Conclusion At a time of increased stress for families of CYP with DDD, and scarce resources to support them, Care Coordinators play a vital role in assisting families to engage with health services, and enabling them to feel supported and empowered. This service reduces the burden on professionals, whilst enhancing relationships with the families.

Abstracts

FORTY-SEVEN YEARS OF REFERRALS AND OUTCOMES IN A UK CHILD DEVELOPMENT CENTRE (CDC): ONGOING DEMAND

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Aims To explore activities and outcomes of a UK Child Development Centre (CDC) based at Northampton General Hospital over 47 years (1974-2020).

Methods The study comprised 2 data sets; all the children referred to CDC from 2019 to 2020 and a peer-reviewed publication from 1974–2014\(^1\). All the referrals made to CDC were analysed and medical notes were assessed for all the children referred over this 2-year period retrospectively like how it was done previously.

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Results 399 children were assessed from 1st January 2019 to 31st December 2020 making a combined total of 4956 children over the 47-year period. For the entire timeline there is a consistent male predominance (figure 1).

The previous study showed median age for assessment to be 2-3 years in 1987, this remains unchanged even in 2019-2020 data.

Different reasons for referrals were observed over the two data sets of 1999-2004 and 2019-2020 (figure 2(a)). Referrals for ‘social interactions’ have increased 3 and half fold, an increase from 10.4% in 1999-2004 to 32.6% in 2019-2020. Referrals for behavioural issues have almost doubled (10.1%-18.7%). However, referral for developmental delay/concerns approximately halved over the time.

Figure 2b shows recorded assessment diagnosis comparing 1999-2004 with 2019-2020 data. ASD diagnosis predominates – 54.5% in 2019-2020. The trend in diagnosis of ‘developmental delay’ has halved from 1999-2004 to 2019-2020 (figure 2(b)).

Conclusion The previous presumptive South Northamptonshire Autism Follow Up Study (SNAFU) showed between 1974-2014 a clear change in recorded assessment outcomes over this period, with from 2004 the fall of the term ‘Developmental delay’ and the relentless rise of ‘Autism/autistic spectrum disorder’ (ASD)(1). This trend for 2019/2020 has continued in the newly presented data for 2019-2020.

Despite the global COVID-19 pandemic, the number of referrals and subsequent diagnosis rates here have not changed much on 2020 data when compared with 2019. It is far too soon to determine for this CDC, the overall impact of COVID-19 for children who will be awaiting assessments.

The 47-year long term trend is one of a consistent rise of referrals for and diagnosis of ASD in the CDC. ASD is the dominant cause for referral and diagnosis given. Commissioners of preschool educational services must take into account these rising case numbers to ensure equitably fully funded, preschool diagnosis and service provision for CDCs, Child Development Teams or other local service formulations.

REFERENCES

Aims The last 30 years has seen a rising recognition of the idea that ‘children have a right to be heard’ and that young people have the right to participate in decisions affecting their lives and healthcare. These are key principles that have become engrained into paediatric training and practice. During the Covid-19 pandemic, non-emergency clinical consultations were transitioned to remote telephone appointments to try and mitigate transmission of the virus. However, telephone consultations provide an added physical barrier that may impede engaging with the young person effectively.

The following standards were agreed for the audit:
1. All children/young people should be directly spoken to. (Target: 100%)  
2. The wishes and feelings of all young people should be recorded. (Target: 100%)  
3. All children should be involved with making future plans. (Target: 100%)

Primary aim of this study was to compare adherence to the above standards.

Methods An audit was carried out of community paediatric electronic records and clinic letters of all telephone appointments, for young people aged 10-18 years, between 1/6/2020 and 30/6/2020 (during the second national lockdown). A direct comparison was made with young people seen in face-to-face appointments between 1/1/2022 and 31/1/2022. Exclusion criteria were for children attending special needs schools.

Results A total of 125 children were included in the audit (88 telephone consultations and 37 face-to-face consultations). In June 2020 a total of 35/88 children (39.8%) were directly spoken to, and of these young people 32/35 (91.4%) were involved with future plan-making and their views were clearly recorded. This is directly comparable to the January 2022 cohort where, 28/37 children (75.7%) were directly spoken to, and all of those children had their views clearly recorded and were involved with future plan-making. In almost 80% of the records, where the child was not directly spoken to, the reason for this was not clearly documented (figure 1).

Conclusion We failed to meet the standard outlined in both the face to face and telephone clinic group (75.7% and 39.8%). Capturing the child’s voice was significantly lower in the telephone clinic group. Where the child was spoken to, their views were captured in over 90% of the consultations. We believe this audit is a reflection of poor record keeping as opposed to a culture not involving the young person in their health decisions.

Telephone clinics are a barrier to capturing the voice of the child. This could be due to a combination of physical distance and poor documentation. We have since implemented a telephone appointment proforma which provides prompts for effectively capturing and documenting the voice of the child. We all agree with the importance of involving the child with their healthcare plans and advocating for a child is a key principle that underpins effective paediatric practice. It is important that we can capture this and document it effectively to ensure that we as paediatricians are providing best care for our patients.