

What is the prevalence of childhood disability in Wales? It depends who you ask!

November 2024

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Executive Summary



Current estimates
are that

0.6-14% of children in Wales have
a disability.

The absence of a complete national dataset and variations between sources makes it virtually impossible for health, social care and education to plan service delivery accordingly.

Family-report sources are substantially higher



8-14%

than statutory-report sources.

0.6-8%



Using population projections and disability figures from the Census, which represents the mean amongst the datasets, we predict that the prevalence of children with disability will rise to between **8.7-17.5%** in Wales by 2035.

We caution policymakers and practitioners to expect and plan for a substantial increase in demand for services.

Introduction

There is little recent data on the prevalence of childhood disability in the UK, with the latest estimates reflecting data reported 20 years ago [1]. Without robust data, accurate planning in health, social care, education and the workforce is impossible.

Disability prevalence among the whole population in Wales is higher than the national average for the UK (28% vs 22% in the Family Resources Survey 2020/21) [2], however we do not have a clear understanding of disability prevalence among children in Wales. Data from other countries suggests childhood disability is increasing; in the USA, childhood disability rose from 6.2% in 1992-94 to 8% in 2009 [3].

One of the challenges in describing the prevalence of childhood disability is the multi-faceted nature of disability: there are varying definitions, with different classifications used by statutory agencies, or by parents/carers themselves. In addition, disability is not a static condition, and its impact on children and young people may alter with age. Collecting accurate data on disability prevalence among very young children has further challenges, including recognition, investigation and classification of disability within this group [4].

ALN Code for Wales

Increasing recognition of the unmet needs of young people with disability led to the introduction of the Additional Learning Needs Code for Wales in 2021. The aim of this Code is to ensure that additional learning needs (ALN) among children are identified early, with interventions introduced in a timely way, to enable them to reach their full potential. The Code places a statutory duty on all education providers to identify and address the needs of these children, and crucially, requires them to identify at age 14 years any young people with continuing ALN and plan for their education provision up to the age of 25 years [5].

According to the 2021 Census, Wales had a total population of 3.1 million. Gwent, which includes five local authorities (Blaenau Gwent, Caerphilly, Monmouthshire, Newport and Torfaen), is representative of Wales as a whole, encompassing the most deprived local authority (Blaenau Gwent) and the least deprived (Monmouthshire) in the 2021 Census [6].



It is well recognised that caring for a child with disability adds a considerable cost burden to families [7], and a significantly increased economic burden to the country [8]. Given the high service demands of this group of children, impacting healthcare, social care, education and their adult carers, it is imperative to estimate the scale of the challenge for policy makers to plan for these service needs. To address this, we aim to determine the current prevalence of disability among children in Wales and Gwent and to predict the prevalence of childhood disability up to 2035.



What did we do?

Sparkle (South Wales) is a charity (1093690) supporting children and young people with disabilities, and their families, living in Gwent. Sparkle works closely with health and social care services to ensure the needs of these children and families are met and deliver enhanced support services, co-located with statutory care services. We also employ a full-time research officer, to investigate areas relating to childhood disability.

Sparkle sought the assistance of a volunteer statistician via the Royal Statistical Society's 'Statisticians for Society' scheme to explore trends in childhood disability over the period 2011-2023, estimate the current disability prevalence among children in Wales and Gwent, and predict future trends in disability prevalence up to 2035.

We analysed six publicly available data sets, three of which are based on family-report sources (Office for National Statistics Census, Family Resources Survey, and National Survey of Wales) and three statutory-report sources (Disability Living Allowance, Stats Wales Schools Census, and Stats Wales Children Receiving Care and Support Census). For Gwent, an additional dataset anonymously recording child referrals to the Integrated Service for Children with Additional Needs (ISCAN) was also accessed. A summary of the data sets, and the definition of disability used within each one, is provided in Table 1.

Statistical Methods

Using figures for childhood disability from each individual data set analysed, and the Office for National Statistics (ONS) population estimates, we calculated childhood disability prevalence over time using descriptive statistics, relative to the data set. The ONS produces population projections for successive years by taking the starting population and accounting for net migration, deaths and births. To predict the future prevalence of childhood disability, we used ONS population projections [9], creating two scenarios, assuming the number of disabled children would either stay constant, or increase at the preceding rate.

