

Swindon Joint Strategic Needs Assessment JSNA Bulletin

Children and Young People with Complex and Life Limiting Conditions



Key Points:

- The JSNA provides evidence to help us understand the current picture regarding children and young people with complex and life limiting conditions
- Children with a disability, complex need and/or life limiting condition are a diverse group. Some children will need multi-agency support across health, social services and education whereas others will have little contact with services unless their condition deteriorates.
- Gathering data on the numbers of people with children and young people with complex and life limiting conditions at a local level is challenging and there are different ways of estimating the number of children who fall into this group:
 - From the 2011 census 1.4% of 0 to 15 year olds and 1.7% of 16 to 24 year olds in Swindon consider their daily activities to be 'limited a lot' by long term health problems or a disability:
 - Local hospital data suggest 79 children were admitted for life-limiting conditions in 2013/14 with 26 of these congenital.
 - Applying national estimates suggest between 17 and 19 babies a year are born with a congenital or chromosomal disorder: the most common being cerebral palsy.
- Asthma affects over 4000 children in Swindon
- Nationally, it is estimated 94% of admissions from long term conditions in children are from asthma, diabetes and epilepsy
- There is a need to Clarify the age cut-offs for support services and aim for consistency across services of what define a child / young person and when transition planning into adult services should start
- The JSNA makes 16 recommendations for future work to improve lives of children and young people with complex and life limiting conditions in Swindon

What is a Joint Strategic Needs Assessment (JSNA)?

A JSNA helps us to understand:

- What we know about the current health and wellbeing needs of local people
- How their needs are currently being met
- What we think their future needs are likely to be; and
- How their needs can be best met in the future.

The JSNA process involves many different partners and is overseen by Swindon's Health and Wellbeing Board.

Understanding Swindon's changing population, the factors that affect health and wellbeing, the town's assets and the implications for future services are vital in setting priorities and planning future services

Children and Young People with Complex and Life Limiting Conditions JSN

This JSNA is part of a suite of documents to understand the needs of children and young people in Swindon looking at Conception to age 5: Best Start, Mental Health and Children with disabilities.

Children with disabilities is divided into 5 areas and this bulletin focuses on one of these areas: children with life limiting conditions and complex health needs.

The purpose of this needs assessment is to:

- understand current provision and where there are gaps
- understand the needs of disabled children and those with complex needs now and in the future
- forecast future demand for services and identify trends in need
- provide insight into what works well, what could be improved, and suggestions for innovative practice from both service users and people delivering the services.

Defining children with complex needs is difficult as it can cover a spectrum of conditions and different needs. It also varies by data source and service. One definition used broadly in this JSNA is that a child or young person with complex needs:

- has a serious on-going illness, a complex chronic condition or a disability that has lasted or is anticipated to last at least 12 continuous months or more and/or
- has an illness, condition or disability that results in the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social or physical barriers or
- is experiencing significant developmental or acquired impairments or delays in one or more areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional development or
- has a condition which has a high probability of resulting in developmental delay or deteriorating functional ability and whose ability to achieve their potential is impaired due to a wide range of barriers facing them.

