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GOFAL A LLESANT **GOGLEDD CYMRU**

**NORTH WALES SOCIAL CARE AND WELL-BEING  
SERVICES IMPROVEMENT COLLABORATIVE**

# Disabilities and illnesses focus

Regional partnership board children's  
sub group toolkit

17/03/2023

## Definitions and population needs assessment summary

'A person has a disability if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.'

- Equality Act 2010

A physical or mental impairment includes physical disabilities, learning difficulties, mental health conditions, medical conditions, and hidden impairments such as learning difficulties, autism, and speech, language, and communication impairments. Substantial is defined as being more than minor or trivial; long-term is defined as being a year or more.

The definition is broad and because of this we have focussed on **respite care** for children and young people with a disability or illness. Respite care was also one of the priorities identified in the Population Needs Assessment.

*Respite care, also called short breaks, is temporary care that lets a carer take a break from looking after the person or persons they care for.*

## Key information from the Population Needs Assessment 2022:

Parents and carers need more respite care themselves as one parent explained,

*"I am beyond exhausted. I've had to leave my specialist nurse job of 23 years to become my daughter's full-time carer, as there's no support for her".*



# Demographics and statistics

We have produced a full update of the section in the 2022 Population Needs Assessment which looked at children and young people with disabilities and / or illness. An outline of the main points from that review is in these bullet points, and the full analysis is available as an appendix to this pack.

## Main points:

- There is no full register of disability or ill-health, so we rely on a range of proxy data sources.
- Numbers, rates, and percentages may look significantly different from those used in the 2022 Population Needs Assessment as estimates of population and what we understand about population trends have been revised following the release of the 2021 Census.
- Statistics on child claimants of Disability Living Allowance (DLA) show an increase in the numbers of claimants across all North Wales local authorities in the last decade. This is despite a fall in the number of children in the population in the same period.
- May 2022 statistics put the number of DLA child claimants in North Wales at about 6,440, which is a rate of about 54.4 per 1,000 children aged 0-15. This is an increase from 34.2 per 1,000 children in 2012.
- For a similar 10 year period local authority have seen a decrease in the number of children on most registers that record disability.
- In 2021 there were 660 disabled children who were receiving care and support from social services in North Wales.
- The number of disabled children in North Wales who are receiving care and support from social services is equivalent to about 1 in 10 of the children who claim Disability Living Allowance benefits.
- In May 2022 the majority (around 73%) of the child Disability Living Allowance caseload in North Wales had one of three main disabling conditions – learning difficulties, behavioural disorders and hyperkinetic syndrome.
- Data from the Children Receiving Care and Support Census suggests social services are working with more children with complex physical needs than in 2011, and that they make up a greater proportion of children receiving care and support.
- All measures show more male children with disabilities than female, with a ratio of about two boys for every girl.
- The sources we have about the age of children with disabilities or illness show that there is a skew towards older age groups when compared to the population as a whole. This is in part because diagnosis of some disabilities and illnesses aren't made until children are older. Similarly, the need for care and support is likely to increase as children get older.

# Engagement

## North Wales Together: Seamless Service for People with Learning Disabilities

North Wales Together: Seamless Service for People with Learning Disabilities produced a consultation where they talked with professionals and citizens to co-produce priorities for children across North Wales. One of the priorities identified was accommodation and respite care. When interviewed people said that there was;

- limited local accommodation for children with complex needs
- not enough respite accommodation in most regions
- not enough short break foster carers with specialist skills.

## ADSS Cymru

ADSS Cymru are currently collecting data for their *Delivering Transformation Grant Work Programme – 2022/23*. They are collecting information regarding day opportunities, residential respite, and short break services for older people, unpaid carers, people with learning disabilities, disabled people (physical and sensory disabilities), people with autism/neurodevelopmental conditions, children with complex needs. Once the information becomes available, we will add it to the toolkit to inform our discussions.

## Conwy County Borough Council

In April 2021 Conwy Social Services commissioned WELV Consulting Ltd to undertake a review of support available to children and young people with disabilities and their families in Conwy. One of the priorities and needs identified was regular short breaks/respite care.

## Amser Ni

Amser Ni is a project in Gwynedd and Anglesey that provides short breaks for children and young people with disabilities and illnesses. Amser Ni prefers the term 'short breaks' over 'respite care' because it sounds more positive and doesn't have the negative connotations of the child sounding like a burden. Below is a case study from the Amser Ni project.

### 14 Year old Boy Case Study Summary:

A 14 year old boy was referred to Amser Ni. He's diagnosed autism with associated learning difficulties, and he also has a recent diagnosis of type 1 diabetes. He lives with his parents and older sister. Following the diagnosis of diabetes, caring for him and his medical needs increased and due to unstable sugar levels, his parents were having to be up during the night also. He was becoming isolated at home and refusing to go out for his parents. His family were struggling and wanted to access respite care support. His parents found it very difficult caring for him and also felt extremely guilty that they were not able to spend quality time with his sister due to always concentrating on caring for their son.

The boy has settled well in the foster carers' home. He is happy and he has a good relationship with both foster carers. During his stay he has 1-1 attention which has encouraged him to develop new skills. He's learning how to shop for food and how to cook and clean up after himself. He is also able to have experiences that he wouldn't be able to have at home such as local outdoor walks, visiting the beach, swimming, and going to the cinema.

The young boy is able to spend quality time with his foster carer and gain new experiences and his family are able to rest and recharge through having a break from their caring role which will enable them to continue caring for him in the future. The young boy will continue to be offered a regular short break of one weekend every 6 weeks.



# Policy background

Due to the sheer volume of policies and guidance on this topic, this is just an overview of the overarching policies, with snapshots of some more specific guidance and is not intended to be an exhaustive list of all policy/guidance.