Table 1: Key information about the data sources used to determine childhood disability prevalence in Wales, UK.

Dataset	Definition of disability used	Time period	Age range	Sample size
Family-report sources				
Office of National Statistics Census ^[10]	All children deemed as disabled according to the Equality Act (2010).	Every 10 years, 2011 & 2021 reported	0 to 19 years	Whole population of UK.
Family Resources Survey ^[11]	A person is considered to have a disability if they have a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities.	April-March 2012 to 2022	0 to 19 years	Usually around 20,000 households, including around 11,000 children, representative of population. Volumes were reduced during COVID-19 pandemic.
National Survey of Wales ^[12]	If child has additional learning or special educational needs, or disability that means they need extra support in school.	2018/19 and 2022/23	4 to 19 years	Data on approximately 12,000 children in primary school. Figures reduced to 1,200 and children in secondary school was 950 in 2022/23*.
Statutory-report sources				
Disability Living Allowance** ^[13]	Children entitled to disability living allowance.	2018 to 2023	0 to 17 years	All Wales data
Stats Wales School Census ^[14]	If child has additional learning or special educational needs (School Action Plus, Statemented and Individual Development Plan)***.	January 2017 to 2023	5 to 15 years	All children in maintained schools in Wales. This is usually around 380,000 children/year.
Stats Wales Children receiving care Census ^[15]	Based on the Equality Act (2010) but <i>excluding those with neurodiversity alone</i> .	April-March 2017 to 2022	0 to 18 years	All children who had a care and support plan for 3 months or more in Wales at Census date (approximately 17,000 children).
Integrated Service for Children with Additional Needs (ISCAN) referrals	Children who present with delay in at least two clinical areas.	2017 to 2023	0 to 18 years	Gwent only. All children presenting to primary care with clinical delay in at least two domains referred for a secondary care opinion.

Legend: *Reduced figures due to impact of COVID pandemic. ***Disability Living Allowance* – a tax free benefit for people with disabilities who need help with mobility or care costs. ****School Action Plus* – A definition used in Wales to define children who need additional support in school. Since 2015, merged into one term – Special Educational needs. *Educational statement* – Legal document defining child's specific special educational needs and additional support provided in school to meet those needs; replaced in Wales by *Individual Development Plan* commencing in 2022.

Childhood disability prevalence - family-report sources

Census

Data from the 2021 Census shows that there were 55,375 disabled children in Wales, a *64% increase* from 33,685 in 2011, and 10,000 disabled children in Gwent, a 50% increase from 6,685 in 2011. This gives a disability prevalence of *8% for Wales* and *7.5% for Gwent*, an increase from 5% for both areas in 2011.

Family Resources Survey (FRS)

The latest FRS data identified 85,000 children with disabilities in Wales in the financial year ending 2023. This is *13%* of the total number of children included in the FRS, *increasing from 6%* of children in 2013, and represents approximately 12% of the child population in Wales (using population estimates from mid-2022). There is no breakdown by local authority in the data and so we were unable to capture figures for Gwent.

National Survey of Wales

Overall, 12% of parents of a primary school child said that their child had special educational needs or additional needs in 2022/23. For secondary school age children, parents identified 16% as having special educational needs/additional needs. Therefore, on average, *14% of school-age children* were reported as having additional needs. These results were similar to those in 2018/19. Gwent-only data was not available from this source.

Childhood disability prevalence - statutory-report sources

Disability Living Allowance (DLA)

The number of children aged 0 to 17 years entitled to DLA in Wales has *increased by 34%* from 25,000 in May 2018 to 33,500 in May 2023. In Gwent, the number of children entitled to DLA increased by 43% over the same time period: 4,400 in 2018 to 6,300 in 2023. This means that in 2018, 4% of children in Wales and 3% of children in Gwent received DLA, whilst in 2023 approximately 5% of children in both Wales and Gwent received DLA (using mid-2022 population estimates).

Stats Wales Schools Census

Based on the latest population estimates for mid-2022, the total number of children aged 5 to 15 years old is currently 397,000 in Wales and 78,000 in Gwent. Data from the 2022/23 Stats Wales school census shows that there are 31,082 children aged 5-15 in Wales identified as having ALN, and 6,232 in Gwent. This equates to *8% of children in both Wales and Gwent*, down from 9.5% in Wales and 10% in Gwent in 2016/17. Of note, different definitions of disability have been used since the introduction of the Additional Learning Needs Code in 2021, therefore there has been a change in how these numbers are counted between the two time points included here.

