

Making Life Better

For children and young people with disabilities
and complex health needs and their families.

A Strategy for the delivery of integrated services in
Worcestershire
2007-2011



I wish people wouldn't stare. You get used to it. I wish they would ask me questions rather than stare. I wouldn't mind. When people stare, I just tell them to take a photo - it will last longer!

When new children joined my class no one knew about me because the teacher didn't explain ----- I wanted to cry and scream.

I've been bullied about my weight, my race and the way I look. I think a lot of names and phrases can hurt more than a hit or a kick.

Whenever I feel angry or alone it makes me feel like a piece of jigsaw puzzle that doesn't fit it

They talk to my pusher. I wish they could see me. They ignore me. I am not invisible!

I wish more people could be more deaf aware. I wish they could have training. I hate it when people talk to me differently when they know I am deaf

Welcome

This is Worcestershire's strategy for the delivery of integrated services for children and young people with disabilities and complex health needs aged 0-19 years (and up to 25 years for some statutory responsibilities).

It represents our way of delivering Standard 8 of The National Service Framework (NSF) for Children and Young People and Maternity Services (2004) which sets out standards for disabled children and young people and those with complex health needs.

NSF Standard 8:

Children and young people who are disabled or who have complex health needs receive co-coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.

The strategy was agreed by the Children and Young People's Strategic Partnership Board on November 19th 2007.

The success of the strategy will depend on the active partnership of people who are committed to empowering and supporting these children and young people to achieve and thrive – at home, in their community and in their learning.

Children and young people themselves, their parents and carers and agencies supporting and delivering services to them, have all influenced and been involved in the development of this strategy.

Consultation with children and young people, parents and carers, agencies both statutory and voluntary has yielded a great wealth of information, ideas and experience. These will contribute to the ongoing working out of the Action Plan which accompanies the strategy. All these stakeholders will also continue to be involved in developing services, monitoring and evaluating how we are doing in Worcestershire.

The Government's report "Aiming High for Disabled Children: better support for families" was published in May 2007. Its launch was accompanied by the promise of increased resources for children and families, especially focused on short breaks, transition and children's equipment. This concurs very well with some of our own priorities. Some funding is also allocated towards the development of parent's forums. This is good news and will support our aim of

Making Life Better.

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Introduction:

This joint strategy and action plan are about Worcestershire's commitment to improving outcomes for and supporting, children and young people with disabilities and complex health needs and their parents/carers and siblings.

Their purpose is to make sure that all professionals work together with families, involving and supporting the children and young people and their family carers in agreed ways and with joint priorities.

The starting point for the strategy is what children, young people and their families have told us that they need and want - and we will want them to continue to tell us whether our strategy is making a positive difference in future.

The strategy and action plan relate to those children and young people whose impairment has a substantial and long time adverse effect on their ability to perform normal day to day activities as defined in the Disability Discrimination Act 1995

The children and young people included are those with a learning disability, autism spectrum disorder, sensory impairment(s), physical impairments, serious illness and those who have special educational needs, emotional difficulties or challenging behaviour as a result of any of these. The disability may have been present from birth or acquired later on in childhood.

It includes children and young people who have a learning disability combined with a mental health difficulty. There is a separate county strategy for all children and young people with mental health difficulties

The integrated and inclusive approach we are taking crosses all agency boundaries and is based on a full partnership between children and young people, their parents/carers, professionals and the voluntary sector developed during a series of conferences.

We embrace the five outcomes of Every Child Matters – Being Healthy, Staying Safe, Enjoying and Achieving, Making a Positive contribution, and Economic Well being.

We also support the Every Disabled Child Matters (EdCM) campaign.

This is the commitment sought for children with disabilities in the Edcm initiative:

Which wants...

- Families with disabled children to have ordinary lives
- Disabled children to matter as much as other children
- Disabled children and their families to be fully included in society

- All disabled children and their families to get the right services and support - no matter where they live
- Poverty among disabled children and their families to be cut by 50% by 2010 and eliminated by 2020
- An education system that meets the needs of each disabled child and enables them to reach their full potential
- Disabled children and families to shape the way that services are planned, commissioned and delivered “

Richard Hubbard Director of Children’s Services

Liz Eyre Cabinet member for Children and Young people

Paul Bates Chief Executive, Worcestershire PCT

Vision and Values:

We want Worcestershire to demonstrate that “every disabled child matters”.

