.g. incorrect dose.

Also concerns that medication is not being reviewed every six months.

#### **Community Health visitor**

Reported on a speech to the Health Visitors conference by Andy Burnham – Health Minister.

Mentioned the following:-

Predict and prevent approach

Money out of hospitals into the community

Nothing matters more than helping a child in need.

Cost of supporting a child in care £300,000 P/A.

Next era reform will be led at local level.

Get out there and make a noise.

#### **Working towards solutions**

Parents were grouped together and given flipchart with one of the titles listed as follows:

1. Diagnosis –how important is it?
2. Why would you need to see a paediatrician

3. What support do you need with your child?
4. Accessing the paediatric team
5. Reports for statements of special educational needs
6. Who can refer?

Parents were asked to work in groups and given a flipchart with a title from list above and to write down their thoughts on this.

Children's development centre model was introduced for discussion. After much discussion "one stop shop" was unanimously agreed to be a good model.

Concerns were also raised about the fact that there were many successful models outside Lincolnshire and why didn't we take on one of these instead of starting from scratch; examples given were Dundee and North Yorkshire.

Gillian Merron MP was introduced as she has been in dialogue between PCT and ULHT and parents.

We will forward report to herself and all MP's in Lincolnshire as well.

Gillian will follow this up and support our consultation.

Thérèse finished the meeting by stating how information collected today would be fed back to parents. The LPCC would collate information in a report and circulate to parents.

Thérèse asked for parents to complete evaluation forms and thanked all for attending.

## APPENDIX B

### **Minutes of the Health Consultation**

**Held at Bishop Grosseteste College, Lincoln**

**on Friday 23<sup>rd</sup> October 2009, 7pm -9pm**

**Organised by the Lincolnshire Parent Carer Council**

The meeting was opened by the chair of the Lincolnshire Parent Carer Council, Thérèse Lord.

Thérèse thanked everyone for coming and explained that it was organised to be a joint consultation with the PCT and ULHT but unfortunately the PCT professionals that were to attend subsequently declined the invite and were on holiday during the consultation. ULHT had cancelled by email the night before.

As the report is to be informed by opinions, the consultation would still carry on and parents' views would be heard.

Thérèse briefly introduced the LPCC and explained that they were all parents of children with disabilities and they were volunteers.

Thérèse then explained that the LPCC facilitates two way communication between parent/carers and service providers such as LCC Children's Services.

Thérèse then went on to explain that the PowerPoint presentation would facilitate the flow of the discourse and that parents would be able to air their concerns verbally or on the feedback form.

She emphasised the need for parents to use this opportunity to not only present their concerns, but also to work on solutions so the LPCC could feedback their views in the form of a proposal.

#### Agenda

#### **Structure of NHS**

Thérèse explained the roles of the Health Service:-

PCT –commissions services  
ULHT –buys and provides the service  
Families –use the service.

## **Concerns**

### **1. Availability of paediatricians**

**Parent** – some parents had no communication regarding being discharged. When phoned to check on appointment secretary tried to filter cases.

**Parent** – Didn't know son had been discharged until received a copy of the letter from the LPCC & PAACT. When phoned, were also filtered by secretary.

**Parent** –assumed case would be taken on by new consultant.

**Parent** –Where is the successive management plan?

**Thérèse**-stated the LPCC had been in dialogue with Alan Kitt since March 2008 regarding this but still there is a gap in services. The locum was only being employed for 4 days in October and November to see a potential of 352 cases from Dr Millns' caseload.

Staff situation:

Dr Betsy Wiggins –holding 20-30 min appointments in Lincoln

Dr Julie Clarke –Stretched

Dr Omar –Left

Dr Baxter –Leaving in November

Dr Goggins –retiring December

Dr Germer - left

Dr ? In south of county left

This leaves Dr Julie Clarke, Dr Johnson & Dr Crawford

**Parent** asked whether anyone was aware of Local Operating Plan and the plan to shift from diagnosis.

**Thérèse** –LPCC members attended this meeting and no changes would happen until they have Tribal's input (the consultants brought in to do the paediatric review).

**Parent** –thought the emphasis was shifting from diagnosis.

**Parent** –asked about the differences between Dr Ikena, Dr Wiggins and consultants.

**Thérèse** –the grading is different.

**Parent** –stated that junior Doctors either cannot or dare not diagnose without back up. Asked what power do the Doctors have when they are the next level down from a consultant

**Parent** –Concerned as it appeared this was also inconsistent. Some can diagnose and some can't. This also appears to happen with prescribing medication.

**Parent** –Some parents are resorting to buying Melatonin over the internet. This was very worrying as it is supposed to be monitored at least every six months by a consultant.

