

SNAP Parent Carer Forum

Review of the implementation of the SEND reforms in Central Bedfordshire



November 2019

‘SNAP Parent Carer Forum’s role is to inform and empower parent carers to be able to participate in the local SEND community’

Introduction

SNAP Parent Carer Forum Steering Group has prepared this document to highlight the information, data and direct feedback that the forum has received from families about their lived experience with regard to the implementation of the SEND reforms within the Children and Families Act 2014.

This document also includes feedback on more generic areas of concern about the provision of local services to young people and families living with SEND.

It draws upon the data and feedback received by SNAP PCF from families since 2014, and particularly references the latest survey carried out by SNAP PCF in November 2019. The full survey is presented in the appendix to this document.

Reasons for this report

SNAP PCF would like to register our disappointment that from the outset of the inspection process we have not been involved as we had expected to be. We would have appreciated the opportunity to run the Tuesday open meeting – participation, involvement and engagement with parents/carers (joint CQC and HMI) for the wider SEND community. We welcome the fact that SNAP PCF was invited to attend four meetings, however we would have appreciated more engagement in the process as we believe that our input and perspective at these events and meetings is vital in ensuring that an accurate picture of the lived experiences of families across the county, both positive and negative, are recognised and fed into the inspection process at every stage.

SNAP PCF believes that over the last five years coproduction has strengthened the local area, but only when the forum’s involvement in key decision-making has been respected and maintained, to ensure that a strong parent voice has been heard across the area. SNAP PCF

continues to be fully committed to the principle that coproduction (i) produces solutions and services that are more fit for purpose; (ii) saves time and money by eliminating mistakes and the need to re-design; (iii) allows young people and families to feel part of the process; and most importantly of all that coproduction leads to greatly improved outcomes for young people and their families.

We would like to forward the following assessment of our work as a forum over the last five years, and also submit our latest findings and feedback from the families themselves who live within our local area.

The positives

Coproduction

Central Bedfordshire Council has made good progress in implementing genuine coproduction with SNAP PCF. The Parent Carer Forum sits in key meetings and has been engaged in important pieces of work, for example joint re-writing of SEN team letters around the EHCP process. Central Bedfordshire Council have engaged actively with parents and have attended events such as parent panels, the SNAP PCF conference and participated in mini-surgeries and ran information stalls.

SNAP PCF and parents have developed good, trusted working relationships with key members of staff in the local area and have appreciated the support we have been given to be able to reflect the views of parents, this is invaluable for positive change to happen. In particular we value the feedback meetings we have with The Director of Children's Services, The Head of SEND and the Heads of the Children with Disability Team.

Our latest survey found that families had very variable experiences of how well their views were taken into account by education, health and social care services with a fairly even spread between "very well" and "poorly". Our survey also found that only 52% of families felt that education, health and social services understood their child's needs at least 'quite well', with the remainder rating their understanding of need as 'not very well' or 'poor'.

However, families reported a more positive experience in their level of involvement in setting targets for their children with 73% and 67% being 'very' or 'quite involved' with education and health services respectively.

Improvements in information for families

The local area has made a concerted effort to improve the quality of information available to families. Valuable training has been made available to families such as training for parents on sensory needs and training for parents on key elements of the 2014 SEND reforms such as SEN

support, the EHC needs assessment and the annual review. Information for parents has also been developed such as the SEND Leisure Services offer and the Preparing for Adulthood Your Journey Guidebook.

The development of the Local Offer website sections on education and health have also been positive.

However, although 58% of respondents in our latest survey were aware of the local offer which is a 12% increase from last year's survey results, unfortunately many still felt that the content was difficult to access. 25% reported that it took a long time to find the information that they needed, with 44% of respondents being unable to find what they needed at all, the format of the website was also reported as not being parent friendly.

Training for workforce

The local area has made a genuine effort to ensure that the local workforce is equipped to support families and deliver the requirements of the SEND reforms. Examples of these efforts include the planned development of SEND training for all staff, the planned roll out of a SALT toolkit for schools, and high needs funding block training for schools.

Early Years support

Support provided to families by the Early Years Team has been identified by our members as a service that families value and access which they rely on.

The Challenges

Schools and SEN Support

Many families are reporting poor experiences for children within mainstream schools on SEN support. In particular, they state that mainstream schools often do not have the resources to support their children appropriately. There is concern about the continuing lack of understanding that some schools have about the needs of children with ASD and ADHD particularly. Some families have reported exclusions (both official and unofficial) where they have felt that reasonable adjustments, that reflect an understanding of the needs of their children, could have been made by schools but were not. A lack of recognition of the condition of Pathological Demand Avoidance (PDA) is also reported by families.