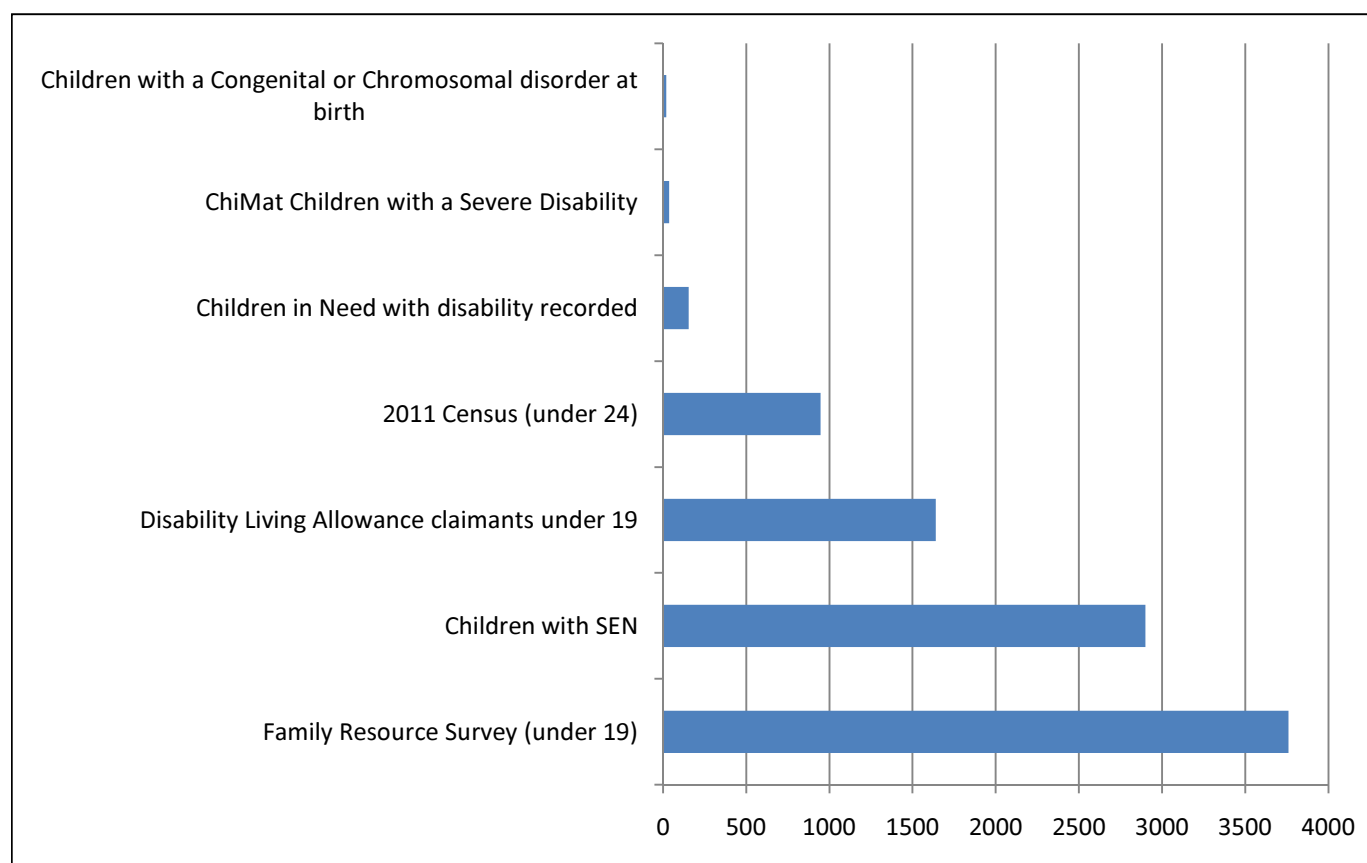
Who is affected?

Children with a disability, complex need and/or life limiting condition are a diverse group. Some will need multi-agency support across health, social services and education whereas others will have little contact with services unless their condition deteriorates. There are different ways of estimating the number of children who fall into these groups – some use prevalence estimates from national studies or specific survey data, whilst others measure service use as a proxy for need.

Table: Data Source

Actual	Estimates
2011 Census Children In Need Survey Children with SEN Children with a Congenital or Chromosomal disorder at birth Children receiving disability living allowance	Family Resources Survey ChiMat Children with a Severe Disability

Figure: Summary of different estimates of children with a disability, complex need and/or life limiting condition.