**Parent** – I have been prescribed Melatonin by my GP. It was thought that GP's were not allowed to prescribe this drug. Dr Millns wrote to her Doctor to ask them to prescribe it. Appeared GP agreed to prescribe due to overview of paediatrician who has now subsequently left.

**Thérèse** –stated new referrals have to go through GP. There is a triage service when referral comes in. The triage team sift to see who fit the criteria.

**Parent** - Phoned up after son had been discharged and GP stated he is unable to refer him. GP's have tried to refer but unable to get support.

**Thérèse** –It appears that GP's are inconsistently referring –some poor quality referrals are being rejected as there is no training for GP's in the referral procedure. They need support and training.

**Parent** –concerned how well trained triage were.

**Thérèse** –they just follow the criteria which has been tightened recently.

**Parent** –child was referred through GP and had to wait 6 months to get a diagnosis.

## **2. Management of replacement of paediatricians**

**Parent**-No succession management

**Parent** –concerned that PCT and ULHT did not attend. Asked who they were.

**Thérèse** –Joanna Fawcus and Dr Julie Clarke, Alan Kitt, Bronwyn Whittaker and Hilary Barrett.

**Parent** –asked whether they will listen to parents’ opinions when they had not attended the important consultation? She thought it was important to publicise what was going on.

**Thérèse** –stated the report will go to the Scrutiny Panel for Health, LINK (who attended consultation this morning), Gillian Merron MP (who also attended this morning to offer her support), and other MP’s in County.

The LPCC were very disappointed that parents’ views were not being listened to at the consultation. By holding the consultation it sends a clear message that parent views are to be taken seriously.

We are also telling PALS what is happening and if parents would like to complain we will send them contact details.

### **3. Communication letter regarding appointments**

All agreed this was very ambiguous.

### **4. Receiving medication**

Agreed it was very worrying when parents were buying drugs over the internet with no monitoring taking place.

**Parent** –Junior Doctor she saw did not even have the equipment to monitor the child. She felt too inexperienced for the role.

**Parent** - who saw Dr W was asked why are you here as you’re not on medication. Parent thought it was a complete waste of time.

### **Working towards solutions**

Parents were grouped together and given flipchart with one of the titles listed as follows:

1. Diagnosis –how important is it?
2. Why would you need to see a paediatrician
3. What support do you need with your child?
4. Accessing the paediatric team
5. Reports for statements of special educational needs
6. Who can refer?

Parents were to discuss and record their thoughts on the flipcharts. After a few minutes' discussion, parents were introduced to the Children's development centre model and further discussion ensued.

Parents were regrouped and it was unanimously agreed that the "one stop shop model" was required and met their needs. A couple of alterations were suggested and noted on the flipcharts. Parents fed back their thoughts and comments from flipcharts.

Thérèse finished the meeting by stating how information collected today would be fed back to parents. The LPCC would collate information in a report and circulate to parents.

Evaluation forms were to be completed and Thérèse thanked all for coming.

## APPENDIX C

*There are two sections to this form. The top part relates to how the Lincolnshire Parent Carer Council carried out its consultation with you today. The second part relates to the service you received (or did not receive) from the NHS. Thank you.*

	Very Satisfied	Satisfied	Not satisfied	Totally dissatisfied	No answer recorded
Please tick <b>in</b> the box between the lines (example)		✓			
1. How satisfied are you with the Parent Carer Council bringing this consultation to you?	<b>86%</b>	<b>12%</b>			<b>2%</b>
2. How satisfied were you with the chance to voicing (or writing down) your concerns at this consultation, either by yourself or someone else?	<b>93%</b>	<b>7%</b>			
3. How satisfied are you with the Parent Carer Council taking this matter up on behalf of similarly affected parents?	<b>81%</b>	<b>19%</b>			
4. How satisfied are you with the choice of venue?	<b>67%</b>	<b>26%</b>	<b>5%</b>	<b>2%</b>	
5. How satisfied are you with the choice of times to attend this consultation?	<b>74%</b>	<b>23%</b>	<b>2%</b>		
<b>The questions below relate to the service from the NHS</b>					
6. Prior to this consultation, how satisfied were you with the information you received from the NHS about the service difficulties with community paediatrics?		<b>2%</b>	<b>16%</b>	<b>74%</b>	<b>7%</b>
7. How satisfied were you with the management of replacing retiring community paediatricians?		<b>2%</b>	<b>5%</b>	<b>93%</b>	
8. How satisfied were you with the correspondence you received about your future appointments to see a community paediatrician?		<b>2%</b>	<b>14%</b>	<b>79%</b>	<b>5%</b>
9. How satisfied are you with the current arrangements to see a community paediatrician even if it is a locum?		<b>12%</b>	<b>7%</b>	<b>79%</b>	<b>2%</b>
10. How satisfied are you with the responses from health professionals in the consultation today?		<b>5%</b>	<b>2%</b>	<b>91%</b>	<b>2%</b>

If you have any additional comments, please feel free to tell us on the back of this page.