To deliver this vision we recognise that children, young people, families and professionals will need to work together effectively. We all share responsibility for achieving better outcomes for children and young people and their families. Professional and parent/carer support must strengthen and empower children and young people in becoming effective and included members of the community.

The values underpinning our approach.

- **Children and Families first:**
Children, young people and their parents/carers are the experts in knowing their needs. Professionals will listen to, hear, value, respect and act on the information they provide. Professionals will support and empower them in their lives.
- **Help as soon as it is needed.**
Help should be provided in an integrated way as soon as it is needed. This can be achieved by agencies working closely together with children and young people, parents and carers, helping them to build on their strengths and offering timely support.

Early identification of need will support early intervention in meeting those identified needs
- **Inclusion**
Children and young people with disabilities and/or those with complex health needs should be full, participating members of their local communities.

Specialist services will be available when this is essential to safeguard and promote the child’s welfare and achieve positive outcomes for that child or young person
- **Involvement**
Children, young people and their families are involved in planning for service development and in monitoring how plans are progressing.

Children, young people and their parents/carers are involved in decisions affecting their lives.
- **Equality of access**
Children and young people and their parents/carers will have access to the same services wherever they live.
- **Choice**
The way we work will demonstrate that we listen to the views of children, young people and their parents/carers and offer choices in the way in which services are delivered wherever possible

- **Integration**

To succeed in this vision everyone must work together in partnership.

Professionals will be brought together into multi disciplinary teams where this will improve outcomes for children, young people and families and where it will improve quality of service.

- **Person centred approaches which respect difference.**

The views of the child or young person will shape their individual plan, the provision of services throughout childhood and in the transition into adulthood. At all times the independence of the child and young person will be promoted and they will be supported in setting and achieving their own goals.

By recognizing and valuing their different views experiences and backgrounds we can provide better services.

THESE ARE OUR KEY PRIORITIES

Being Healthy

1. Early identification and intervention are provided through a thoroughly joined up assessment for all children and young people with significant disabilities /children and young people with complex health needs under 5 years, rolling this out to all children and young people with severe and enduring disabilities/complex needs within 3 years
2. Clear pathways are in place to ensure timely support and intervention

Staying Safe

3. Children and young people are protected from bullying and hate crime
4. Children and young people with disabilities/ complex health needs are protected from significant harm
5. Children and young people have timely access to the equipment they need

Enjoying and Achieving

6. Children and young people with disabilities/ complex health needs have access to play and leisure opportunities
7. Children and young people with disabilities/ complex health needs receive the support they need to enjoy learning and achieve well within their local communities
8. Families are offered a range of appropriate family support services that are flexible and responsive to their needs

Making a Positive Contribution

9. Children, young people and their parents/carers have the information they need so that they can make informed choices
10. Children, young people and their families are actively and routinely involved in decisions that affect their lives at all ages and stages
11. Children and young people are engaged in community activities that enable them to give as well as receive support

Economic Well Being

12. Families caring for disabled children and young people/ those with complex health needs are able to access appropriate childcare
13. Young people with disabilities/ complex health needs are supported to remain living within their local community and their independence, learning needs and employment opportunities are promoted
14. Families of children and young people with disabilities/ complex health needs have accommodation appropriate to their needs.

The Worcestershire Context:

How many disabled children and young people or children and young people with complex health needs are there?

Worcestershire is home to approximately 120,000 children and young people. Nationally, it has been estimated that 3% of the child population have disabilities/have a longstanding illness. Of these, just over half have severe disabilities; the remainder mild and moderate disabilities.

Applying this estimate to Worcestershire would suggest that there are approximately 3,550 children and young people with disabilities/longstanding illness in the County. Up to 1800 could therefore have severe disabilities.

