

Strategy for Children with Disabilities 2011- 2016

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Introduction

Children and young people with disabilities deserve the very best services. We want a workforce that is able to work alongside children with disabilities and their families, to support them and help them access appropriate services.

We want to ensure that children and young people with disabilities have the same opportunities as their peers.

1. Vision for Children’s Services as agreed by CYPSP on

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 CWD Commissioning 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 NHS providers e.g. Community Services, Therapy Services, Paediatric Services (Community and Hospital Based) etc; 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 JSNA, CYPSP Plan, Child Poverty Strategy, DPH Annual Report and **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 disability.

The Equality Act 2010.

A person has a disability if:

- they have a physical or mental impairment
- the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities

For the purposes of the Act, these words have the following meanings:

- 'substantial' means more than minor or trivial
- 'long-term' means that the effect of the impairment has lasted or is likely to last for at least twelve months (there are special rules covering recurring or fluctuating conditions)
- 'normal day-to-day activities' include everyday things like eating, washing, walking and going shopping

This is supported by all services providing support to children, young people and their families adopting the social model of disability.

The social model has been developed with the aim of removing barriers so that disabled people have the same opportunities as everyone else to determine their own lifestyles.

Access to services is through a variety of processes and information on this can be found in the LSCB Meeting the Needs which sets out how to access services.

4. CYPSP 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
 - Children and young people and their families should receive services at the earliest opportunity, to promote healthy development and to ensure that families are appropriately supported.
 - Services should be inclusive, flexible, convenient and responsive to the child or young persons need including a single point of access.
 - Children with disabilities will have access to universal health services and universal services in the same where as their peers
 - All children and young people with a disability should be given opportunities that enable them to remain in the family home and to access activities and services in their community.

Safeguarding

2. Research evidence indicates that due to their unique circumstances vulnerable children with a disability may be more vulnerable to abuse. CYPSP in partnership with LSCB will ensure that inclusive safeguarding practice will continue to be promoted and developed.

Aspiration and Well Being

3. All children and young people with a disability will be involved in decision making that affects their lives, including assessments and service design, delivery and evaluation. This will be supported by ensuring that those practitioners who communicate best with the child or young person will support the child to communicate their views and needs.
4. Parents/carers are the experts on their children's needs and are essential partners in decision making processes, including assessments. This will be reflected in all organisations policies, procedures and work.

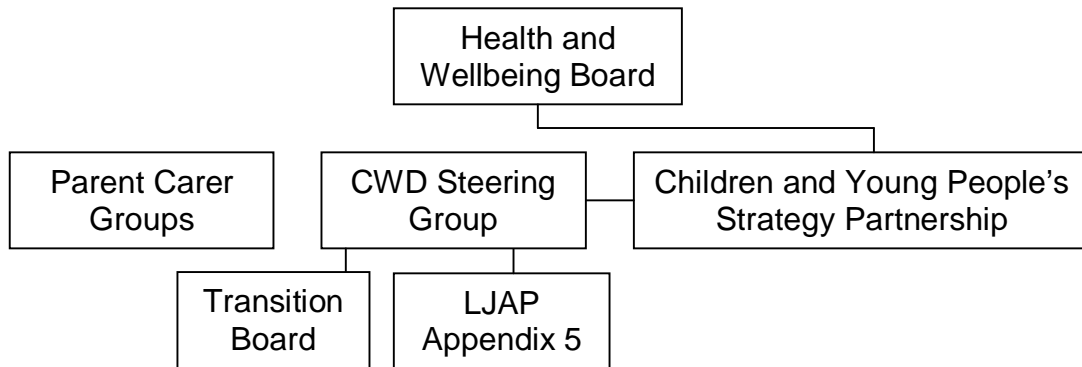
Learning and Achievement

5. 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

6. 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.
7. Access to services for children and young people with a disability will be fair, equitable and transparent and reduce health in equalities.

5. Governance of Arrangements for Children with Disabilities



The Terms of Reference for the CWD Steering Group are attached as appendix 1.

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)

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. A group has been established to bring together the different databases to ensure a consistent profile of numbers of children with disabilities to ensure sound planning and commissioning of services to meet needs appropriately and flexibly.

An overview of current data available and trends from this data is attached as Appendix 2.

