

Summer Term Newsletter 2020





Virtual meetings

We are finding a new way of meeting parents virtually. What has been interesting is the virtual world enables more parents to participate, as it is easier to log on and attend a meeting than to travel to a venue and for some, it feels more comfortable attending a meeting whilst in the familiar setting of their own home. We can see a real value to us as a forum and our members using Zoom to meet up, we will also have some face to face events once it is safe to do so.



<u>Information</u>

We have worked with Central Bedfordshire Council and the Bedfordshire Clinical Commissioning Group to put together a list of <u>frequently asked questions</u> to help families through the shutdown which we hope was useful to you.

SEND School Transport

We are working with Central Bedfordshire Council to update their school transport policies. We jointly held with CBC some virtual feedback meetings in May for parents to give their feedback.

We are members of the SEND School Transport Board which enables us to ensure parents' views are taken into account before any changes are made.

Due to Covid- 19 and the social distancing measures in place we have asked the SEND School Transport Board to promote their policy of paying personal mileage (currently at 36 pence per mile for four journeys) a day to be paid to parents who would usually receive transport from CBC, whilst adapting their current offer to ensure parents who could not or did not want to take their children to school were provided with transport to school. CBC agreed with us and have promoted this policy to parents, we appreciate SEND school transport is very costly to the council however, it is a statutory duty and for many children, there is no other option than to travel a distance to attend a suitable school that meets their needs and acheives the right outcomes.





SNAP PCF Update

SNAP PCF have been working with the Bedfordshire Clinical Commissioning Group on their Neurodevelopmental Pathway. The Joint Commissioning Manager will be attending the Parent Panel to present on this piece of work. We raised the issue there was not a peer mentoring service in Central Bedfordshire yet their was one in Luton, we felt this was unfair and have raised this with the BCCG. We have been working with them on a new peer mentoring service for families and a 18 month pilot will soon be launched, this will link into the Neurodevelopmental Pathway.

SNAP PCF wrote an <u>update report</u> in May following Area SEND Inspection in November 2019, SNAP PCF only had seven days to both consult our membership and to write <u>a report for the Inspectors</u>. Since the WSoA was received on the 24th of February 2020, we have reflected on our Inspectors Report, Survey Results and the anecdotal information received from our members. We also wanted to introduce ourselves, to anyone who is not already familiar with our Forum and how as a critical friend, we work in partnership with Central Bedfordshire Council and the Bedfordshire Clinical Commissioning Group.



Children with Disabilities Team update for parents who receive Direct Payments

We asked Children's Social Care if they would be flexible with parents who receive Direct Payments as we wanted parents to be able to spend this money flexibly to meet their child's needs during Covid. We worked with Nigel Stock, Head of Specialist Services who wrote this update, please note your social worker will have been informed of this too.

Four things CBC is doing to support parents of children with disabilities during this Covid19 period

SUMMARY:

Direct Payments (DP) 1: Flexible use Parents and carers who would normally use their direct payment to pay for a carer for their child, but are unable to do so due to the pandemic restrictions, can now use this money more flexibly. For example, using the money to make one off purchases of equipment that will help to support their child during the pandemic.

Direct Payments (DP) 2: Saving up your hours. Parents and carers can carry over any unused hours of care into the rest of the year, to be used when the pandemic restrictions ease.



Direct Payment Update Continued

Direct Payments (DP) 3: Financial Support to DP Carers. If your child cannot receive care from you DP carers due to Covid19/Coronavirus we are willing to financially support your DP carers during the period of the virus so that they do not have to seek alternative work and will be available to resume care as restrictions ease.

In addition, if parents and carers can find an alternative temporary carer for their child during the restrictions, CBC can both fund the temporary carer and offer the financial support to the original carer until they are able to resume caring for the child.

Payments to Care Agencies: If your child normally receives care from a Care Agency who are unable to provide it during to the pandemic, CBC are supporting the agency financially during this period. This should to allow the care agency to resume providing the care as soon as restrictions ease, preferably with the same carer(s) as before.