Under the Social Services and Well-being (Wales) Act and the Disabled Persons Act there is a duty to both assess and meet the needs for children who require care and support, and those of their carer. There is also legislation that allows children; the right to disabled facilities grants, the right to make a discrimination claim, and children with special educational needs and disability the right to mainstream education if this is their parents wish and the education is adequate.

There are many policies around education including the special educational needs code of practice that provides guidance on; the identification, assessment, and provision for special education needs, involving parents, involving pupils, etc. There is a section on the Welsh Government website that contains various policies and guidance to support additional learning and special educational needs including; regulations, workforce planning, tribunals, transitioning, assistive technology, etc. There is guidance for supporting learners with healthcare needs, that discusses; arrangements that should be considered, individual healthcare plans and unacceptable practice. There is also specific guidance for supporting those with hearing impairments and visual impairments in educational settings, which looks at the efficacy of interventions on delivering positive outcomes.

Welsh Government has a page specifically for guidance and policies around individual health conditions although these are not specifically for children, they do include conditions that impact children; autism, cancer, chronic fatigue, diabetes, learning disabilities, and many more. Each condition has links to relevant policies, plans, reports, standards and guidance. Some policies around specific conditions that specifically refer to children include; the learning disability strategic action plan and the autism spectrum disorder strategic action plan.



## Policy background continued...

The Children's Commissioner for Wales completed a report to help those with learning disabilities transition to adulthood, including; what's important, what support is needed, good practice and recommendations.

The North Wales Safeguarding have set out guidance specific to disabled children, that includes why these children are more vulnerable and additional actions that are needed in order to keep them safe.

There is guidance around continuing care for those children with complex needs, where existing services do not meet all of their needs, providing help with; identifying, assessing, decision making, provision and review of services.

In terms of carers for children with disabilities, the strategy for unpaid carers prioritises; identifying and valuing carers, information/support, respite and support in education/work. There is a guide for disabled children and their families explaining their rights and the law in Wales. There is the Families First programme an early intervention to prevent problems escalating, for the whole family, multi-agency working to ensure joined-up support. It incorporates a disability focus aspect to ensure the needs of those with disabilities are met.

A national review from Care Inspectorate Wales called Let Me Flourish highlighted areas requiring improvement, recommendations included; well-being support, consistent approach to listening to and capturing the voices of children, ensuring needs assessments are completed and support plans actioned.



# Good practice examples

Please ask to see a fully referenced version.

Examples and learning from short break provisions.

Shared Care Scotland (2022) is a collection of good practice short breaks and respite care examples of those for children and young people include:

- 'Respality' provides a short vital break for unpaid carers in Scotland when they need it most. This is achieved by connecting carers' organisations with hospitality, tourism and leisure businesses who are willing to donate a break free of charge.
- 'The Outdoors' a transition to work programme for young people with autism.
- 'Time to Live' (creative breaks programme) awards grants to carers so they can arrange and pay for the short break that suits them best themselves.
- 'Better Breaks' funding to deliver quality short breaks tailored to their needs.

A vision of short breaks from Carers Trust, examples of child-based breaks were listed including:

- 'Touch Trust' - movement based arts experiences for those with multisensory needs, learning disabilities and ASD. Person-centred celebrating guests' individuality <https://www.touchtrust.co.uk/>.
- 'Equate Land Base' - for parent carers and their children to enjoy horse-riding <https://www.facebook.com/EquateCIC/posts/2011785692444521>.
- 'CWTCH Together' - parent carers formed community cooperative, comprising parents, carers and volunteers providing a play scheme for children with disabilities and peer support <https://care.wales.coop/case-studies/cwtch-together/>.

The Council for Disabled Children explored short breaks and selected 4 as key learning examples:

- Bi-Borough Short Breaks Service - two in-house dedicated disabled children's centres.
- KIDS - large domiciliary care service, overnight respite service, 12 short break provisions, 4 London adventure playgrounds and Early Years settings. Provides other services including advice/guidance.
- Barnado's Include Me 2 - social opportunities for disabled children unable to access universal services (football, Guides/Scouts or other clubs).
- Charlton Athletic Community Trust - short break services for young people aged 12-17 with special educational needs, also working with families who need extra support.



## Good practice examples continued...

A review from the Health and Social Care Board (2017) in Northern Ireland found short breaks may be most effective if they take account of what each family wants and needs. Intervention alongside respite/short breaks to support parental stress and coping may be particularly beneficial. Opportunities for the young person to undertake new activities through befriending, summer schemes or youth activities positively benefits the young person and family. This may be important to develop life skills and independence. This review did not include families of children with acquired brain injuries, end-of-life care or very complex healthcare needs.

In an evaluation of a purpose-designed pilot short break service for 18-24 year olds, young adults described how they benefitted from specialist, age-appropriate, on-site clinical skills facilities and opportunities to socialise with peers. Mothers benefitted from time alone or with family members in the knowledge the service met the needs and preferences of their child as they transition to adult services. All mothers and staff expressed concern for when they left the service at 24 years old.

An evaluation of the Mockingbird family model (MFM) approach to supporting foster carers and the children placed with them, the effectiveness and potential issues, includes section on respite.

The Ealing model is a provision to families and carers of positive behaviour support interventions alongside short breaks and therapy. This service is accessed at crisis point to try and prevent family breakdown, it highlights a need for early intervention to prevent reaching crisis point.

There is a directory from National Autistic Society where you can search for respite care by postcode, this may be a useful tool to browse examples of respite care to gain further ideas.

The Easy Evaluation Toolkit from Shared Care Scotland is designed to help people evaluate their short break or respite care service.