7. Views of Parents

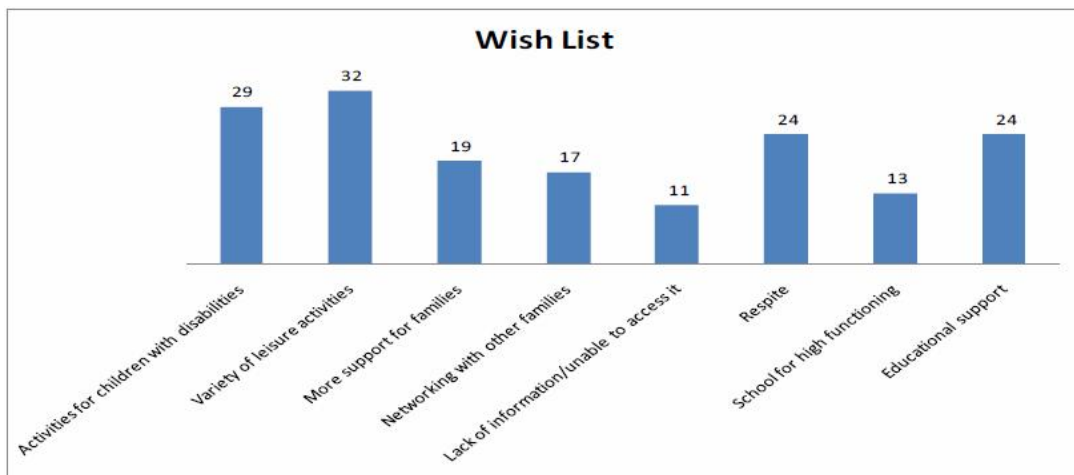
7.1 LPPC

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 CYPSP Do Based on Views of Parents and Needs Assessment to ensure the principles are met?

Early Intervention and Prevention

- Develop a single point of access for children with disabilities which provides integrated services that support children with disabilities.
- Support all organisations and groups working with children and young people to provide inclusive provision so that children can access activities and services in their community.
- Ensure staff have appropriate training to support a range of needs and ensure inclusivity of services both within statutory and voluntary organisations.
- Provide training and support to organisations to ensure activities for Children and Young People are inclusive.
- Introduce personal budgets to ensure children and young people have personalised packages of support that meet their needs.
- Ensure families can access short break provision as required to support social inclusion of children.
- Ensure families can access short breaks in an emergency.
- 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 who are parents. This will be achieved through establishing parent focus groups and support groups.
- Ensure parents can access parenting programmes to support interaction with their disabled child.
- Provide quality information to enable children, young people, families, practitioners and communities to be aware of services in their community and promote access to these services and activities.

Safeguarding

- Work with LSCB to ensure that issues specific to CWD are identified and 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 practitioners who communicate best with a child attend the relevant reviews of their child to ensure their voice is heard. Continue to hear young people's voices through the Shadow Transition Board.
- Ensure that wherever possible children and young people are supported in independently managing their condition and developing independence in adult life.

Learning and Achievement

- Work with schools, employers and parents to ensure all children and young people with a disability are able to reach their full potential through education, employment or training.
- Ensure there is a multi-agency approach to Transitions to ensure a smooth move between children's and adult services and this is monitored by the Transitions Board and the Shadow Transitions Board.

Best Use of Resources

- Ensure that Children with Disabilities are everyone's business through training and promotion and holding to account by CYPSP and Health and Well Being Board.
- Through promotion and challenge ensure practitioners and parents have high aspirations for the children and young people they work with and care for.
- Agencies involved in supporting families of CWD and vulnerable adults work together to jointly plan, commission and deliver services including health, education and social care services to children and young people 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 are everyone's business

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

- Children with disabilities, family members and professionals having high aspiration of what can be achieved.
% of children with disabilities who are in education, employment and training.

- Children and young people feel that their views are listened to and that the packages of support are personalised to their needs.
% of children who participate in their transition plan

- Children with disabilities going to clubs and activities within their communities
% of children with disabilities accessing short breaks

- Children with disabilities staying in their families and in their communities
% of children with disabilities who become looked after children

- Professionals working together to improve the quality of life for children with disabilities.
 - Parents perceiving they are supported in ensuring their child receives the services and support they need.
Assessed through bi- annual parent satisfaction survey led by parent focus groups

11. Success is Measured by:

- Children and young people telling us they are happy with services through feedback from shadow transition board.
- Parents showing satisfaction with the services through annual parental satisfaction survey.
- A culture of high aspiration for children with disabilities in Lincolnshire by annually running a conference for practitioners, parents of CWD and young people with disabilities and through young people with a disability finding meaningful work or training opportunities as assessed through EET figure.
- All community activities accessible to children with disabilities as assessed through short breaks data.
- Health measurements to be provided by Lynne McNiven. Potentially access to services – 18 week wait.

