Objectives

1. To identify parental anxiety in children with Neurodisability
2. Can a digital platform with the child's developmental profiling and visual report, app-based support with tailored individualized informed based profiling address parental anxieties.
3. Do children have better outcomes If parental anxieties are addressed

Methods A parental stress index (PSI) with 5 items was constructed. 83 parents enrolled in the intervention program were interviewed. 50 parents scored higher than 30%. The parents were shown visual profiling of their child's development. We ensured that the parents could identify the developmental areas the child needed help. We provided parents with an app that had some targeted tailored information with play ideas to perform at home. We repeated the parental Stress index interview every 2 months with these parents. Only 44 parents continued the program.

Results After 8 weeks of support, the Parental stress index interview was reperformed on all 44 parents. Significant improvement was noted in PSI with a mean difference of 19.71 and t value of 7.56, with a significant .00 level. Their children's developmental progress also improved in parents with lower PSI.

Conclusions We believe that addressing parental anxiety improves interaction with the child. The result is limited on the number of parents and inability of a control population due to lack of resources, it highlights an important area of empowering parents and using digital technology for its implementation.

British Academy of Childhood Disability

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CHANGES IN HEALTHCARE USE DURING TRANSITION FROM PAEDIATRIC TO ADULT CARE FOR CHILDREN WITH LEARNING DISABILITIES OR AUTISM IN ENGLAND: POPULATION COHORT STUDY

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Background Children and young people with learning disability (LD) and/or autism spectrum disorders (ASD) often have multiple health needs, requiring frequent involvement with healthcare services. Transition from paediatric to adult services can disrupt continuity of care, and impact on health outcomes of young people with LD/ASD.

Objectives To describe changes in emergency and planned secondary healthcare use for young people with LD/ASD before (at ages 10–15 years), during (16–18 years) and after (19–24 years) transition from paediatric to adult services.

Methods We used Hospital Episode Statistics, a national hospital admissions database, to develop one cohort of young people with LD, and one cohort of children with ASD, born in 1990–2002 in England, who were admitted to hospital in 1998–2019. We included individuals who had a diagnosis of LD, a condition associated with LD in more than 30% of

cases, or ASD. Young people were followed-up from their 10th birthday until death, their 25th birthday or 31st March 2019 (end of the study period).

We determined the annual (year-on-year) change in rates of planned and emergency admissions before, during and after transition, using multilevel negative binomial regressions models, accounting for area-level deprivation, sex, year of birth, presence of comorbidities and allowing for multiple observations per child using random intercepts. We ran analyses separately for individuals with LD and ASD.

Results The cohorts included 63,017 young people with LD and 58,363 with ASD. Overall, young people with LD aged 10–24 years had 219 emergency admissions per 1000 person-years. Emergency admission rates increased by 2% per year of age before (incidence rate ratio [IRR]: 1.02, 95% confidence interval: 1.02–1.03), by 3% per year during (IRR: 1.03, 1.01–1.05) and by 4% per year after transition (IRR: 1.04, 1.03–1.05). Emergency admission rates for individuals with ASD were 181/1000 person-years. Rates increased sharply by 14% per year of age before (IRR: 1.14, 1.13–1.14), remained constant during (IRR: 1.01, 1.00, 1.02), and increased by 6% per year after transition (IRR: 1.06, 1.05–1.06). Increases in emergency admission rates for young people with LD or ASD were mainly due to non-specific symptoms (eg. headache, abdominal pain), injury due to self-harm or mental health conditions.

For planned admissions, young people with LD aged 10–24 years had 491 admissions per 1000 person-years. Rates were highest and constant before transition (IRR: 0.99, 0.99–1.00), declined most rapidly during transition (IRR: 0.87, 0.86–0.87), and by 3% per year after transition (IRR: 0.97, 0.97–0.98). Young people with ASD had 239 planned admissions per 1000 person-years. Admission rates increased moderately before transition (IRR: 1.04, 1.04–1.05), declined during transition (IRR: 0.95, 0.94–0.95) and increased moderately after transition (IRR: 1.04, 1.04–1.05).

Conclusions Increases in emergency admission rates after transition among young people with LD or ASD could reflect unmet health needs due to higher thresholds for planned hospitalisation or accessing support from adult mental health or social care services, or loss of support from schools. Our findings are of relevance to the NHS Long Term Plan, which prioritises improving care of young people with LD/ASD and supporting young people during transition.

Quality Improvement and Patient Safety

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REVIEW OF THE NICE GUIDANCE FOR EARLY ONSET NEONATAL SEPSIS WITH THE USE OF A SEPSIS RISK CALCULATOR

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Background The incidence of culture proven Early Onset Neonatal Sepsis (EONS) is approximately 0.5/1000 live births, but with high morbidity and mortality, it represents an infrequent but significant risk. NICE guidance states that any infant with ≥ 2 risk factors for sepsis or 1 red flag risk factor should be screened for infection and intravenous antibiotics given within 1 hour of being identified. A previous audit in this level 2 unit demonstrated that only 11.8% of asymptomatic infants,

who met the NICE criteria for empirical antibiotics, received antibiotics within the 1 hour target. As part of the action plan for the aforementioned quality improvement project, we endeavoured to review whether all infants identified using the current NICE guidance in fact required empirical antibiotics.