Further Detail:

Direct Payments (DP) 1: Flexible use: In normal times, the money that parents receive as direct payments must be used as originally agreed with the Council. However, emergency legislation and guidance provided by the government now allows us to invite parents to use this money more flexibly. If it is not possible for your child to receive care from their usual direct payment carer due to the pandemic, you are now able to use the money in a different way that will help you to support your children during this difficult period (such as purchasing activity equipment).

You can now do this by contacting your child's social worker agreeing what you are going to purchase, and ensuring that receipts for any purchases that you make are retained until the end of the financial year.

Direct Payments (DP) 2: Saving up your hours.

Direct payment care hours are usually agreed as a weekly allowance of hours. If your child is not able to receive this care during the pandemic restrictions, you will be able to exceed your normal weekly allowance of hours once restrictions have lifted, to enable you to make up for any care hours lost.

Direct Payments (DP) 3: Financial Support to direct payment Carers. If your child's carer is not able to provide care during the restrictions, and they won't be able to provide the missed hours over the rest of the year as outlined in (2) above, the Council can arrange to pay your carer 80% of what they would have been paid had they worked during the restrictions. This is to try and ensure that the carer does not seek alternative employment during the pandemic and so will be available to resume caring for your child after restrictions ease.

Each parent or carer can decide how best to use this more flexible approach, by choosing which option above is most appropriate for their child's needs. If you have any questions about how these options might work best for your child and family, please speak with your child's social worker who can discuss your options with you.



Meet the Director Sessions

Following the WSoA it was decided to hold meetings for parents to attend to share their experience and give their views of the changes they want to see.

Who attended?

The three Directors who attended the sessions were Sue Harrison, (Director of Children's Services), Anne Murray (Chief Nurse) and Kirsty Green, (Director of SNAP PCF.) Cambridge Community Health Trust who run the children's community health services in Bedfordshire attended along with East London Foundation Trust who run CAMH and Chums, Heads of Service and the Assistant Director responsible for the SEND services and the Lead Councillors for Children's Services at CBC all attended to meet the parents and hear their experiences.

What was the point to the sessions and why did SNAP PCF get involved?

SNAP PCF was initially concerned that these meetings were unnecessary. Parents had given their feedback to OFSTED and the CQC who had agreed with their judgement that services offered to their families did not meet the children's needs and had to be fought for which is unacceptable. This is why they now have a WSoA.

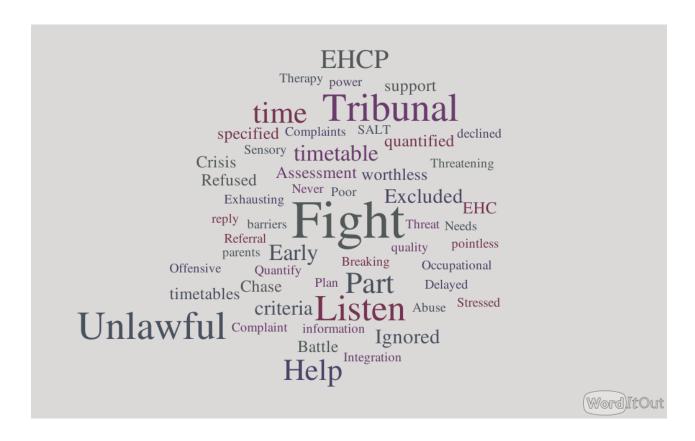
We understood that this may be difficult for parents to come forwards so we ensured before the meetings that no service was going to try to defend or justify the current service. SNAP PCF felt there was strength in parents uniting together with their Parent Carer Forum to hold CBC and the BCCG to account for their treatment of families, many who are broken by fighting a system that is so disjointed that it hurts the people it is trying to support. No longer were parents just an email address and no longer was any one Head of Service hearing complaints in isolation, dealing with them how they chose. CBC and the BCCG were now in front of each other, hearing the parents' voices together. There was power in that, parent fighting back, who will not be silenced, who will have their say regardless of how painful it was to share this at the sessions. We would like to thank those parents who attended the sessions. SNAP PCF will continue to push the SEND agenda and work with CBC and the BCCG to improve the services families receive.



Meet the Director Themes and Next Steps

What were the main themes from the meetings?