12. Consultation

Lincolnshire County Council and NHS Lincolnshire undertook a consultation on the proposed strategy between Thursday 16th June and Thursday 15th September 2011.

The following questions were asked:

- 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?

Consultation was open to all but the following groups were targeted for response.

- 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
- Parent consultation

The responses to the consultation are in full in appendix 5.

The main issues were:

- Partnerships working needs to be emphasised
- The Strategy needs SMART targets

- Which definition of disability to use, children act (deficit model) DDA, medical model or social model
- Need to involve children, young people and parents throughout decision making process
- Need for 'critical friend' focus group
- Family friendly document
- Support parent leadership
- Need clearer statement around closer working with adult services and transition
- Need to remain child focussed
- Need more emotional support for parents particularly fathers

Appendix 2

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

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
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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.

6.10CQC submission Feb 2011

The CQC submission which pulls together information from Health Services stated that these 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 pen 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

Appendix 4

Lincolnshire Joint Agency Panel Policy and Procedures

1. The Lincolnshire Joint Agency Panel (LJAP): meets quarterly with ad hoc meetings added as necessary and agrees joint resource allocation for accommodation or support packages for children and young people with complex and challenging needs. Commissioners and Heads of Service from LCC and PCT Children's Commissioners form this panel Through this panel we will be able to develop multi-agency packages of interventions to enable children who would have previously accessed out of county provision or hospital to remain living within the county.
2. LJAP will allocate resources according to the needs of children being identified as having Complex, Severe or Specialist/High Risk needs. It is expected that cases referred to LJAP will have had Head of Service agreement to be presented.
3. The LJAP plays a critical role for all agencies in their management of services for children with complex needs, by:
 - Managing the threshold for access to services
 - Agreeing funding and monitoring resource intensive packages of interventions based on 'Value for Money' principles.
 - Planning and monitoring that the appropriate provision meets required ongoing need and appropriate transition to Adult & other services as required.
 - Monitoring areas in which clarity and/or risk sharing is required in child care planning.
 - Ensuring that resources are appropriately allocated and reviewed.
4. LJAP will meet every month. Normally, 30 minutes will be set aside to discuss each case presented to the panel.
 - Chairmanship will be shared by the Assistant Director of Adult Services and the Director of Commissioning of NHS Lincolnshire.
5. The Core members with one vote each of LJAP are:
 - Children's Services – Debbie Barnes
 - Director of Commissioning, NHS Lincolnshire – Allan Kitt
 - Head of Services Commissioning – Richard Collins (AWD)/Justin Hackney (CWD)
 - Head of Service, CWD – Meredith Teasdale
 - Head of Service – Additional Needs – Gary Nixon
 - Lead Nurse for Continuing Healthcare (Adults & Children) – Sue Pearce
 - Lead Nurse for Continuing Healthcare (Mental Health & Forensics) – Lisa Lassmans / John White

The Supporting members of LJAP will change dependant on case but is likely to include representation from:

- CAMHS Clinician
- Additional Needs
- CWDT
- Regulated Services

Cases that need to come to LJAP

6. Cases where a long-term placement, specialist placement and/or treatment are required which is funded by statutory agencies.
 - All cases will need to have completed due process by LCC resource panel, additional needs complex case panel, OATS or Continuing Care Panel before being presented at JAP.
7. LJAP does not agree funding for:
 - a. Holidays for children,
 - b. Childminding (unless this is required longer than 3 months and part of a wider package of support)
 - c. CWD home support commissioned services
 - d. Transport
 - e. Supervised contact, day care (unless part of a high level family support package)

These should all come out of section 17 or other appropriate budgets and be agreed by the appropriate Head of Service or as delegated.

