

Strategy for Children with Disabilities 2011- 2016

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1. Vision for Children's Services

VISION

"That every child in every part of the county should achieve their potential".

PRINCIPLES

1. Early Intervention and Prevention

- Strong universal services, providing early action and intensive support to vulnerable children and young people.

2. Safeguarding

- Ensuring children are safe in every environment.
- Encouraging community responsibility for safeguarding.

3. Aspiration and Well Being

- Ensuring all those working with children champion the importance of aspiration.
- Develop self-esteem, self belief and resilience in all children, young people and their families.

4. Learning and Achievement

- All children being the best that they can be.
- Closing the gap between vulnerable groups and children living in disadvantaged communities.

5. Best Use of Resources

- Integrating delivery with a focus on outcomes, life chances and opportunities.
- Effective use of resources to provide better services locally.
- Empower communities, creating opportunities for them to engage.

The successful delivery of our objectives will lead to:

- Children and Young People who feel and are safe
- A shared aspiration for all Children and Young People achieve their potential
- A strong sustainable education system which provides high quality, diverse and rich educational opportunities
- Parents supported and empowered to take responsibility for their child's outcomes
- Resources directed at those communities who are most vulnerable so that poverty and inequalities are addressed
- A profile of investment in evidence based programmes which are known to support vulnerable families including Family Nurse Partnerships
- Communities that are confident and caring where people are able to look after themselves and each other
- Children and young people who are healthy
- Services which are better value for money,

2. Purpose of This Strategy

The Family Resource Survey 2010 estimates that there are approximately 952,741 disabled children in Great Britain – 7.3% of the child population in Great Britain (Disabled Children: A Legal Handbook 2010). In the past ten years the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of pre-term babies and increased survival of children after severe trauma or illness. It is estimated that there are up to 6,000 children living at home who are dependent on assistive technology. Children and young people with life limiting conditions, such as cystic fibrosis have better life expectancy and improved quality of life due to improved treatment and support.

A third of parents with a severely disabled child under the age of two use more than three pieces of equipment daily to provide basic care. Four out of five 12 to 14 year old severely disabled children need help with self care – for most these needs are long term. The majority of children with disabilities live with their families who carry day to day responsibility for caring for their child (NSF Children, Young People and Maternity Services 2004).

Children and young people with a disability, and their families, make use of a wide range of services and support. Perhaps the most valued support is provided through families and communities. Formal support services are provided by health; Lincolnshire County Council and the District Councils (in particular education, social work, leisure and housing) and through the voluntary, independent and or faith sector. Support for children and their families is therefore not the responsibility of a single organisation but is shared across a number of agencies working in partnership with families and communities.

This can make things complicated, and at times frustrating for children and young people and their families, who have to negotiate contact with a number of different services that are not always well coordinated and connected. It also presents a challenge for strategic planners. Different services have different ways of defining children with a disability, different approaches to planning and budget setting, may be driven by different targets and objectives, and work in different ways.

Progress has been made but we want to continue to change that for the better.

This strategy is being developed alongside the **Special School Review** which will address the learning needs of school age children and young people with additional needs (this is inclusive of disability). **The development of services under the Council's changing core offer** will have implications for children with a disability. The link with the work of the Paediatric Review, the local implementation of the Healthy Child programme (DH 2010) and the pathways that have been drafted around autism and continuing care are also key to implementing the strategy.

3. What is a Disability?

There are many definitions related to disability, including definitions of special educational needs (SEN), learning disability, physical impairment, learning difficulty, learning difference, and developmental disorder. Although many of these definitions have a statutory basis they have little consistency with each other.

In the UK, the Warnock Committee has suggested that learning difficulties should be used to refer to specific problems with learning in children that might arise as a result of issues such as medical problems, emotional problems, and language impairments. Learning disability can be a useful term in that it indicates an overall impairment of intellect and function. Though at present there is no clear consensus it is widely accepted that whatever terms are used they should be clear, inclusive, and positive.

For the purposes of this strategy we have decided to employ the definition of a disabled child from the Children Act 1989:

[. . .] a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and in this Part – “development” means physical, intellectual, emotional, social or behavioural development; and “health” means physical or mental health. The Children Act (Section 17(11) 1989).

Further definitions that support eligibility to services for CWD is attached in appendix 3.