Stats Wales Children Receiving Care and Support

As of 31 March 2022, there were 3,700 disabled children *receiving* care and support in Wales and 490 in Gwent. This was 21% of all children receiving support in Wales and 13% of those in Gwent. When dividing this by the total population of children aged 0-17, currently 620,000 in Wales and 122,000 in Gwent, the data suggests that only 0.6% of children in Wales and 0.4% of children in Gwent have a disability and receive care and support from their local authority. Using data from 2017, the prevalence has remained the same in Wales and increased from 0.3% in Gwent.

Children with Autistic Spectrum Disorder (ASD) were not included in the dataset; however, it has been reported that 13% of children receiving care and support in Wales as of March 2023 had a diagnosis of ASD [16]. This equates to approximately 2,277 children, 0.4% of the children in Wales.

Integrated Service for Children with Additional Needs (ISCAN)

This dataset provides information for Gwent only. Referrals were accepted for children and young people aged 0-17 years with complex needs, however 89% of referrals were for children aged less than 5 years. In total, 3,164 referrals were received in 2023, representing 2.5% of the child population; this is fairly consistent with data from 2018, when 2,661 referrals were received, representing 2% of the child population in Gwent.

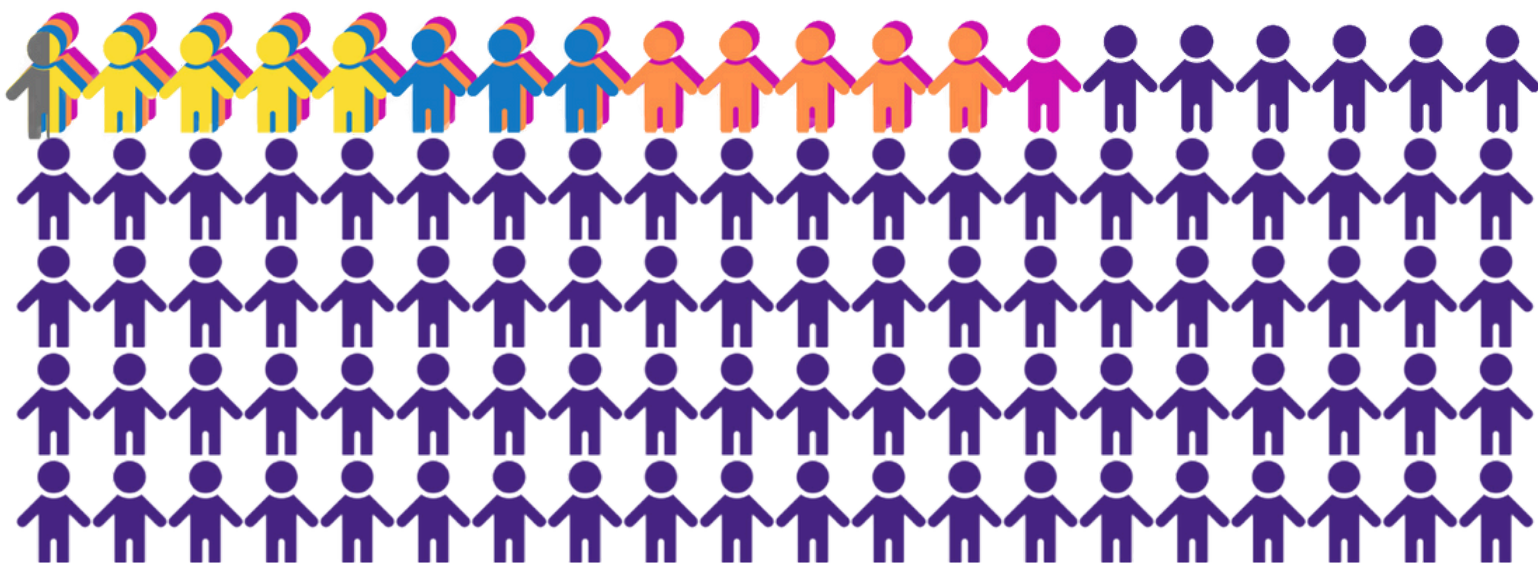
It is important to note that ISCAN figures reflect the *incidence* (number of new cases per year) rather than the *prevalence* (total number of cases in the population), which is reflected by the other sources discussed, and thus the figure will be lower.