Roles and Responsibilities of LJAP

8. (a) Chair LJAP meeting, ensuring the views of all the members are brought to bear on how best to meet the assessed needs as presented by the referrer.
- (b) Advise LJAP on professional services that can be commissioned to meet needs.
- (c) Agree the recommendations, proposals and action plans of the meeting, which promotes best practice within the resources we have available and the timescales we must meet.
- (d) Agree the allocation of tasks to LJAP members that may facilitate the care/service plan, and ensure completion, within agreed timescales.
- (e) Ensure constructive questioning and challenges to the proposed care plan from health or education in order to see whether there is a better, or more effective, or better value for money, way to provide the service, whilst achieving the desired outcome.
- (f) Act as a panel to address disputes between clients and continuing care panel **with regards to provision of care.** On these occasions the panel will

assess whether procedures have been followed appropriately by the continuing care panel and ultimately assess whether an appropriate care package of care has been recommended. Papers will be submitted to the panel prior to the meeting and presented by the relevant officer. Deliberations and decision will be by the panel with any officers with an interest in the case withdrawing from decision making process.

Analysis

9. LJAP relies on good analysis to identify the underlying needs of the child and family. The analysis stage should therefore take the following into account:
 - a. A child's needs must be based on knowledge of what would be expected of this child's development.
 - b. Parenting capacity should draw on knowledge about what would be reasonable to expect of parental care given to a similar child.
 - c. Family and environmental factors should draw on knowledge about the impact these will have on both parenting capacity and on a child's development.
 - d. Clear assessment of learning needs, particularly from the perspective of the child's school.
 - e. Current financial and proposed financial resources and/or human resources.

Judgements of the Panel

10. The panel should be mindful of safeguarding procedures and processes of LSCB.
11. Due consideration is given to the child or young person's race, religion/belief, gender, cultural and linguistic backgrounds (section 22(4) and (5) of the Children Act 1989) disability and sexual orientation (where relevant).
 - a. LJAP will ensure that in the case of any child or young person who is accommodated, our duty to safeguard and promote his/her welfare is considered and that the decision of LJAP promotes and safeguards his/her welfare.
 - b. LJAP will ensure that where we provide accommodation for children or young people being Looked After, where possible the accommodation is near the child or young person's family home, and is with any siblings who are also accommodated; so far as this is reasonably practicable, and is consistent with the child or young person's welfare and our duties under Part 3 of the Children Act 1989. In addition LJAP will ensure that our duties in relation to the promotion of contact are considered and that the decision made is consistent with those duties.
 - c. Identifying what the child regards as highest priority – Evidence that the child's views have been considered.

- d. Ensure that the provisions of the 1996 Education Act are integral to the decision making process.

Decision Making

12. Decision making factors include:

- a. What types of interventions, Health, Social Care or Education, are known to have the best outcomes for the particular circumstances of the child who has been assessed as being in need. Whether appropriate procedures have been followed and whether all relevant information and advice has been gathered.
- b. How the necessary resources can be mobilised within the family's network and within professional agencies and all voluntary sector agencies.
- c. What alternative interventions are available if the resources of choice cannot be secured. How do we bridge the gap between service provision if necessary.
- d. Assessing and discussing the achievability of early success and beneficial impact of the provision.
- e. Decisions will be made on the day in most cases, but where this is not possible clear time-scales for a decision will be agreed.
- f. Decisions will be recorded on the decision part of the LJAP application, typed, signed by the chair and then emailed to panel members, referrer and other who may have attended. This will normally occur the Monday following panel and letter of confirmation by the panel.
- g. The complete LJAP Application/Decision Sheet should be placed on the child or young person's file and also attached to the child/young people's record.
- h. Normally all service provisions agreed at LJAP will be subject to review and review dates/proposed exit criteria will be set out on the day of the decision being made.
- i. It is the responsibility of the allocated referrer to inform the parents/carers and young person of the LJAP decision. Any feedback about the decision, including disagreement, should be discussed with the referrer's team manager and not with panel chairs or members.
- j. Appropriate commissioning portfolios are being followed?

The person presenting the case will not be present during the deliberations of the panel with regard to decision-making.

The decision made by the panel will be confirmed to the presenting officer within 5 working days of the Panel.

13. Emergency Cases

If an emergency decision is required then paperwork should be sent to all panel members immediately. A timescale should be set out for response and the presenting officer should be available to take calls to explain case.

In emergency cases agreement from 3 panel members from 2 separate organisations is acceptable. This should include agreement from 1 of the co-chairs.

14. Resolution Policy

Where agreement or compromise can not be reached by all members at the JAP the issue should be escalated to Director level for immediate resolution. This should only be in unique circumstances.

