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Overview & Scrutiny CHILDREN'S SERVICES AND SAFEGUARDING PARENT/CARERS SUB-COMMITTEE

MEETING HELD AT THE BIRKDALE ROOM - SOUTHPORT TOWN HALL, LORD STREET, SOUTHPORT, PR8 1DA ON TUESDAY 17TH SEPTEMBER, 2024

PRESENT: Councillor Hardman (in the Chair) Councillor Danny Burns (Vice-Chair) Councillors Evans, Richards and Christopher Page

## 4. APOLOGIES FOR ABSENCE

No apologies for absence were received.

#### 5. DECLARATIONS OF INTEREST

No declarations of any disclosable pecuniary interests or personal interests were received.

#### 6. MINUTES

RESOLVED:

That the Minutes of the meeting held on 16 July 2024, be confirmed as a correct record.

# 7. ATTENDANCE OF PARENTS/CARERS - FETAL ALCOHOL SPECTRUM DISORDER (FASD).

Members of the Sub-Committee considered verbal representations from parents/carers about Fetal Alcohol Spectrum Disorder.

The Chair advised that following the receipt of a petition regarding FASD Training at the 4 June 2024 Overview and Scrutiny Committee (Children's Services and Safeguarding), it was agreed that a sub-committee meeting would be dedicated to hearing from parents and carers about their experiences of having a child with FASD.

The Sub-Committee heard from representatives of the Sefton Parent Carers Forum and the Voice of the Families Group.

- An attendee provided Members with a useful document describing some of the issues and characteristics of FASD
- The Committee were informed that damage to the function of the frontal lobes of the brain meant that a person with FASD may confabulate, which meant they would often make up things that

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were not true. This was not to be confused with lying, it was due to their brain damage and not being able to know what is and isn't reality.

- A parent described how confabulation can be difficult when dealing with Social Workers and Teachers who do not understand FASD, as they may be inclined to believe the child and act upon information that was not true.
- There was currently no diagnostic pathway at Alder Hey Hospital, no strategy group, action plan or lead officer in Sefton to coordinate services for children with FASD.
- All of those in attendance at the Sub-Committee were adopters, fosterers, or special guardians of children and all these children had FASD.
- All the parent/carers in attendance had negative experiences of getting a diagnosis of FASD and getting the help they required.
- The Parents/Carers described their experiences of being refused an Education and Healthcare Plan (EHCP), difficulty in finding suitable school places and suitable 1:1 teaching support.
- It was noted that FASD training for Teachers and Social Work Staff was historically severely limited, which subsequently meant there was little understanding of the condition amongst school and children's services staff.
- It was noted that a trainer from the 'National Association for FASD' had been promised to deliver some training for Sefton but it was unclear why this had not been progressed.
- Schools, including Special Schools, were not providing the support required due to not understanding the condition.
- Over 400 co-morbidities exist which meant that children with FASD often had other conditions alongside FASD, which also made getting a diagnosis more difficult.
- It was felt that there was a lack of support for parents who become ill and need help caring for their child with FASD. There was also a lack of respite care places to give parent/carers a break.
- Even if support was given to a child with FASD by the time they reached high school, it was common to see that support slip when the child moved on to Higher Education such as college or university. EHCP's were not being taken into account in higher education settings.
- Young people between the age of 16-25 were often expected to manage complicated timetabling, student finance and to retain important information as part of their higher education course, with no support.
- Post 18 support was not widely available for young people with FASD
- The Police and criminal justice system do not understand FASD and the sub-committee's attention was drawn to data for the numbers of people in the prison system with FASD, being as high as 19%.

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- Post adoption support was important as children with FASD often needed to come to terms with their FASD diagnosis as well as their sensitive adoption circumstances.
- Parent/Carers physical and mental health often suffered due to their experiences of parenting a child with FASD and the challenges they faced trying to obtain support.
- EHCP's stop at age 25 and then there was little support for adults with FASD.

**RESOLVED:** That

- (1) The Sub-Committee thanked the Parent/Carers for attending the meeting.
- (2) The information provided would be taking into consideration as the Overview and Scrutiny Committee (Childrens Services and Safeguarding) Committee develops further work on FASD.

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