4. Our Principles for CWD Based on Lincolnshire's Children's Services Vision

Early Intervention and Prevention

1. Children and young people with a disability are always children and young people first
2. Families should receive services at the earliest opportunity, so as to promote the healthy development of the child or young person and to ensure that families are appropriately supported. Services should be inclusive, flexible, convenient and responsive to the individual and promote the achievement of desirable lifelong outcomes. Children with disabilities will have access to universal health services
3. All children and young people with a disability should be given opportunities that enable them to remain in the family home and can access activities and services in their community.
4. That there is a single point of access to services for children with disabilities and their families.
5. Parents/carers are the experts on their children's needs and are essential partners in decision making processes, including assessments.

Safeguarding

6. Research evidence indicates that due to their unique circumstances vulnerable children with a disability may be more vulnerable to abuse. Inclusive safeguarding practice will continue to be promoted and developed.

Aspiration and Well Being

7. All children and young people with a disability can communicate and have the right to be involved in decision making that affects their lives, including assessments and service design, delivery and evaluation.

Learning and Achievement

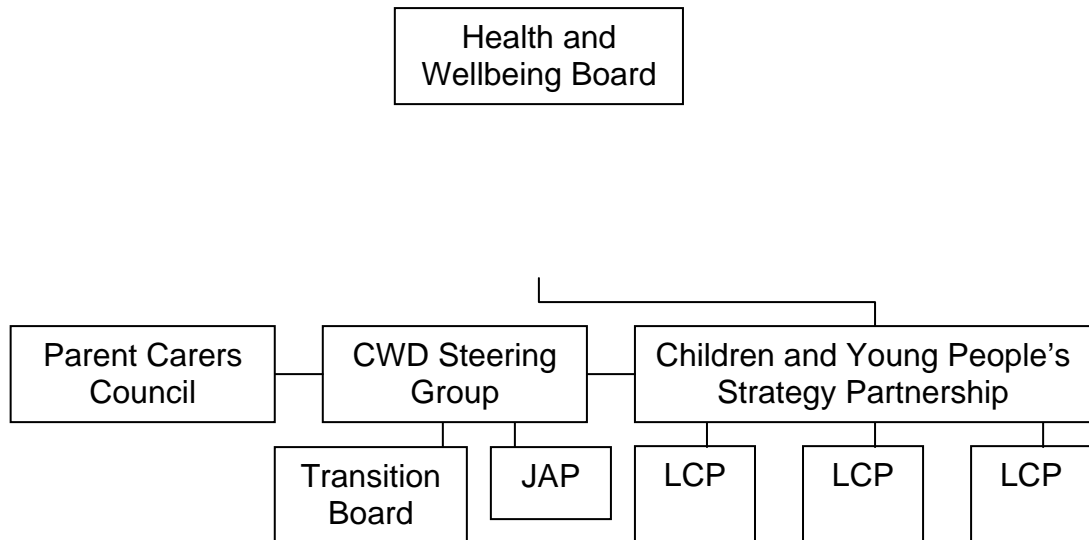
8. That children and young people with a disability fulfil their potential and can live independently accessing employment and training opportunities and where appropriate have smooth transition to adult services.

Best Use of Resources

9. Improving outcomes for children and young people with a disability is everyone's business and not just the responsibility of those who work in specialist services.

10. Access to services for children and young people with a disability will be fair, equitable and transparent.

5. Governance of Arrangements for Children with Disabilities



Terms of reference for CWD Steering group and its membership will be developed in line with the strategy. This will include its link to the CYPSP, Transition Board and Joint Agency Panel.

6. Needs Analysis

A third of parents with a severely disabled child under two years old use more than three pieces of equipment daily to provide basic care. Four out of five 12 to 14 year olds who are severely disabled need help with self-care e.g. eating, washing, dressing, and going to the toilet. For many of these children, their needs are long term. The majority of children live with their families, who carry day-to-day responsibility for caring for their child. (NSF children Young People and Maternity Services 2004)

6.1. The number of Children with a special educational need in all schools in Lincolnshire are:

Jan 2011 Data - All Schools

SEN Type Code	No. of Pupils	Percentage
ASD	1110	11.36%
BESD	2359	24.14%
HI	131	1.34%
MLD	2520	25.79%
MSI	13	0.13%
OTH	383	3.92%
PD	315	3.22%
PMLD	94	0.96%
SLCN	1037	10.61%
SLD	243	2.49%
SPLD	1489	15.24%
VI	78	0.80%
Total	9772	100.00%