15. Complaints Policy

Complaints with regard to the decision and package of support should be raised through the relevant organisation. i.e. educational support through SENDIST tribunal.

16. Dispute Policy

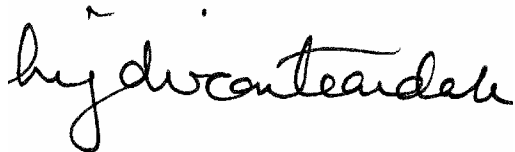
Disputes with regard to following of procedures should be made in writing to the Director of Children's and Adult Social Care for resolution and investigation.

Please find enclosed a copy of the Initial Consultation Feedback (ICF) for the Children with Disabilities (CWD) Strategy. This document contains the feedback that we have received from Young People through the Shadow, Transition Board, Parents through LPPC and Parent Partnership, GPs, LCHS staff, PCT staff, Lincolnshire County Council staff, LSCB, Schools and Voluntary Agencies involved with Children and Young People with a disability.

Thank you for making the effort to provide this feedback; we have received 6 responses so far.

Kind regards

Meredith Teasdale

A handwritten signature in black ink that reads "Meredith Teasdale". The signature is written in a cursive style with a large initial 'M' and 'T'.

Head of Children with Disabilities.

Feedback

Feedback has been received from the following people:

Headteacher
LCC HOS
Children and Young People Voluntary Sector Forum
Mencap Partnership and Campaigns Officers - East
Boston Clinical Commissioning Group
Lincoln GP
Parent
LCC Employee
ASC LCC
Public Health

1. Any strategy document that is 25 pages and over 4000 words long is not going to be well understood by so many stakeholders.

2. I feel the strategy is clear, and think the direction of travel appears sensible. However it is a large implementation plan, which has some gaps in responsibilities, and one or two of the recommendations are general rather than smart, for example, the second one, i.e. review the use of personal budgets - is this to give better clarification or is it to manage budgets?

Other than this, ambitious but reasonable.

3. Please find below a collective response from the Children and Young People Voluntary Sector Forum (CYPVSF). We hosted a consultation event for the CYPVSF members on 20th July 2011 and the response has been based upon the outcomes of that session.

The following response to the Children with Disability Strategy 2011 – 2016 is as a result of a consultation held for the CYPVCS Forum on 20th July 2011.

Is the strategy understandable?

- Strategy can mean what ever you want it to be
- Language changes considerably throughout the document – definition i.e. CWD, CYP – too many acronyms & use of names no-one knows
- Its open ended
- Not specific enough at whom it is aimed at i.e. not parent/child friendly
- If this is part of core offer it should be in participation from day one with parents and children and not consultation at a later date
- Stats would be better in appendices at the back

Is the direction we wish to travel clear?

- Focus is on visible disabilities
- Strategy is very local authority – does not seek partnerships such as health, sport, leisure, social care and education
- Should be complementary to national strategy
- Feels like a quick update to get something out

How would you like to see success measured?

- Who measures the outcomes of the strategy?
- Steering Group should be partnership of ‘critical friends’ who reflect as feedback/strategy
- Seeking continuous view of ‘service’ users and partner agencies
- Needs to be a ‘working’ document
- Define what is meant by success – SMART targets are needed

Do you agree with our principles?

- They appear to be very broad
- Not very clear as to how they will be achieved and by who nor the depth is clear
- Some require clarity of definition i.e. criteria and success

Do you agree with what we propose to do?

- Closer working with adult services – especially in shared definition
- Access to community based activities definitely is problematic – ‘not’ accessible to all and will be reduction in availability due to changes to grants and funding
- Transition needs a greater profile – is every bodies business to support transition

Other comments

- Plagiarism to be acknowledged to source and references should be accurate and information should be correct
- Definition from Children’s Act is not appropriate as its out of date- stick to one definition from DDA
- Looking at National Strategies i.e. personalisation
- Some statistical data is too old
- Data doesn’t correlate with LCC SEN data
- Data is ‘hotchpotch’ and poorly presented
- School review is moving away from designation – there are more designations in here than DfE
- Good services for 0-5 ESCO programme to be rolled out for all up to the age of 25

4. In answer to the 4 questions at the end of the presentation we received, we feel the answer is yes to them all.

As long as the following comments are taken into consideration:-

Early intervention, as not all children with disabilities are known to local councils, therefore some are missing out on valuable advice, information and services;

Make sure there is a seamless service between children and adult services;

Have the child at the centre of what is being provided, almost a 0 - 90 approach that goes through their lives with them, to encompass all aspects of their lives e.g. health, education, employment, etc.