From the mapping which has taken place we know that 3% of the current school population has a Statement of Special Educational Needs (SEN). This represents 2499 children and young people, 1449 of these children and young people are educated within special schools. Not all children with Statements of SEN are disabled and not all disabled children have a Statement of Special Educational Needs. A range of SEN and specialist teaching services work with schools in Worcestershire to ensure that children and young people with SEN make appropriate progress in learning

Health data on live births suggests that 2,052 children born in Worcestershire between 1st September 1987 and 4th May 2005 have a disability.

Disability/Condition	Number
Physical	292
Learning	474
Multiple	298
Hearing	40
Vision	14
Language	261
Illness	30
Other	643
Total	2052

*NB: this data may not be fully accurate due to recording processes but it does give some information about the range of disabilities/illness.

The following national trends are also found in Worcestershire.

- More children born prematurely are surviving and it is known that such children have an increased likelihood of additional medical needs as well as the need for social and emotional support.
- There is evidence of an increase in the number of children with severe disabilities.

- Autism spectrum disorders are now more effectively recognised and there does also seem to be a real increase, although evidence on this is not conclusive.

Not all parents/carers need support from social care services. They may have good family support, support from health professionals, school, Early Years and Childcare Service SEN services or voluntary organisations. When families are finding it difficult to cope and need further support they may ask for help from the local authority Children's Services. The specialist Children with Disabilities social work teams currently work with approximately 450 children and young people with significant disabilities and complex health needs and their families.

Where we are judged by stakeholders as strong and where do we need to improve?

Children and young people and their parents/carers tell us frequently that they are very pleased with the services they receive in Worcestershire. However, not everyone is satisfied and we know that we can do better.

Our Stakeholder Conferences held in 2005 and 2006 involved a wide range of professionals, agencies and parents/carers. At the events they identified many excellent services in schools, health, social care and in the voluntary sector. Delegates also described many examples of excellent collaboration where services are working together in partnership to deliver a whole child and family approach.

Some of the examples of excellent partnership working in Worcestershire identified by professional stakeholders and parents are:-

- Neonatal hearing screening and support (Health and Education)
- CASBAT (Communication and Social Behavioural Assessment Team) – the identification of autism and early intervention (Health & Education)
- Orchard – Palliative Care Service (Health and Social Care)
- Children's Short Breaks and holiday playschemes (Health, Early Years, Schools, Social Care and Barnardo's)
- Child Development Teams (Health, Social Care and Education)
- Information – Family Information Service led by Early Years and Childcare Services: Autism packs (Health & Education); Carers pack (Children's Social Care, Adult Social care, Health and Education)

However, this is not the whole story. It was also reported that:

- some services are not available in all areas of the County
- some services are difficult to access because of where they are situated or because they have a waiting list
- the experience for young people moving on to adulthood has also presented many difficulties.

An audit of services in Worcestershire against the standards set out in the National Service Framework using the material from stakeholder events has set a baseline from which the Implementation Steering Group can measure progress.

Children with disabilities and complex health needs are very clear about what is important to them. Both locally and nationally they say they want to :-

- > Be listened to when decisions are made about their lives.
- > Have friends of the same age or who share similar experiences.
- > Do the same things as other children and young people of their age.
- > Have the opportunity to be involved in out of school activities.
- > Be safe from harassment and bullying.
- > Have control of spending money and have enough to enjoy life.
- > Live in a society where they don't face prejudice.
- > Be able to get around locally on footways or transport.

Our local consultation events in the summer of 2007 generated a wealth of feedback from children and young people aged 5 to 24 years of age. Participation and engagement workers met with groups in Worcester, Kidderminster, Malvern, Bromsgrove and Evesham.

Feedback was sought using creative play and focusing on 5 areas within the Strategy –

- Bullying
- Accessing Play and Leisure
- One worker – One Plan
- Transitions and
- Having what you need (aspirations of the children and young people)

Bullying was something of real importance and only 8 out of 19 commenting said that their school had a good Anti Bullying policy. 5 were not sure and 6 did not agree.

“Sometimes people call me dumb and daft, but I can't tell the teachers.” When asked why the young person replied, “...because no one asked me.”