- From the 2011 census 1.4% of 0 to 15 year olds and 1.7% of 16 to 24 year olds in Swindon consider their daily activities to be 'limited a lot' by long term health problems or a disability.
- Applying Family Resources Survey estimate would suggest 3760 under 18 year olds have a disability with the most frequent being a learning disability, stamina / breathing or fatigue problems, or social / behavioural disabilities.
- 9.5% of children in need in 2013/14 in Swindon had a disability recorded but this did include autism which is out of scope for this JSNA.
- Estimates from the Child and Maternal Health (ChiMat) Intelligence Network suggest 38 children in Swindon have a severe disability.
- Local hospital data suggest 79 children were admitted for life-limiting conditions in 2013/14 with 26 of these congenital. Applying national estimates suggest between 17 and 19 babies a year are born with a congenital or chromosomal disorder: the most common being cerebral palsy.
- Cancer is relatively rare in young people and survival rates are improving. In Swindon there were 43 cases in a 5 year period with rates per population similar to the rest of the south west.
- Asthma affects over 4000 children in Swindon and for some it has a significant effect on their daily activities. Nationally, it is estimated 94% of admissions from long term conditions in children are from asthma, diabetes and epilepsy.

What services do children use?

Children with complex and life-limiting conditions (LLC) are cared for at home, in hospital, in the community and in hospices. There were 208 hospital admissions for LLC from 79 children in 2013/14 in Swindon. Lymphoid leukaemia has the highest number of admissions by emergency followed by cystic fibrosis. For elective admissions, lymphoid leukaemia again has the highest number of admissions followed by malignant neoplasm of other connective and soft tissue.

The Community Outreach Nursing Service (CONS) looks after children with long term/ life limiting conditions including diabetes, epilepsy, complex needs, cancer and generic complex needs. The team includes a paediatric oncology nurse with a caseload of 25 children aged 0 to 16. The team support:

- with enteral feeding – NG (Naso Gastirc), gastrostomy fed babies and children – supporting the child at home and also training families and carers
- babies discharged home on oxygen therapy from SCBU(Special Care Baby Unit) to work with their families to wean the infants off oxygen
- children with cardiac diagnosis – for example a child who needs an INR (blood clotting) checking on a weekly basis.
- Children post liver transplant
- Endocrine problems.
- Cerebral palsy.
- Muscular Dystrophy
- Congenital abnormalities

The Complex and Continuing Care service provides intensive, around the clock medical support and help for children who, depending on their health condition, need very specialised care. Each child or young

person is allocated a Healthcare Professional to provide them with individual help (including overnight support) at the child's home and to enable them to attend school. The service also supports and sustains children with terminal illness and provides palliative and end of life care. There were a total of 35 children active on the register from mid-2008 to April 2015. A further 41 children have had past involvement with the service and 9 have been referred but no further input in care from the service was required/needed.

Community Support Services include paediatric therapies, speech and language therapy, the Disabled Childrens' Team, educational psychology, and Koala's Playgroup and Portage Education groups for children with special needs.

As part of the education other than at school provision (EOTAS), Swindon has a hospital school and home education service which is part of the Stratton Education Centre. This includes supporting children who are inpatients on the children's ward at Great Western Hospital, and children who need home tuition.

Hospice support is offered via Helen and Douglas House in Oxford, Naomi House in Winchester and the Rainbow Trust. Parents are offered a specific number of nights a year; some hospices allow the purchase of more. Facilities include education, healthcare, leisure, psychology and family support.

What do organisations and young people think?

Hospital services are generally viewed positively. One of the challenges is meeting the demand for services and the recruitment of paediatric nurses. There is also scope for clearer delineation between who does what for children and young people. One theme which emerged was the relationship between hospital services, school nurses, and primary care and who could and would provide different elements of care in different settings.

In terms of education the hospital and home service provide a limited number of hours compared to standard schooling, and also find that their time with children covers much more than curriculum teaching.

The hospice provision for children and young people is well regarded and there were no identified problems with accessing places. The hospices generally felt that there was a clear process for referrals and they were seeing appropriate children. There is generally no waiting list. Children are reviewed every year and most are given an initial low allocation of nights which can then build up.

When a child gets sick at home there was concern that support for the families at home could be stronger. The child may be well supported in the school or hospital environment but when at home there is less support available.

Swindon Ten to Eighteen Project (STEP) were commissioned to consult with young people. Their views are summarised below:

What works well

- Young people with complex needs enjoy doing exactly the same things as any young people and praised opportunities to do this.