There are clear routes for parents, carers and professionals, to gain access to these services, almost like a one stop shop, where to go for what, what's out there, links between projects. Maybe a dedicated worker or helpline?

Most importantly, listen to the child and their families, involve them in the planning of services where possible

Success can be measured by the number of disabled children receiving the services they want and thus making a real difference to their lives.

5. I would just like to say that I found the document easy to read, the strategy clear and I agree with your principles and propositions.

I think the measure of success is in positive outcomes for those the strategy is aimed at.

6. Looking for a reference to Supporting Families (working families). Early intervention is fantastic re Early Years, would like to see a note that there's still access to this level of care. Would like to see how parents cope emotionally, (especially for fathers) would also like to see more interventions for fathers.

Local Services mentioned (really, really good). Community Based support, severe complex cases, still have specialist residential supervision.

More inclusive support to be made available for 0-18 (child care providers) most support available is for 0-11.

“8 views of the children” is a REALLY good list. These are some of the views that I have been trying to express. Ensure that these services are available. However, it’s important that we do value and listen to what they have to say. Children do need motivating to achieve their best so it’s important to get that balance.

I would like to see within the transition model that there is evidence of staggered targeted specialist supervision. Achieving the longer term goal as the child is approaching adult services, ensuring a smooth transition.

Parents’ emotional, mental capacity and specialist care of their children should be recognised and shouldn’t be undermined or discredited.

Professionals should continue to work effectively with parents to maintain links (bonds) between families.

How do working families with a CWD continue to function (with a specialist requirement) to enable their family to work. Resources should be directed to support this beyond the age of 11.

I would like to see this consultation passed to parents to seek their feedback.

7.

- 1.1. Vision: I think the Principles should include something about partners working together to achieve the overarching aim
- 1.2. Safeguarding: one of the objectives would also be timely identification and intervention
- 1.3. Aspiration and wellbeing: include reducing the gap in health inequalities experienced in children
- 1.4. P4. Objectives will lead to..... should reflect the additions to the overarching vision: lead to efficient interagency working, improve the early identification of safeguarding issues and improve timeliness of addressing these and reduce the drivers of health inequalities in children
- 1.5. P5. Children and young people with a disability..... should include NHS providers e.g. community services, therapy services, paediatric services (community and hospital based), psychologists, etc, etc
- 1.6. P5. This strategy has been developed alongside.....should include JSNA, CYPSP Plan, Child Poverty Strategy, DPH Annual Report and the upcoming Health and Wellbeing Strategy for Lincolnshire
- 1.7. P6 Children’s Act Definition.....I agree that it is a little harsh....but it could be modified as it does obviously include all areas of disability (if a little insensitively!)e.g. dumb: communication difficulties
- 1.8. P7. CYPSP Plan: I am in the process of collating a health response as the Plan as it stands needs to include more health outcome data and relate how this links with social outcomes as per the JSNA

- 1.9.P7. Safeguarding: as before there should be an emphasis on interagency working, improved efficiency of detection and quicker action as a direct result.
- 1.10. P8. Point 7: should also include reducing health inequalities
- 1.11. P.11 Views of Parents: What age were the children of these parents? This should be included and any gaps acknowledged and these included in the evaluation
- 1.12. P14 point 9: again interagency working should be stressed: the document states there will be a single point of access but we also need to state how this will be achieved and what steps we are going to put in place to do this. Reducing Health inequalities should also be included as a key outcome.
- 1.13. P17 Evaluation: All of these need to be SMART outcomes:
- 1.14. I think we need to have a proactive plan for engagement to measure service user satisfaction: how we will do this / timescales/ frequency of measurement.
- 1.15. Can we actually measure the numbers of young people with disability in training or work? If not we can't use this as an evaluation method.
- 1.16. The development and implementation of a single point of contact would provide an evaluation of improved access to: benefits advice, equipment, groups, etc, etc (all of the issues brought up in the parental feedback). However, this again would need clear timescales and methodology to support it.
- 1.17. How do we measure a 'culture of high aspiration for children' ? I think we would have to proactively engage with staff: how we will do this / timescales/ frequency of measurement. For example we could run an annual interagency conference and include service users?
- 1.18. I hope this helps, please give me a call if you want to talk about any of my suggestions. I do think the document reads much better and has a clear 'Commissioner' slant, it has examined:
- 1.19. **'Where we are'** (the additional data will also back this up)
- 1.20. **'Where we want to be'**: you have very clear vision and objectives
- 1.21. The **'How we get there'** : I think needs to be clearer hence the emphasis on interagency working to improve outcomes, how we will set up a single point of access, etc
- 1.22. The **' How will we know we are there'** section I think needs a little more work as this really needs to address how we will evaluate the outcomes of this strategy. These do need to be SMART (specific, measurable, achievable, realistic and timely).....I'm sure Ginny and Debbie will come up with some further measurements but I am more than happy to do some more work with you on this if you need me to.