The Kaiser Permanente Sepsis Risk Calculator (SRC) is a multivariate model of assessing the risk of EONS, using maternal risk factors in combination with assessment of infant's clinical state after birth, that has been developed in the USA. The use of SRC has been shown to significantly reduce antibiotic use in newborn infants when compared to current NICE guidance.

Objectives To review whether the use of a validated EONS risk calculator (Kaiser Permanente) could reduce antibiotic use in infants at a level 2 unit.

Methods 43 infants over 3-month period (May–August 2020) were identified who met the following criteria:

- ≥ 35 weeks
- screened for sepsis and received antibiotics
- symptomatic or asymptomatic
- complete data available

Maternal and neonatal notes, and pathology results, were retrospectively reviewed to ascertain the risk factors to calculate the SRC score, determine clinical status and length of antibiotic course, and to review blood/CSF cultures and CRP results. Clinical assessment criteria were altered slightly to be more in keeping with current practice in this unit. The calculated SRC score and recommended actions using EOS incidence 0.5/1000 were analysed in comparison with the management the infant received and pathology results.

Results The results showed that if implemented the SRC, using an EONS incidence of 0.5/1000 live births and also giving empirical antibiotics to any baby who is recommended a blood culture (which is the practice in some UK units), then antibiotic use could be reduced by 53.5% whilst also capturing all those babies who had a CRP of 20 or above. There was one infant with a positive blood culture but this was confirmed as a contaminant.

Conclusions This project demonstrates that implementing the SRC using an EONS incidence of 0.5/1000 live births could reduce antibiotic use by 53.5%. There were no specific safety concerns raised from this data, although the low numbers in this sample needs to be considered. There is also a potential for reduction in length of stay for some infants, however, this data needs to be interpreted with caution as it does not capture those infants with risk factors who did not receive antibiotics, but would be recommended an enhanced period of observation when compared to NICE guidance. Further prospective data from this unit would be useful to inform further on the decision to change practice.

Background The West Midlands Regional Children's Tumour Registry (WMRCTR) is a specialist paediatric cancer registry. Established in 1984, it records all cases of childhood cancer (including benign CNS tumours) in the West Midlands region which accounts for around 9% of the UK population. The WMRCTR has detailed records of children's cancers from 1957 onwards. The past 60 years have seen huge improvements in childhood cancer survival with five year survival for many diagnoses now exceeding 90% both nationally and in the West Midlands region.

Objectives The West Midlands region has a diverse and multi-ethnic population with wide variations in population structure, density and deprivation. The main objective was to produce an historical overview of childhood cancer incidence and survival rates in the West Midlands region using the detailed information available within the WMRCTR.

Methods 7913 cases were included; 4411 males and 3502 females (M:F ratio 1:1.3). Cases were aged 0–14 years, resident in the West Midlands with a malignancy/benign CNS tumour diagnosed between 01/01/57 and 31/12/16. International Classification of Childhood Cancer coding was applied. Detailed descriptive statistics for 45 different diagnostic groups and sub-groups were compiled including subsequent malignancies and deaths from all causes. Survival by decade of diagnosis was calculated using Kaplan-Meier survival analysis. Age and sex-specific incidence rates per million and directly age standardised incidence rates were calculated. Vital status was verified against PHE data and the NHS summary care record.

Results Most diagnoses showed steady survival gains over time. Five year survival from leukaemia was 4.6% [CI 2.6–7.3] between 1957–1966 but 88.5% [CI 84.9–91.3] by 2007–2016 with acute lymphoblastic leukaemia reaching 91.8% [CI 88.1–94.3]. Although not reaching statistical significance, other diagnoses (NHL particularly) showed a decrease in five year survival between recent decades (77.4% [CI 66.4–85.9] during 2007–2016 compared with 85.9% [CI 74.7–92.4] during 1987–1996). Patients with CNS tumours showed improved survival overall. By 2007–2016 five year survival for ependymoma, astrocytoma and medulloblastoma was 95.7% [CI 72.9–99.4], 86.9% [CI 80.3–91.3] and 68.0% [CI 52.0–79.7] respectively. Deaths within 1 year of diagnosis fell from 57.41% to 7.19% over the study period however certain diagnoses showed a notable rise in late mortality. Despite survival rates in excess of 95% for the past two decades, 13% of patients with bilateral retinoblastoma developed a subsequent malignancy with 23.68% of deaths after 20 years. In Hodgkin's disease, 19.35% of deaths occurred after 20 years with 9% of patients developing a subsequent malignancy.

Conclusions Statistics were comparable to national data with a small number of disease groups requiring further case mix evaluation (notably NHL, neuroblastomas > 1 year and renal tumours). Amongst patient with liver tumours, ependymoma, astrocytoma and medulloblastoma, the prognosis over the last decade is substantially better than equivalent nationally reported outcomes although small numbers and thus wide confidence intervals must be considered. Overall, steady, sustained improvements in survival were seen, attributable to a greater understanding of tumour biology, intensification of multi-agent chemotherapy and new treatments. The importance of follow-up throughout adulthood to monitor for late effects and subsequent malignancies was clearly demonstrated.

Children's Cancer and Leukaemia Group

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60 YEARS OF CHILDHOOD CANCER IN THE WEST MIDLANDS

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