Gender, ethnicity and type of impairment

The prevalence of disability is greater amongst boys than girls. The FRS reports 14% of boys as having a disability as of 2023, and 12% of girls. However, according to the Census, there was a greater increase in the percentage of girls with a disability between 2011 (4%) and 2021 (7%) than for boys (6% in 2011 and 9% in 2021). Disability is reported at a slightly higher prevalence in white children than children from black and minority ethnic (BAME) backgrounds; the 2021 Census reported 8% of white children in Wales as having a disability, but *only 6% of BAME*

children. According to the FRS, *social/behavioural impairments (54%) and learning impairments (41%) were the most commonly reported disabilities*. Similarly, the Schools Census found speech and language impairments (37%), behavioural/emotional/social impairments (32%) and ASD (24%) were most common. This appears to be reflected in Gwent, where referrals to ISCAN for neurodevelopmental impairments have increased while referrals for other disabilities, such as physical impairments, have decreased (despite the total number of referrals increasing since ISCAN's inception in 2017).

Childhood Disability Prevalence - Wales



 All children in Wales

Children with disabilities according to:

 National Survey for Wales

 Family Resources Survey

 Census & Schools Census

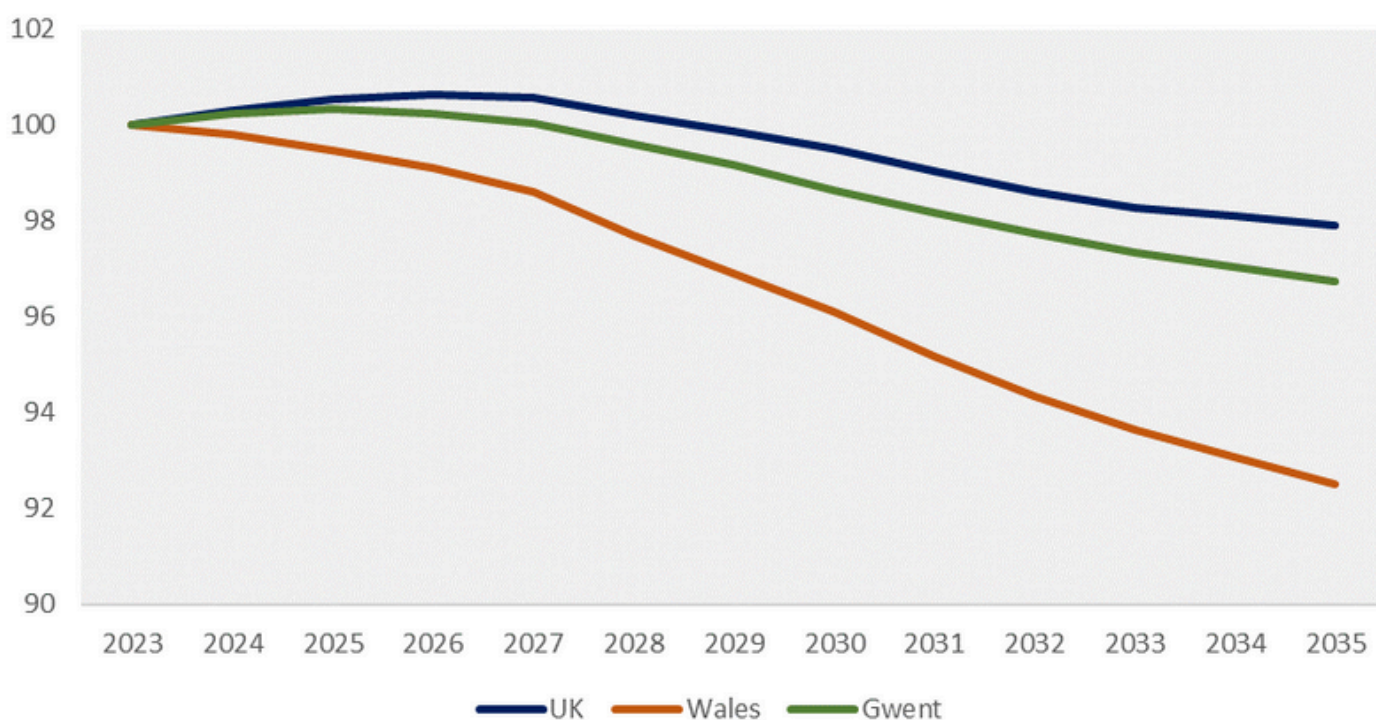
 Disability Living Allowance

 Children Receiving Care and Support Census