**Thank you for completing this form.**

43 people completed an evaluation sheet. Additional comments were noted on the back of 4 sheets with an additional 19 feedback sheets as follows:

- *Diagnosis: effectiveness of treatment of autism depends critically on early intervention. GP's are not capable of making this dx. No diagnosis means no effective intervention*
- *My child is likely to need competent medical services (paediatrics, psychiatry) for management of depression, anxiety and social adjustments*
- *I am absolutely disgusted that no-one came to the consultation from the PCT or ULHT. It demonstrates very clearly that children with additional needs are very low on their list of priorities, yet they are part of the future of our country. Does every child REALLY matter?*
- *It is disgusting that the PCT and the ULHT didn't attend the consultation, extremely disrespectful. Do they realise this is our children they are affecting? We need to have somebody supporting our children and us as parents. Feel very isolated. When are you going to do the right thing and support vulnerable families?*
- *Re: Q.6 on evaluation sheet - I knew that Dr Millns was retiring but did not know how dire the situation is with paediatricians*
- *Re: Q.7 on evaluation sheet - Had to chase up annual paediatricians and hip x-ray appointments. Dr Bissendat helpful*
- *Re: Q.8 on evaluation sheet - No communication received*
- *Re: Q.9 on evaluation sheet - Dr Bissendat is a staff grade doctor not a consultant paediatrician*
- *Re: Q.10 on evaluation sheet - They didn't turn up.*
- *This is a viable workforce for the future, autism will impact the society if nation more shambolic if not dealt with*
- *Bounced by triage service in Sleaford they stopped access to service after referral from school.*
- *No offer of advice for complaints procedure. Children should come first!! Children need help!! As parents we should enjoy life with young kids not*

*be constantly stressed because of an inadequate system with so called health professionals*

- *What screenings are provided for the developmental delays – the earlier diagnosis the better? Are Surestart centres doing screenings? Relying on routine visits with Health visitors, nurse or GP is insufficient. Screenings for pre-school (age 3-5) children should be routinely provided every six months in a centre where educational psychiatrists, Occupational Therapists, vision, hearing, speech etc are tested/screened. Leaflets on screenings should be provided to all services*
- *Concerns our child is coming up for 16 years and already we are having to fight again about the services we are trying to access for him due to adult services saying no and children services trying to hand it over to them so me being treated appalling and piggy in the middle scenario. Obviously we just a statistic not real people*
- *PCT/ULHT conspicuous by their absence – every child matters – children’s entitlement; where does Lincolnshire figure in this? I am alarmed and perplexed (Head teacher and SENCO and grandmother)*
- *? consultations between NHS, services and dialogue with LEA/schools. Peterborough have dedicated autism working group led by paediatricians, with dedicated Educational psychologists, attended by Occupational therapists, speech and language and outreach. These all work together, but schools may not take up recommendations. Also link into resources at private specialist school. Contact and mutual support with local NAS branch. NOTE: referral from a paediatrician outside the county to Lincs was ignored.*



Child Health  
Orchard House  
Greylees  
Sleaford  
Lincolnshire  
NG34 8PP

Tel: 01529 416017

Dear Parent/Guardian,

Re: Dr Millns' Retirement

Due to Dr Millns' retirement we are aware that many children have not been offered follow up appointments.

The Community Paediatric Team and United Lincolnshire Hospitals Trust wish to ensure that the most urgent cases are seen as a priority. If you feel that you are one of these cases please phone us at Orchard House on 01529 416017 quoting reference code **JDCCM** to request an appointment. You will be offered an appointment with another member of the Community Paediatric team once the lines close on Friday 11<sup>th</sup> September 2009, this will be sent to you in a letter.

If, however, you feel that your current situation is stable and we do not hear from you by Friday September 11<sup>th</sup>, we will discharge your child from follow up. We will be happy for them to be re-referred to us by your GP in the future if new difficulties arise.

If after you have received an appointment you do not give due notification of being unable to attend you will not be offered a further appointment. This is in order to ensure that all available appointments are utilised and are not wasted.

We are grateful for your cooperation.

Yours sincerely

Lincolnshire Community Health Services

Cc: GP