

# Children and Young People with Complex and Life Limiting Conditions Joint Strategic Needs Assessment

Health and Wellbeing Board

Date: 21 October 2015

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Author: Director of Public Health

Wards: All

Locality Affected: All

Parishes Affected: All

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## 1. Purpose and Reasons

- 1.1 The aim of this report is to inform the Health and Wellbeing Board of the findings of the Children and Young People with Complex and Life Limiting Conditions Joint Strategic Needs Assessment (JSNA) and seek support for its recommendations.
- 1.2 The Children and Young People with Complex and Life Limiting Conditions JSNA (Appendix 1) looks at available local and national data to describe the current picture with regard to Children and Young People with Complex and Life Limiting Conditions in Swindon. It provides a summary of the estimated numbers of children affected in Swindon; information about support and services available; and the experiences of children and young people living with complex and life limiting conditions in Swindon. 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.
- 1.3 The findings from the JSNA inform a suite of recommendations that aim to support all children and young people with complex and life limiting conditions in Swindon to live fulfilling and rewarding lives and have access to the right support at the right time.
- 1.4 A steering group will be established to develop the action plan and oversee delivery against these recommendations.

## 2. Recommendations

The Board is recommended to:

- 2.1 Note and agree the recommendations from the Children and Young People with Complex and Life Limiting Conditions Joint Strategic Needs Assessment Bulletin attached as Appendix 1 to this report.

## 3. Detail

- 3.1 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:

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- 3.1.1 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
- 3.1.2 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
- 3.1.3 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
- 3.1.4 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.
- 3.2 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.
- 3.3 Gathering data on the numbers of 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:
  - 3.3.1 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.
  - 3.3.2 Local hospital data suggest 79 children were admitted for life-limiting conditions in 2013/14 with 26 of these congenital.
  - 3.3.3 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.
  - 3.3.4 Asthma affects over 4000 children in Swindon.
- 3.4 Nationally, it is estimated 94% of admissions from long term conditions in children are from asthma, diabetes and epilepsy.
- 3.5 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.

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- 3.6 The JSNA makes 16 recommendations which are applicable for a number of different organisations and can also inform the commissioning of services for children with complex and life limiting illnesses. These are:
- 3.6.1 Improve liaison between hospital and school to ensure appointments do not clash with examinations / tests.
  - 3.6.2 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.
  - 3.6.3 Scope for schools to look at disability and challenging stereotypes as part of the PSHE curriculum to improve understanding.
  - 3.6.4 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.
  - 3.6.5 A clearer pathway defining roles between secondary care, primary care, community and educational services for both professionals and parents.
  - 3.6.6 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.
  - 3.6.7 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.
  - 3.6.8 Look into whether commissioners across different areas could standardise the performance data required for both Great Western Hospital and for the hospices.
  - 3.6.9 Increase access to hospital services such as x-ray, radiology, and blood testing at weekends.
  - 3.6.10 Reduce the number of young people with life limiting conditions treated on adult wards where possible.
  - 3.6.11 Consider improving early emotional and mental health support for parents to reduce high levels of depression and relationship breakdown.
  - 3.6.12 Improve wifi connection in hospital on the children's ward to improve teaching.
  - 3.6.13 Improve flow of information between hospital and home liaison service and schools.
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3.6.14 Investigate whether school nurses could do more e.g. heights and weights to reduce the need for hospital visits.

3.6.15 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.

3.6.16 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.

3.7 The full JSNA for Children and Young People with Complex and Life Limiting Conditions can be found on the Swindon JSNA website.  
<http://www.swindonjsna.co.uk/>

## 4.0 Alternative Options

4.1 Not to support the recommendations identified in the JSNA.

## 5.0 Implications, Diversity Impact Assessment and Risk Management

### Financial and Procurement Implications

5.1 There are no financial or procurement implications arising from the recommendations of this report.

5.2 If additional resources are needed to implement these recommendations a detailed business case will be developed.

### Legal and Human Rights Implications

5.3 Legal and Human rights have been taken fully into account in compiling this report. It is considered that the recommendations within this report are compatible with Convention Rights.

5.4 In consideration of any future guidance and an understanding of best practice from elsewhere, the council will work with the NHS and other partners in order to ensure that equalities and a respect for human rights are at the heart of the development of the Swindon JSNA and that everyone in Swindon has fair access to services and are free from discrimination.

### All Other Implications (including Staff, Sustainability, Health, Rural, Crime and Disorder)

5.4 There should be no significant staffing or other implications arising from this report.

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## Diversity Impact Assessment

- 5.5 A Diversity Impact Assessment has not been completed at this stage.

## Risk Management

- 3.6 No specific risks identified at this stage for this report.

## **6. Consultees**

- 6.1 The Board Director, Resources (Section 151 Officer) and Director of Law and Democratic Services (Monitoring Officer) have been consulted in respect of this report.

## **7. Background Papers**

- 3.1 None.

## **4. Appendices**

- 4.1 Appendix 1: Children and Young People with Complex and Life Limiting Conditions Swindon Joint Strategic Needs Assessment (JSNA) Bulletin.