Future predictions

The UK population is at an all-time high. Looking ahead, there are four major components of the UK's current demographic shift, including falling fertility rates, increasing life expectancy, changing family structure and migration. This trend is also seen in Wales, which is projected to have a decline in the number of births, and thus children, that is greater than the UK as a whole (see Graph 1). For example, between 2023 and 2035, the population of children aged 0 to 19 years is projected to decline by 7% in Wales compared to 2% in the UK as a whole. In Gwent, the number of people aged 0 to 19 years is expected to decrease from 138,000 in 2023 to 134,000 in 2035 (3% decrease).

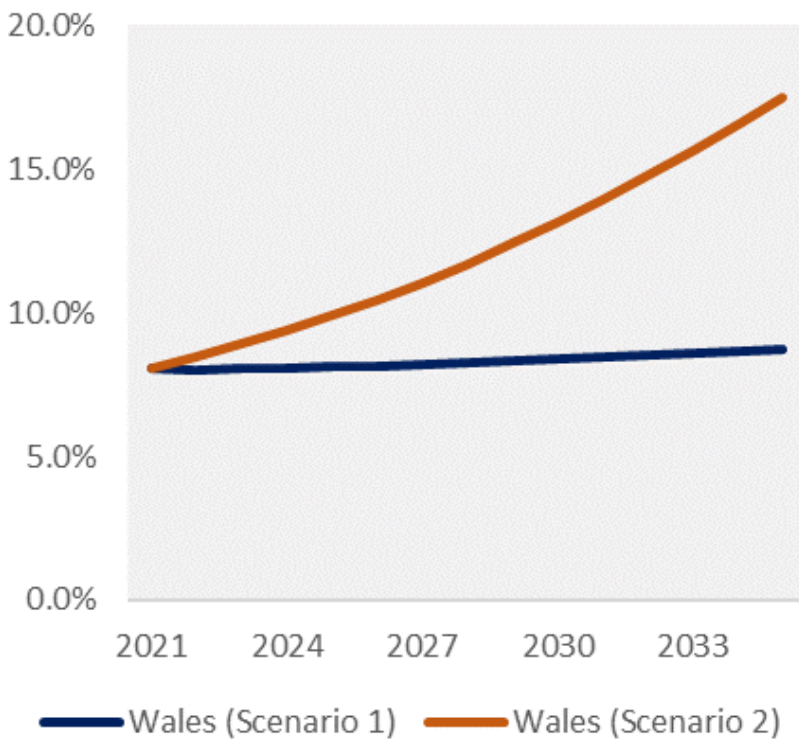
Predicted Child Population



Graph 1: Indexed population projections for children aged 0 to 19 years in the UK, Wales and Gwent, 2023 to 2035 (index=100). Source: 2021-based interim national population projections from the Office for National Statistics.

Between 2023 and 2035, the *absolute number of children with disability may fall, but the disability prevalence is predicted to increase*, thus the proportion of all children with disability will rise to between 8.7% and 17.5% in Wales and between 7.5% and 13.2% in Gwent, when assuming the number of disabled children will continue to increase at the preceding rate. Graphs 2 and 3 show predictions of the future prevalence of childhood disability in Wales up to 2035, using data