8.

Is the strategy understandable?

Yes

Is the direction we want to travel in clear?

Yes

How would you like to see success measured?

We would like to see what percentage (or actual numbers) of this population subgroup get into paid employment? How many of them get into university and complete their education compared to peer group. What percentage went to shopping with their peers and not their moms compared with their peers. What percentage of children felt that they could assess the facilities like transport and leisure activity. What percentage of children feel that their choice of leisure has increased due to this programme.

Do you agree with our principles?

Yes, but there is a conflict.

The vision is ***“That every child in every part of the county should achieve their potential”***.

And under principle 4: all children being the best they can be

But in this real world of resources under principal 5: effective use of resources

The conflict arises as limited resources mean that you will not be able to provide for every child to be their best but rather” every child should achieve their potential where affordable- or within confines of the budget – or where cost effective.”

Do you agree with what we propose to do?

Single point of access is a recent catch phrase. Are you aware how many single points of access for services we are going to have in this locality in years to come.

We favour working together, what is wrong with a parent/child coming and seeing a GP and GP speaking to health visitor /school nurse and all that could be sorted. I am sure we already have their on single point of access team’s phone numbers. Can we really afford another team and committee?

9.

1.23. Section 1: Vision for Children’s Services

- a. We would like to see a principle of adopting a person-centred approach; however, we also feel this could be adopted under the Aspiration and Wellbeing heading.
- b. We would also like to see something about supporting parents.

1.24. Section 2 & 3: Purpose of This Strategy & What is a Disability?

- a. We would like to see more of an emphasis on the inherent value of the child and celebration of their uniqueness.
- b. We would also prefer to see a definition of disability in terms of a social model of disability, rather than the medical model presented in section 4, or the deficit model in section 2. We would like to see a definition written in terms that parents would value for their own child. We would like to see something about the kinds of lives that families want, under the heading Purpose of This Strategy, rather than being defined (in our terms) in relation to services they use.

Please note that people with learning disabilities self-define as 'people with learning difficulties' (People First).

- c. It would be excellent if we could put ourselves in the parent's and child's shoes and express the great aims of the strategy in terms that make sense to families and which they value.

1.25. Section 4: Principles for CWD

- a. Again, a principle of adopting a person-centred approach and/or incorporating under the Aspiration and Wellbeing heading would be welcomed.
- b. We would prefer to see an approach that recognises and promotes the inherent capacity of families to be resourceful and meet their own needs.
- c. It would be good to see a strong statement of commitment to inclusion in relation to point 3: inclusive communities.
- d. We would also like to see a commitment to strengthening and supporting families to plan and self-direct their support under the Aspiration and Wellbeing heading, not just the right to be involved.
- e. We welcome the emphasis around employment and training under the Learning and Achievement heading but would also welcome a commitment to working in a person-centred way, including the introduction of person-centred planning within CWD/ education.
- f. Under the same heading, Learning and Achievement, we feel a commitment to fostering peer support networks/ families leading planning would be a welcome addition. This could also come under the Best Use of Resources heading.

1.26. Section 6: Needs analysis

- a. It would be helpful, if possible, to have a breakdown of CWD from the Schools Census 2011 by age classifications. This would also be

appropriate for the figures generated (as a whole) from the Clients with a Disability category.

- b. It would be good to see a recognition of parents as parent carers, to identify the importance of a carer's assessment to support parents with the impact of caring.
- c. We welcome the commitment to more systematically gather data re: the prevalence of disability amongst children and young people in Lincolnshire.
- d. We would like to see this information inform the Joint Strategic Needs Assessment.