(School census January 2011)

Table of Terms

ASD	Autistic Spectrum Disorder
BESD	Behaviour, Emotional & Social Difficulties
HI	Hearing Impairment
MLD	Moderate Learning Difficulty
MSI	Multi-Sensory Impairment
OTH	Other Difficulty/Disability
PD	Physical Disability
PMLD	Profound & Multiple Learning Difficulty
SLCN	Speech, Language and Communication Needs
SLD	Severe Learning Difficulty
SPLD	Specific Learning Difficulty
VI	Visual Impairment

This is a decrease since 2008 of 22 pupils. The table below shows the SEN growth areas in all schools between 2008 and 2011. Many children have a range of needs; however, this data captures a child's primary need.

SEN Growth 2008 - 2011 – All Schools

SEN Type Code	2008	2011	Growth
ASD	8.25%	11.36%	37.67%
PMLD	0.80%	0.96%	20.77%
SLCN	9.52%	10.61%	11.51%
HI	1.22%	1.34%	10.32%
BESD	23.24%	24.14%	3.87%
PD	3.30%	3.22%	-2.27%
VI	0.83%	0.80%	-3.50%
OTH	4.27%	3.92%	-8.18%
SPLD	16.76%	15.24%	-9.07%
MLD	28.71%	25.79%	-10.19%
SLD	2.84%	2.49%	-12.40%
MSI	0.28%	0.13%	-51.75%

The number of children assessed with Autistic Spectrum Disorder increased from 808 pupils to 1110. Profound & Multiple Learning Difficulty increased from 78 to 94. Speech, Language and Communication Needs from 932 to 1037. Hi from 119 to 131. Behaviour, Emotional & Social Difficulties from 2276 to 2359. Physical Disability decreased from 323 to 315. Visual Impairment decreased from 81 to 78. Specific Learning Difficulty decreased from 1641 to 1489. Moderate Learning Difficulty decreased from 2812 to 2520. Severe Learning Difficulty decreased from 278 to 243 and Multi-Sensory Impairment decreased from 27 to 13.

The number of children with additional needs from a black or minority ethnic background equates to 5.9% of the population of children in schools with an additional need. The breakdown of need is as follows:

Jan 2011 Data - All Schools

SEN Type Code	No. of Pupils	Percentage
ASD	41	7.07%
BESD	132	22.76%
HI	10	1.72%
MLD	116	20.00%
MSI	0	0.00%
OTH	38	6.55%
PD	13	2.24%
PMLD	7	1.21%
SLCN	124	21.38%
SLD	13	2.24%
SPLD	81	13.97%
VI	5	0.86%
Total	580	100.00%

This is a growth in the number of children from a black and/or minority ethnic background with an additional need since 2008 when the total number was 396. The table below indicates the increase in the number of children assessed as having additional needs and the main areas of growth for the black and minority ethnic population.

BME SEN Growth 2008 - 2011 - All Schools

SEN Type Code	2008	2011	Growth
VI	0.25%	0.86%	241.38%
PMLD	0.51%	1.21%	138.97%
HI	1.01%	1.72%	70.69%
SLD	1.77%	2.24%	26.80%
SLCN	17.42%	21.38%	22.70%
ASD	6.06%	7.07%	16.64%
BESD	21.21%	22.76%	7.29%
OTH	6.57%	6.55%	-0.21%
MLD	24.75%	20.00%	-19.18%
PD	2.78%	2.24%	-19.31%
SPLD	17.42%	13.97%	-19.85%
MSI	0.25%	0.00%	-100.00%

The main growth with a large number of children is Autistic Spectrum Disorder with a growth from 24 pupils to 41. Speech, Language and Communication Needs with a growth from 69 to 124 and Behaviour, Emotional & Social Difficulties with a growth from 84 to 132.

6.2 The number of children who are on the Additional Needs database is 4266 pupils.

Additional Needs Pupils - split by area of need.

Autism Spectrum Disorders	708	16.60%	
Special Learning Difficulties	484	11.34%	Includes Dyslexia
Moderate Learning Difficulties	855	20.05%	Includes Moderate and General Learning
Behavioural, Emotional and Social Development	724	16.97%	
Speech, Language and Communication	830	19.45%	Includes Hearing and Visually Impaired
Other	42	0.98%	Includes Epilepsy and pupils not specified
Physical Difficulties	118	2.77%	
Medical Support/provision	505	11.84%	

4266

This includes all Additional Needs pupils as recorded on SEN database as at 8 March 2011.