- People were generally positive about planning for transition to adult services, that this started early and the planning for post school life.
- People were complimentary about ward staff and doctors who knew them well. People felt clinical staff spoke to and listened to the young person themselves rather than their parents.
- Support either via secondary care or therapy services was felt to be good, and equipment and adaptations very useful.

What could be improved

- Many of the young people highlighted that there could be better liaison between school and the hospital in terms of timing of appointments as these can exacerbate problems with missing lessons and missing key tests or exams.
- There is also a feeling that the onus is on the parent to inform the school about their child's condition and what is needed rather than it being seamlessly passed from school to school or class to class which puts added pressure on parents.
- Every young person spoke about feeling pressure to catch up at school, and a lack of recognition at times that because of their condition it may be difficult to do this at the pace expected
- There was a feeling that people were less understanding of a complex condition that wasn't visible, and for young people that had an illness where sometimes they needed a wheelchair and sometimes not, people couldn't understand this.
- Some experience of hospitals was very positive but a few people spoke about notes not being available at appointments and having to tell their story over and over again.

Best Practice

The JSNA highlights a range of guidance and best practice all of which is defined by a focus on the individual and person centred care.

In January 2015, the South West Strategic Clinical Network published a report on 'Children's Community Nursing (CNN) – development of regional good practice'. It highlights issues around limited learning between areas and limited regional strategic knowledge, the need for more regional leadership and visibility and an over reliance on acute care. The report identifies that there are different models of delivering services but that these should all be underpinned by

- Staff with the appropriate skills and competencies to meet the varying and complex needs of ill children
- Access to a safe, high quality and effective CCN service staffed by qualified children's nurses, wherever they live 24/7
- The flexibility to be responsive and adapt services when children's needs change
- A 'critical mass' of staff to sustain service delivery in line with local population needs and geographical spread

Conclusions and Recommendations

The following recommendations are applicable for a number of different organisations and can also inform the commissioning of services for children with complex and life limiting illnesses.

1. Improving liaison between hospital and school to ensure appointments do not clash with examinations / tests
2. Schools to look at pressure for young people to catch up post time off and whether this could not be at the expense of breaks / social time which is highly valued by young people.

3. Scope for schools to look at disability and challenging stereotypes as part of the PSHE curriculum to improve understanding.
4. A common theme from the hospices is that there is more capacity to be used for Swindon. Make more appropriate use of hospice provision which has expertise in this area and gold standard care and facilities
5. A clearer pathway defining roles between secondary care, primary care, community and educational services for both professionals and parents
6. Clarify the age cutoffs for support services and aim for consistency across services of what define a child / young person and when transition planning to adult services should start
7. Training to improve the confidence of GPs and practice nurses in supporting children with complex and life limiting conditions. Clarity over responsibility for wound care.
8. Look into whether commissioners across different areas could standardise the performance data required for both Great Western Hospital and for the hospices
9. Increase access to hospital services such as x-ray, radiology, and blood testing at weekends
10. Reduce the number of young people with life limiting conditions treated on adult wards where possible.
11. Consider improving early emotional and mental health support for parents to reduce high levels of depression and relationship breakdown
12. Improve wifi connection in hospital on the children's ward to improve teaching

13. Improve flow of information between hospital and home liaison service and schools
14. Investigate whether school nurses could do more e.g. heights and weights to reduce the need for hospital visits
15. Recognise the need for more employment opportunities and supported employment for young people with complex healthcare needs particularly in the future as young people are able to live longer.
16. Highlight to universities and Higher Education the needs for more paediatric nurses and work with Severn Deanery to look at ways of making children's nursing more valued / desirable and easier to recruit to in the South West

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Where to find more information

Background documents and other Swindon JSNA Briefings can be found on Swindon's [JSNA website](http://www.swindonjsna.co.uk). <http://www.swindonjsna.co.uk>

If you have any queries (or would like to contribute to needs assessment activities in Swindon) please contact: JSNA@swindon.gov.uk

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