CBC has <u>published feedback</u> on the Local Offer of what parents told them. SNAP PCF put together a word cloud, yet again and to no surprise the main word used was FIGHT. We also heard of unnecessary Tribunal cases, children stuck on parent time time tables, unlawful practice and broken families falling into crisis.



So what happens now?

SNAP PCF has membership of every strategic board for the WSoA. We have three new Steering Group Members join us and are getting ready to hold some Parent Panels for our members to get involved and participate in the action plans.

Children's Centres update

SNAP PCF continues to push the SEND agenda to ensure the decision makers are constantly thinking about parents who have children and young people with additional needs and disabilities. We do this by having good working relationships with staff at Central Bedfordshire Council and the Bedfordshire Clinical Commissioning Group who value and trust our input.

When we heard Children Centres were being brought back into the Council and would now be for children 0-12 years of age, we contacted the Head of Service to discuss what offer there was for families with children who have SEND. We explained that for many families they needed a specific offer from Children's Centres to make them feel included as many would like to meet other parents who are in a similar situation them and understand the additional challenges they sometimes experience.

Fiona Side, Head of Service for 0 – 12's Family Services, said that she is keen to revisit the offer of support for families within SEND and as a starting point the Children's Centres are planning to pilot virtual SEND coffee mornings for parents of children with SEND.

The virtual coffee mornings have been discussed with SNAP PCF. The focus will be on enabling parents to come together in an informal way with an open agenda; to share ideas and activities, to talk about their current experiences and explore options for both peer and professional support.

Further information about the coffee mornings will be publicised through the 'SEND News' – Fortnightly <u>Email bulletins</u> delivering the latest news updates, useful resources, advice, guidance and support on education, health and social care SEND services available across Central Bedfordshire.





SNAP PCF VIRTUAL GET TOGETHER

Wednesday 8th of July, 11:00 - 12:30

Members please join us for our 2nd virtual get together

Please email admin@snappcf.org.uk for the Zoom link

Things to discuss

Anything that is important to you, some ideas to focus on could be:

- The Children's Overview & Scrutiny Board would have met that week.
- Next steps we are involved with from the Meet the Director sessions





What is the Sunflower lanyard scheme?

Not all disabilities are visible – such as learning difficulties, mental health as well as mobility, speech, visual or hearing impairments. Living with a hidden disability can make daily life more demanding and it can be difficult for others to recognise the challenges you face.

Be visible when you want to be by wearing the lanyard or carrying the card discreetly indicates to people around you that you may need additional support.

The lanyards & cards will be given to our members.

If you would like a card and/or a lanyard please email admin@snappcf.org.uk and

we will pop one in the post.

<u>LINK TO MEMBERSHIP FORM</u> https://www.surveymonkey.co.uk/r/MembershipformtojoinSNAP

Please note membership is for parent carers of a child or young person aged between 0-25 years with any additional need and live in Central Bedfordshire









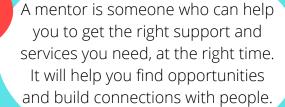


Parent Panel

Do you want to hear about a new Neurodevelopmental Pathway?

Would you like to give your views about a new Parent Mentoring Service for Central Bedfordshire families?

The pathway can lead to a formal diagnosis of autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), global developmental delay (GDD) and difficulties with attachment.



Tuesday the 14th of July 2020, 1:00 - 2:30

We need eight parents to give their views. As a thank you for attending we will send you a £20.00 M&S voucher.

Please email admin@snappcf.org.uk
Places will be booked on a first come, first served basis. We will send you a
Microsoft Teams link to join the Parent Panel.



The benefits of joining your Parent Carer Forum

It is free to become a member
Receive our termly newsletter
Be invited to attend our parent training and events
Ask for a free Max Card
Attend our Parent Panels

Who are we?

As parents of children and young people with SEND, we bring a real-life perspective and experience to the planning and development of the services that our families use. We constructively challenge decisions that are taken by the Local Authority and Health Authority about the future planning of services.

You must live in Central Bedfordshire and be a parent of a child or young person with ANY additional needs aged between 0-25 years of age.

To find out further information please visit our website http://www.snappcf.org.uk/