(All statements, medical -short and long term provision, pupils going through SEN assessment stage)

6.3 The number of children who are Child in Need with a disability are:
(make clear this is section 17 open cases to social care)

Clients with a Disability Category by Team

Count of Swift ID Number	
Current Team	Total
Children's Boston	1
Children's County CWD SW	181
Children's CWD Bourne	1
Children's CWD OT	113
Children's East Lindsey	4
Children's East Lindsey North	1
Children's Fostering Serv North	1
Children's Lac North	1
Children's Lac South	9
Children's Lincoln City	3
Children's North Kesteven	1
Children's South Holland	3
Children's South Kesteven	4
Children's West Lindsey	2
CWD OT Sleaford	4
CWD SW Sleaford	1
ESCO	4
Pat Stamford/Spalding	1
TAC Coordinators	8
Transition Service	64

Grand Total	407
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6.4 The number of children with a disability by ethnicity are:

Clients with a Disability Category by Ethnicity

Count of Swift ID Number	
Ethnicity	Total
Asian-Other	2
Black-Any Other Black Background	1
Mixed-Any Other Mixed Background	2
Mixed-White And Asian	1
Mixed-White And Black Caribbean	2
Not Given	1
Not Recorded	40
White-Any Other White Background	6
White-British	352
Grand Total	407

6.5 The number of children with a disability with a child protection plan are:

CPP by Team

Child Protection Plan	Yes
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Count of Swift ID Number	
Current Team	Total
Childrens County CWD SW	3
Grand Total	3

6.6 The number of children with a disability who are Looked after by the Local Authority is:

LAC by Team

Looked After Child	YES
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Count of Swift ID Number	
Current Team	Total
Childrens County CWD SW	1
Children's LAC North	1
Children's LAC South	8
Children's South Holland	1
Transition Service	10
Grand Total	21

6.7 The number of children with a disability with an out of county placement is 6.

6.8 Parent Carer Council database

Lincolnshire Parent Carer Council have an inclusive recruitment approach with parents registered whose children have a broad range of needs. The current number of families on their database is 1,800 of which 1,400 have registered themselves as having a child with an additional need.

6.9 Children Act Register

In Lincolnshire the Customer Service Centre manages the Children Act Register. The Children Act Register in Lincolnshire is called the 4All database. The 4All Database is a confidential computer record of disabled children and young people who live in Lincolnshire. It is voluntary.

The Database is used to help plan and monitor services for disabled children and young people or those with special needs. Young people's information remains in the Register until they're 25 years old. The current number of children on the database is 1,210.

6.10 CQC submission Feb 2011

The CQC submission which pulls together information from Health Services stated that there were 6,500 children with a disability in Lincolnshire (Public Health Service).

Supplied by Assistant Director of Public Health, details as below:-

The methodology sanctioned by Together For Children is to use the higher of 'children with SEN statement' and 'Disability Living Allowance claimants <18' as the lower bound, and use the sum of the two as the upper bound.

The number of children with a SEN statement at the last school census was 3671.

Our estimate of the number of under 18s claiming DLA is 4690

Thus our estimate for the number of CwD in Lincolnshire is between 4690 and 8361.

If you want a single figure you can take a value around the mean of the two, which is approx 6500.

6.11 Geographical Distribution

A limited amount of information is available allowing a geographical picture of where children with disability live.

- Special School Review

An analysis of home location of pupils attending special schools was completed in April 2010.

Children with Disabilities are distributed across the county, however, there are, as would be expected, larger clusters of children around Market Towns and Lincoln City. This includes; Gainsborough, Louth, Horncastle, Mablethorpe, Skegness, Spilsby, Boston, Grantham, Sleaford, Bourne, Spalding, Market Deeping and Stamford.

