#### **Public Question Time**

## Agenda item 5 Work Programme + link to Agenda item 9

#### Marianne & Sarah

26 March 2018 is Purple day is the international day for epilepsy

Epilepsy is one of the most common serious neurological disorders worldwide.

Epilepsy is the fourth most common neurological disorder, a chronic disease of the brain that affects more than 50 million people worldwide. Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Some seizures many not be diagnosed for many years.

Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BC. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disease and their families.

People with seizures tend to have more physical problems (such as fractures and bruising from injuries related to seizures), as well as higher rates of psychological conditions, including anxiety and depression. The risk of premature death in people with epilepsy is up to three times higher than in the general population. Some deaths could be preventable, such as falls, drowning, burns, prolonged seizures and SUDEP

Up to 70% of people living with epilepsy could become seizure free with appropriate use of anti-seizure medicines. This also means some people have epilepsy that are not responsive to medication or could be a symptom of another progressive disease.

Somerset has a basic neurology team with all expertise in neuropsychology, further investigation services and VNS surgery available in Bristol. This can often mean that people are delayed in referrals being made and greater epilepsy management. But also hospitals need to share care.

Through experience we have found there is an urgent need to help GP's, paramedics, care staff, teachers, school governors and our communities to understand epilepsy with over 40 different types of seizures that affect day to day schooling, work and life skills.

Please could we ask this committee to raise the question for this county council to promote an education program for families and practitioners to be more aware of epilepsy seizures and SUDEP. Also for a greater epilepsy pathway of support including assessments for co conditions, audits on assessments, advice and referrals for a more rapid response to investigations and treatment. Simpler access to EHA and EHC assessments and plans.

## Agenda item 6 Children and Young People's Plan 2016-2019

## Sarah Baker - not attending

How many children or young people have been consulted on for this report?

Does the children's trust feel they have provided all opportunities for CYP to have their voice heard? for example at the Young Carers consultation, where the remaining 115 CYP are still waiting to be contacted.

## Agenda item 7 Children and Young People's Plan 2019-2022

#### Sarah Baker

With more than twice the National average of young people in Somerset, why is there such a delay in Somerset targeting this urgency of hospital admissions for self-harm? One family were told after asking the DCS for help, that it wasn't the LA's area to help them with the child self-harming whilst in school. Children and young people have been made MORE vulnerable by the services who are meant to help them here in Somerset and this must change. The way Young Carers have been treated is just one small example of how little this authority is taking safeguarding duties seriously.

Which schools have had access to school nurses as referenced on p14, especially as our county has the lowest national record of school nurses.

#### Agenda item 7 Children and Young People's Plan 2019-2022

#### Eva Bryczkowski

I am concerned about some of the negative publicity regarding Discovery, particularly around safeguarding issues.

In relation to the new Children's and Young People's Plan that is being put to the Committee:

QUESTION ONE:-What steps are being taken to ensure young people in the care of Somerset County Council are supported and have opportunities to express concerns, and have them investigated and responded to?

QUESTION TWO:-How will this plan be evidenced and who will see the reports and at what periods of time?

QUESTION THREE:-Regarding partnership working, how will partners feed into children's services, and how will it be monitored?

#### **Agenda item 8 Family Support Services**

#### Nigel Behan

Q1 It is stated that: "Commissioning and Specification • A service specification is in place for PHN post April 2019, this has been shared with strategic partners. • Between February and April 2019, Healthwatch will be facilitating meetings with

service users to explore how the HV service could be delivered most effectively and what has worked well historically • The business case for FSS has been signed off, based on PHN finances only at this time, by both the DCS and DPH,"

- a) Can you clarify what "based on PHN finances only....." indicates?
- b) "Will you publish the latest version of the "The business case for FSS"?

## **Agenda item 8 Family Support Services**

#### **Elvira Elliott**

RE: Groups to replace GETSET and Young carers

It is encouraging to see that the council are now intending to support the creation of nurture groups, and that there will be some staff and money available to help with funding applications. Also encouraging that the council intends to have something in place for the young carers. These statements and questions apply to both early years and young carers group provision.

There are still some issues with the community groups concept that I can speak on from personal experience.

A few years back there was an attempt to start a breastfeeding peer support group local to me. I expressed an interest along with some other women. I believe it was la leche league or a similar large, well-funded organisation looking to start it due to the group at the children's centre being cut.

After a huge amount of back and forth during which half the participants lost interest, I was asked to be a coordinator. This involved finding and booking venues, organising the groups, and also training in my own time to become a breastfeeding peer supporter and offering support. I said "sorry, is this a paid position?". No parent who has tiny children is going to be able to do all that reliably. Even expecting people with babies to be able to turn up every week was a big ask. Combine this with the inevitable travel issue we have in Somerset and it was simply put a nonstarter. The group folded before it ever began. The setup took so long that by the time negotiations were starting to progress most of the original cohort of interested people had finished breastfeeding and were no longer interested.

If the council staff are only going to help with funding applications and seed investment and not the managing and running of groups there must be measures will be in place to support the actual running of the groups and the constant recruiting as volunteers move on.

With the loss of our community centres and the children's centres being decommissioned and used only as private nurseries and health visitor hubs we have run into another issue with running community groups. In more than one case we have been offered rooms from the town hall and toys from the children's centre, but nobody can provide storage.

I have also spoken to a lady online in another deprived area who put her heart and soul into setting up a sensory play centre for disabled children after her local sure start centre closed. 6 months in she was close to burnout and running into debt because she was still awaiting charitable status and in 6 months of daily fundraising, she had secured only one small grant from a town organisation. She only wanted to provide a safe place for children like hers to play. This huge backlog in charitable status applications only serves to demonstrate how many groups are vying for the same pot of money.