1.27. Section 7 & 8: Views of Parents; Views of Children

Very valuable section with useful feedback for Adult Services also. It would be good to know how parents have contributed to the production of this strategy. It would be interesting to know how you have engaged with children, and how their voices are heard. How has the Shadow Transition Board been involved? As emerging young leaders they have useful lived experience to contribute.

We are keen to identify agendas in common with yourselves (e.g. information and advice), particularly given the Health and Wellbeing strategy and JSNA, and emphasis on 'life course' thinking: how great the experience of early years is on later life.

1.28. Section 9: What we will do. . .

- a. It is not clear from the title of this section that the strategy will also address the views of children highlighted in Section 8.
- b. We really welcome the focus on early intervention and prevention.
- c. Under the Early Intervention and Prevention we would like to see effective signposting from maternity units, health visitors etc as well as support for parents who wish to set up parent support groups and share their knowledge and expertise with health community, and cost effective access to Makaton & BSL training.
- d. Under the Aspiration and Wellbeing heading, we would like to see a commitment to person-centred reviews.
- e. Equally, under the Learning and Achievement heading, a commitment to a person-centred approach.
- f. Under the Best Use of Resources heading, we would like to see a commitment to increase the uptake of Direct Payments and the personalisation of services.

- g. Under the same heading, we feel both an acknowledgement of and a commitment to use the expertise of families would be a welcome addition. This could include seeking to utilise such expertise through peer support, families leading planning or as trusted assessors etc
- h. We welcome in particular the commitment to strengthen co-ordinated family support for children under the age of 5; review of joint assessment processes for a single point of contact (common agenda with adult services: trusted assessment)
- i. We would like to see more on:
 - peer support
 - supporting parent leadership (eg Partners in Policymaking)
 - Person centred planning
 - supporting parent networking to create their own solutions and ideas
 - mentoring and coaching eg. Disabled adult to disabled child
 - cost effective information days, training, learning and development for parents about specific impairments & best practice.
 - Joint action with Adult Services

1.29. Section 10: Successful Delivery

- a. We would like to see an acknowledgement that it will also mean 'Young people with disabilities living independently and participating in their communities, planning and directing their own support by the age of 25.'
- b. We like the implication of inclusion, and feel this can run more strongly as a theme throughout this document.

1.30. Section 11: Success measurement

- a. Again we would like to see a commitment that living independently and participating in the community will be a measure of success.
- b. Another measure of success may be children, young people and their families planning and directing their own support via Direct Payments etc.
- c. Equally, whilst an arbitrary measure if not acted upon, the number of young people with person centred plans/ reviews in place could be another measure of success.

1.31. Overall we feel there should be more emphasis on personalisation of services, including using person-centred approaches to help people plan and direct their own support.

This should come with a commitment to Direct Payments as one of the key mechanisms to help people achieve this and prepare children, young people and their families for the transition to Adult services (where applicable).

These can also be incorporated into the Implementation Plan as both aims and actions where appropriate.

All of this can come through an overarching thread of empowering people to become more independent, self-directing planning and support.

10,

Is the strategy understandable?

P.9 Various acronyms, not clear what these are.

P.20 Lots of nice words about supporting and informing. Where is the hard information about who will do what for how many hours to enable the client/family to have what improvement in quality of life?

Is the direction we want to travel in clear?

No. Inconsistency re withdrawal from CAMHS? Focus on the physical despite definition of disability on p.6. Other than that too woolly to discern a direction of travel too much focus on structures and processes of organisation. Too little on outcomes.

How would you like to see success measured?

Single point of access good. Need define actual outcomes sought not a long worthy sociological wish list concerned with education of how 'we' of disability. Bottom 9.22 looks briefly at shortbreaks, aids and adoption – so how much, who for (eligibility). Define some measurable outcome parameters that are concrete. i.e. how many clients get breaks this year compared to last year. What equipment provided and what improvement to whom.

Do you agree with our principles?

Well, yes, how could one not? It reads like many such documents: being nice, working together, being inclusive. But it's this on actual actions to help clients – how much up or down resources, what clients will receive that is any on.

Do you agree with what we propose to do?

Not really clear what you propose to do (see 4). I'm sure you will meet your targets, not sure clients will notice any difference because not stated what you do will be any different.