- Early Support Co-ordination Review

A review of locations of children with disability sent to the Early Support Co-ordination team aged 5 or under in September 2009 showed the following:

Gainsborough – 24 Children
Market Rasen – 9 Children
Louth – 29 Children
Mablethorpe – 20 Children
Horncastle – 8 Children
Lincoln – 123 Children
Skegness – 9 Children
Grantham – 30 Children
Sleaford – 39 Children
Boston – 54 Children
Bourne – 15 Children
Spalding – 12 Children
Holbeach – 5 Children
Stamford – 5 Children
Market Deeping – 6 Children

6.12 Issues with accurate estimates of number of children with disabilities

At present there is no single cross-referenced database giving accurately to the number of children with disabilities in Lincolnshire. A key reason for this is the different definitions of disability which are used.

An aim of the strategy is to ensure an accurate calculation of the number of children with disabilities in Lincolnshire.

7. Views of Parents

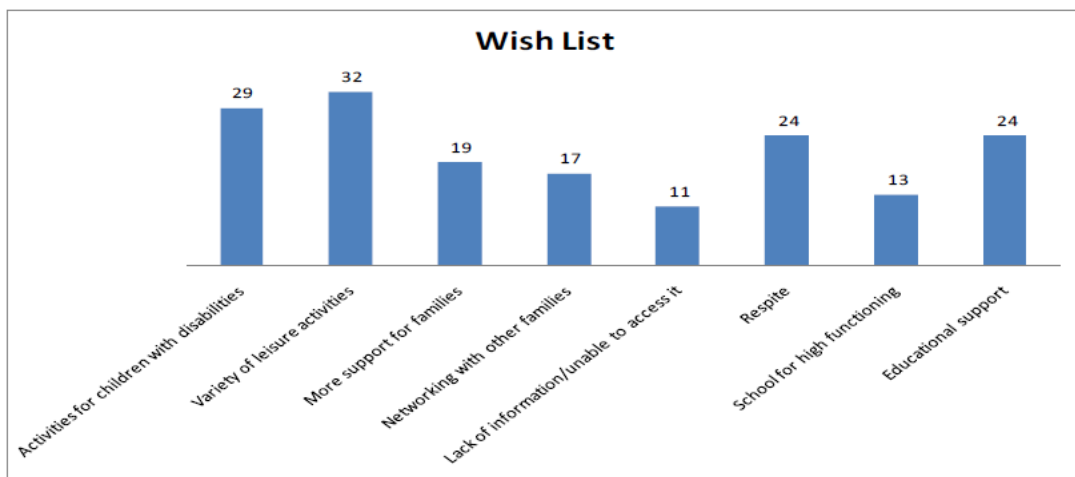
7.1 LPPC

LPPC undertook 7 conferences and asked delegates to complete feedback forms in January and February 2010. A total of 139 feedback forms were received. The main topic was direct payments but also looked at three things that would improve family life, hidden carers and whether GP recognise parents of CWD as carers.

7.1.1 LPPC and direct payments

61% of parents had heard of direct payments however only 28% understood how to apply for direct payments and only 24% understood whether they qualified for them. 24% understood how they could use direct payments, with 31% understanding the legal implications and 25% knowing about support from Pendralls. 91% thought that there should be a clear and simple factsheet about direct payments.

7.1.2 Three things that would help improve family life



7.2 Aiming High for Disabled Child results for Lincolnshire November 2009

7.2.1 AHDC undertook a national survey to assess parents' perception of services for children with disabilities. The survey findings for Lincolnshire are based on 237 questionnaires completed by parents of disabled children. The full report is attached as Appendix 3.

7.2.2 The main criticisms are:

- The lack of useful information about entitlements
- The lack of information about accessing services
- The need to give the same information a number of times
- Not being asked for opinion around the services received
- Child not being asked for opinion on services received.
- Not feeling that professionals worked together

7.2.3 The main positive points were:

- Being given enough information about needs and that the information was clear and relevant
- That on the whole parents were happy with decisions made around assessment
- That parents understood the decisions that were made about the services their child received
- That there was some consultation about services their child received.