She had a LA worker help her search for funding and they drew a blank. She didn't meet any criteria until she could become a registered charity.

It seems to me that the children's centre spaces could be used for YC groups and nurture groups if the will existed from councillors to allow that to happen. We ask here for some joined up thinking along with the partners who have taken and are taking these spaces on.

Question 1) What happens if the charity and crowd funding is not forthcoming and the seed fund is exhausted?

Question 2) What measures will be in place to help people overcome these kinds of unseen barriers like storage, lack of available spaces and volunteer burnout, to setting up community support? It's not just a matter of throwing funding at the groups they will need support to be sustainable.

Question 3) What is the likelihood of any groups being concretely in place by March 2020? Has any capacity for this been identified yet?

Additionally, It has come to my attention that following the massacre of GETSET level 2 and universal, pressure has increased on GETSET level 3 which is now failing. I also spoke to a health visitor about my daughter showing signs of autism and she told me not only did she have 4 kids like mine in her caseload, but she had no idea what to do about them. She was terrified of how they were going to cope with taking over from GETSET level 2.

I include in this document the following screenshots of a conversation I had yesterday with the most vulnerable family I know. This family have been homeless living in a hostel for a year with 2 children under 2. They have just moved into a house with baby 3 about to arrive. Mum has chronic kidney disease and is regularly hospitalised. Both parents have very poor literacy and mum has ADHD so there are a lot of spelling mistakes, but you can get the general idea of how the support has fallen off the cliff. It hasn't taken long for the cracks to show from the staff quitting.

I want to stress that these are two good, loving parents who do their absolute best for their children. They simply need some help to navigate parenting and family life with their health and learning difficulties.



#### **Agenda 8 Family Support Services**

#### Sarah Baker

Please could we see a comparative table for the referrals to teacher advisory services since 2013, just before the SEND reforms were introduced. Also, to which services it identify the age groups and services referred to especially as there is a delay or refusal in some schools still making referrals.

Which other services are moving into the family support services and what services and criteria changes from other services could we be expecting?

Is this the area that will be overseeing Young Carers provision and assessments?

How many young carer referrals have been made in the last 6 months and how many new assessments relating to those referrals have been carried out?

Where is the Family services section for the complex nurse teams, and school nurses' team that help with children with medical needs but also ensure that children with medical needs are safeguarded by the schools adhering to the schools and governors' medical duties? Please could we have a list of the areas these nurses cover with their titles.

## Agenda item 9 Higher Needs Funding Provision

#### Sarah Baker

3.2 What would other authorities use their 'inclusion fund' on and are many others using it offset their HNF deficit?

How does an underspend occur on EY's when we have a clear delay on early intervention and health visitors who are no longer enabling the early identification?

Please could we see the numbers of MAISEY referrals for the last few years?

- 3.3 What is the processing time for the EWO to work with families who are waiting for their child to receive a school placement and what support is being provided?
- 3.3 What is the current diagnosis ASD pathway for 0-5, 5-18, 18yrs and up? Is there such a term as being too young to assess for ASD?

How well is Somerset assessing and diagnosing ASD as a co condition, in-line with Nice guidelines?

How many EHCP's were transitioned from statements with social care packages?

How many EHCP's have social care packages within their EHCP's?

How many children with EHCP's or waiting for EHCP's are on part timetables?

What is the number of EHE students for 2019?

How many students are on dual placements, where they may access provision and another school or place?

SEN caseworkers seem to be continually be short. These SEND reforms started to transform in 2014, but 5 years later the department has had many staff. The recent job adverts for 12month posts is concerning that new applicants are not receiving sufficient training to write 'legal' documents on behalf of SCC. The recent decision to ask for ALL high needs funded students to have EHCP's has been stressful for families and schools. How many staff posts are there? What has been the staff turnover since 2012 for SEN caseworker team, including the teams that merged? What training is provided to write EHCP's?

## Agenda item 9 Higher Needs Funding Provision

#### Jos Sartain

Question 1 - There are key omissions in the higher needs document, part of the public report pack for scrutiny. There is no mention of the costs associated with the role of the virtual school head which, legally should cover the needs of children looked after and adopted children, many of whom have high needs and send; nor is there mention of the costs associated with alternative provisions such as care farming and equine assisted learning via personal budgets; and no mention of the tutoring team who help transitions to school (previously sent). How does Somerset county council account for these services financially, descriptively and statistically within the high needs budget and where do these services fit in with the county council children and young person's education plan?

Question 2 - Somerset has a lack of specialist provision for girls with asc and semh with the consequence that boys can receive support at Sky College and Brymore but girls are excluded on the basis of their gender alone. This is discriminatory. How will the needs of girls be met in a way that fosters equality of opportunity? The fact that mainstreams with bases can exacerbate social exclusion and shame in some vulnerable children, leave them prone to bullying as the children do not fit in the base or mainstream class and furthermore, leave them in receipt of a second rate education as the bases are not always staffed by qualified teachers, it is not surprising that some children end up being home educated or educated other than at school. because of the gender bias, there is not an inclusive approach to education and the stated aim of reducing independent provision is not good news for girls. What assurances do you have that girls with semh and asc will not be forced into bases because of a lack of specialist inclusive Semh and asc provision?

# Agenda 10: School Performance 2018 - National Curriculum Test and Public Examination Results

#### Sarah Baker

Please can information be provided on where SCC is challenging schools, as this is a long ongoing and deteriorating relationship between SCC and schools, resulting in our families vulnerabilities increasing and resulting in a false 'Troubled Families' view.