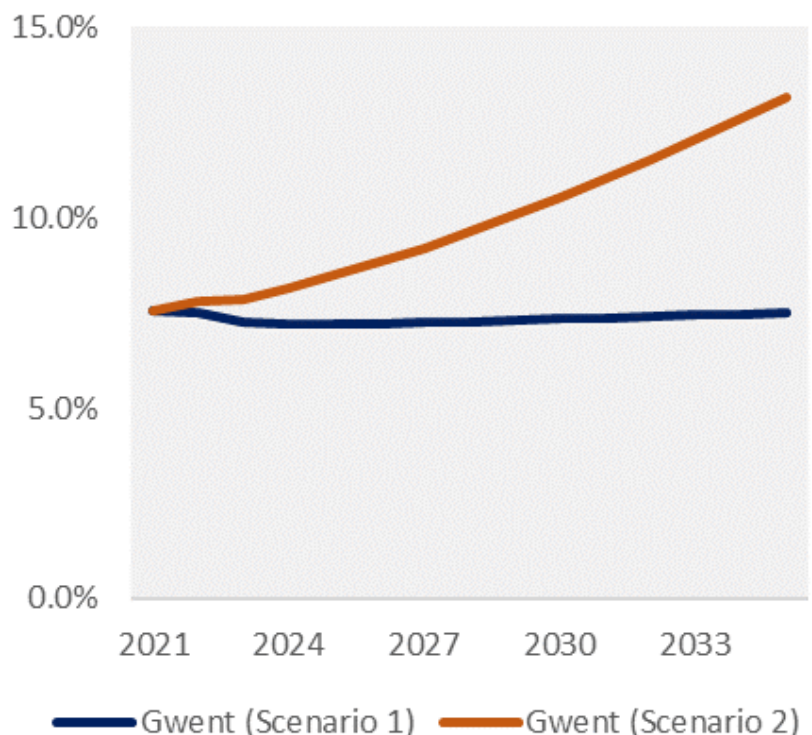
from Census 2021 and population projections. This estimate is determined using the number of disabled children (aged 0 to 19 years) in 2021 held as a numerator and the population projections for each year as the denominator. Scenario 1 assumes the number of disabled children will stay constant from the 2021 Census. Scenario 2 assumes the number of disabled children will increase at the same rate it has between the 2011 and 2021 Census.



Predicted Childhood Disability Prevalence (Wales)

Graph 2: Projected percentage of children (aged 0-19 years) with a disability in **Wales**, 2021 to 2035. Source: 2021 Census, and 2021-based interim national population projections from the Office for National Statistics.

Predicted Childhood Disability Prevalence (Gwent)



Graph 3: Projected percentage of children (aged 0-19 years) with a disability in **Gwent**, 2021 to 2035. Source: 2021 Census, and 2018-based local authority population projections for Gwent from Stats Wales.

What does this mean for policy and practice?

- ★ It is estimated that 0.6-14% of children in Wales have a disability, depending on the data source used. Not only is there a substantial difference in prevalence when comparing statutory-report sources (0.6-8%) and family-report sources (8-14%), but inconsistencies between statutory-report sources and a lack of a complete national dataset makes accurate service planning impossible.
- ★ There has been a rise in developmental, neurodevelopmental and intellectual disabilities internationally [17], which is reflected in the data from the FRS, Schools Census and ISCAN. Increased recognition of ASD, particularly among girls, could be contributing to this increase, however there also appears to be a true increase in ASD. Data on the number of children with a disability receiving care and support from their local authority shows the lowest prevalence (0.6% in Wales and 0.4% in Gwent), however children with a diagnosis of ASD or ADHD were not counted within this dataset until 2023.
- ★ It is surprising to note the lower recorded prevalence of disability among BAME children in Wales, as it has been highlighted in the literature that those from BAME communities may be more likely to be disabled [18] and children from Pakistani families in particular show higher prevalence of learning disabilities, hearing and visual impairments, ASD and cerebral palsy [19]. There may be specific barriers to identification of disability, particularly neurodevelopmental disabilities, among these children due to cultural factors or low engagement with statutory agencies.



- ★ We have estimated that the prevalence of disability among children could rise to 17.5% in Wales and 13.2% in Gwent by 2035. Therefore, we caution policymakers and health, social care and education providers to prepare for such an increase, which will also impact adult health and social care providers, in their service delivery plans.

With thanks to...

Sparkle are extremely grateful to Statisticians for Society, a Royal Statistical Society scheme which connects charities with volunteer statisticians, for their support with this project.

Find out more about the scheme here:

<https://rss.org.uk/membership/volunteering-and-promoting/statisticians-for-society-initiative/>



Find out more about Sparkle...

The charity's guiding principle is to ensure children and young people with disabilities, and their families, are fully supported and able to participate in valued childhood experiences, with access to the same range of opportunities, life experiences, activities and community services as any other child and their family.

Find out more and watch our video tour here:



<https://www.sparkleappeal.org/>



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