8. Views of Children

- Children told us that they wanted;
- Greater choice of leisure facilities
- Better facilities with better access and transport
- Informal meeting places with social opportunities for making friends/relationships
- To be respected, listened to and safe
- To have workers who are friendly, kind and fun
- To learn from their own experiences and have the opportunity to take risks.
- Different sorts of activities such as bowling, football and swimming which they could go to with their friends
- To go shopping with friends, not with their mum

9. What Will We Do Based on Views of Parents and Needs Assessment?

Early Intervention and Prevention

- Strengthen co-ordinated family support for children with disabilities under the age of 5 in line with principles of integration and early support
- Review the use of personal budgets and support services to ensure personalised packages of support are available
- Continue to support organisations and groups to provide inclusive provision and where appropriate specialist provision for children and young people with disabilities.
- Develop a local core offer to improve access by CWD to activities in their community.
- Ensure families can access short break provision as required to support social inclusion of children. Ensure provision is also available in an emergency to prevent family breakdown and ensure children can remain in their home and community.
- Review joint assessment processes and procedures so families can have a single point of contact and integrated support
- Ensure equipment is purchased timely and cost-efficiently to improve life quality of children and young people with disabilities
- Ensure parents voices are heard particularly vulnerable adults voices in the shaping of services.
- Work with parent led organisations and the Parent Partnership to ensure parents voice, particularly the vulnerable parents voice, is heard
- Ensure parents can access parenting programmes to support interaction with their disabled child
- Provide quality information to enable self and community to access services and activities e.g. mainstream play, sporting, leisure and cultural activities, particularly over holiday periods.
- Improve availability of information related to children and young people with disabilities and their families including to GPs and all universal services and the internet

Safeguarding

- Work with LSCB to ensure that issues specific to CWD are shared with all staff in multi-agency training.

Aspiration and Well Being

- Ensure children and young people's voices are heard at reviews and incorporated into the shaping of services.
- Ensure that wherever possible children and young people are supported in independently managing their condition and developing independence.

Learning and Achievement

- Ensure all children with a disability are able to reach their full potential through education, employment or training.
- Ensure children with disabilities can lead an independent life and can access job opportunities
- Ensure there is a multi-agency approach to Transitions to ensure a smooth move between children's and adult services including the introduction for young people at the age of 13. That organisations work to the multi-agency transition protocol and take responsibility for the transition of the children in their care to Adult Services.
- Improve links between CS and Adult Services to improve transitions

Best Use of Resources

- Ensure that Children with Disabilities is everyone's business
- Review accountability arrangements for agencies providing services for CWD to ensure aspirations for integration are understood.
- Ensure that all agencies involved in supporting families of CWD and vulnerable adults work more closely together to jointly plan, commission and deliver services including health, education and social care services to children and young people with disabilities. Create a joint multi-agency care pathway for children with disabilities
- Continue to focus on improving access to universal services, especially leisure and play services by removing physical, organisational, informational and attitudinal barriers

- Ensure comprehensive workforce development programme to ensure children with disabilities is everyone's business
- Ensure eligibility criteria for access to services for children with disabilities is published and understood
- Achieve better co-ordinated, family focused services for all disabled children
- Bring together therapy teams to improve services available to children and young people in the community and within school settings – including Occupational Therapy, SIS, SALT and Physio.
- Review pooling of resources for short breaks and aids and adaptations.

10. The Successful Delivery of Our Objectives Will Lead to:

- Young People with disabilities in education, employment or training by the age of 25.
- Children and young people feel that their views are listened to and that the packages of support are personalised to their needs.
- Professionals working together to improve the quality of life for children with disabilities.
- Children with disabilities going to clubs and activities within their communities
- Children with disabilities staying in their families and in their communities
- Children with disabilities, family members and professionals having high aspiration of what can be achieved.

A detailed implementation plan for the coming year has been drafted and is available on the website.

11. Success is Measured by:

- Children and young people telling us they are happy with services.
- Parents showing satisfaction with the services.
- Young people with a disability finding meaningful work or training opportunities.
- All community activities accessible to children with disabilities.
- A culture of high aspiration for children with disabilities in Lincolnshire.

12. Consultation

Lincolnshire County Council and NHS Lincolnshire would like to invite comment from stakeholders on the new draft strategy for Children and Young People with a Disability.

The consultation will run for 3 months from 16th June to Monday 15th September.

We would like to know:

- Is the strategy understandable?
- Is the direction we want to travel in clear?
- How would you like to see success measured?
- Do you agree with our principles?
- Do you agree with what we propose to do?

Comments should be sent to: CWDStrategy@lincolnshire.gov.uk

Consultation will be with:

Young People through the Shadow Transition Board

Parents through LPPC and Parent Partnership

GPs

LCHS staff

PCT staff

Lincolnshire County Council staff

LSCB

Schools

Voluntary Agencies involved with Children and Young People with a disability