More generally, parents have expressed concerns about the lack of appropriate SEN provision within the local area, with this resulting in some of their children being schooled out of county. This is reflected in our survey results, where 67% of parents rated local SEND educational

provision as poor or inadequate, with 50% of families feeling that their children's needs were being met 'poorly' or 'not very well' by education services.

Our survey also found very variable satisfaction levels with the identification of need from education, with 42% of families still reporting that their children's needs were not being adequately identified.

Education Health and Care Plans

Families continue to report concerns about their children's Education Health and Care Plans. Many families report that their child's EHCP is of variable quality, with input that is sometimes poor or missing from health and social care services. Many families have expressed concerns that their EHC plans do not incorporate "SMART" targets, and that annual reviews are often delayed. Parents have also continually reported frustration because of difficulties in communicating with the local authority SEND team.

Social care

Many families report that accessing social care services is becoming more challenging – with thresholds being raised and many who feel that they need support are not getting it. There is a sense that social care services are being rationed or cut. For example, many families in the south of the county have been reassessed recently and they report that they will no longer be receiving support from Kingfishers from January 2020. Many parents have also told us about the lack of autism training and understanding exhibited by some social care staff.

Our survey found the families were concerned about the ability of social care staff to appropriately identify needs, with 63% of respondents stating that they felt that their young person's needs were either poorly or not very well identified by social care services.

Concerns with health services

Parents report that they sometimes find it difficult to access the health and medical services that they need. Many tell us of difficulties or long delays in getting appointments at the Edwin Lobo centre; and of delays and raised thresholds when trying to access CHUMS and CAMHS.

In addition, there are concerns about the delivery of SALT services to children within schools. Whilst the SALT service works directly with school staff, families would like more direct access to their child's speech and language therapist themselves.

These outcomes for families are reflected in our survey results, which found that 48% of families felt that their child's needs were being met 'poorly' or 'not very well' by health services, with most of the remainder 43% describing their needs being met only 'fairly well' .

Our survey found very variable satisfaction levels with the identification of need by health services, with an even spread of responses ranging from ‘very well’ to ‘poor’.

In summary, only 44% of survey respondents gave local health provision an overall favourable rating, with the remainder classifying local provision as ‘inadequate’ or ‘poor’.

Joined-up working

Families tell us that they would benefit from a more joined-up approach from services across the local area. For example, they report a lack of information and support for families at the start of their SEND journey and at the time of the Multi-Disciplinary Assessment (MDA). They also tell us that they are still having to repeat information about their child many times to different services – and that there is no “single door” to access services.

Our survey gives a very strong message on this, with 73% of respondents saying that they felt that professionals from different services worked together either ‘not very well’ or ‘poorly’ when supporting their child or young person.

Only 36% of responses, across a number of key areas, indicated that a child or young person had access to the help that they needed to be able to achieve their potential.

Our survey asked parents “Do you feel there is anything that Central Bedfordshire Council and the Health Authority could change to make things easier for your child/young person and your family?”

The key themes of what parents said:

- Listen and communicate effectively
- Support and training for parents and schools
- The need for joined up working
- Timely referrals and appointments
- Better resources and provision

Our survey also asked parents “Is there any piece of advice you could give parent carers who are at the start of their journey?”

The key themes of what parents said:

- Get ready to fight for services
- Do your research
- Get help from professionals

“Keep fighting for your child. Jump through hoops required of you and seek honest and realistic feedback” Parent, November 2019

“Hold on tight – it’s going to be a rollercoaster ride! Make connections with other parent carers and local charities providing support. Understand the law, knowledge is power. Don’t just accept what you are told, inform yourself and make your own decisions. Get involved with other parents and work collectively for change.” Parent November 2019

In summary

Whilst there have been positive joint-working relationships and some success stories over the last five years, the forum is still seeing too many families struggling to understand and navigate local SEND services and provision. The 154 families that completed our survey are still feeling that their views are not being actively sought or listened to; that different services are not communicating and working together effectively; that local provision in the county is not adequate to meet their child’s needs; and that their children are not receiving the help and support that they need to reach their full potential.

Thankyou to all the parents who took the time to complete our survey. We recognise 154 families is a modest number from the SEND community in Central Bedfordshire.