Everyone agreed that they should be able to access the same activities as everyone else and it was very encouraging to hear about the range of activities being accessed – volunteering, horse riding, fishing, outings, discos, craft work, shopping, sport and a lot more!

Barriers included – friends living far away, too expensive, there aren't any, mum and dad want to do other things, transport, the cost of adaptations.

There was unanimous support for the idea of - One Worker – One Plan. The young people also had their own idea for a website with a question page so that if they posted a question a professional could get back to them with an answer.

The experience of these groups of children and young people on transitions between schools and from school to college was very positive – they said that they had had good support. (Parents and carers have a different perspective on transition to adulthood, as they are the ones having to find information and support their children)

Their dreams were as wide a range as any other young people's dreams – to be an air hostess, win a million, have chips once a week, swim with the dolphins, have more gold paper, have more sleepovers with friends, live in Spain, open a nightclub, work with reptiles ----and so on!

Other dreams expressed some of the frustration at having perhaps more limitations than some other children and young people – “I wish I could make friends at my sports club but they all go to a different school to me” “I wish I could have more weekends away and more holiday activities – my mum and dad would take me up to 20 miles” “I wish I could have a helper with transport to take me out”, “I wish I could give some money to the council to make places safer to go” (broken pavement)

There was great enthusiasm from the groups taking part in the consultation and they were very willing to continue the dialogue about their experience in the future

So where does this take us!

- ✓ We have a really good idea of what we do and how well we do it!
- ✓ We have a lot of information about what matters to children and young people and their parents and carers
- ✓ We will set out the way ahead in our Strategy and Action plan -Our Strategy follows the 5 outcomes from Every Child Matters
- ✓ Partnership between parents and carers, agencies and children and young people is vital to putting our plans into action and to making sure that they are making a difference

Our strategy:

Outcome 1: Children and young people are healthy

What is it like in Worcestershire for children and young people with disabilities and/or complex health needs?

In Worcestershire children and young people with disabilities and/or complex health needs have access to a wide range of services which promote their health and well being.

Pre birth:

A range of professionals in hospitals locally and regionally, together with community services provide support and services as well as signposting parents/carers to sources of information about their child's health needs.

Early identification and intervention

For young children with significant developmental delay or complex health needs a multi disciplinary assessment is co-ordinated through the 3 locality Child Development Teams. A pathway approach is improving access and information sharing. Following multi disciplinary assessment, appropriate treatment and therapy is arranged and regularly reviewed. However, further development is needed to ensure that parents are fully involved in planning services. The pathway is still to be embedded in practice in all three Child Development Centres.

At present we have no common tools for integrated assessment. However, the Early Support programme has been piloted and will be rolled out in Worcestershire from Spring 2008, providing a tool for effective and coordinated early intervention. The Common Assessment Framework and the Early Support Programme should make the experience of assessment and service delivery for families much more streamlined and supportive.

The Portage service provides advice to parents in the home to support them in promoting their child's development. Good links between the Child Development Centres (CDC's), Area Special Educational Needs Co-ordinators and local pre school providers support children in the transition from home to childcare settings and then into school.

Palliative care

Children with life threatening illnesses, health and emotional care needs are supported by the Orchard (palliative care) service and by Acorns Hospice Services. The Orchard nursing team has a social worker and access to psychological advice. In both services staff provide support to families in the event of a child's death. These services are excellent examples of multi disciplinary teamwork.

School health provision

Many of the health needs of children with disabilities and complex health needs in special schools are met on site through the provision of school nursing and therapies. Children and young people in mainstream school do not have such integrated provision of health services.

Sensory Impairment

Pathways are in place for the immediate provision of support to families of children who are born with sensory impairments through the integrated working of health and specialist education professionals.

Therapies

Timely access to therapists (speech and language therapists, occupational therapists and physiotherapists) can prevent painful and enduring deformities and surgery and/or the social and emotional difficulties associated with both communication difficulties and postural problems. Investment in speech and language therapy, Nursery Talk initiatives and the use of therapy assistants has led to improvements in access to Speech and language and other therapies. Equipment needs are given high priority by the Paediatric Occupational therapists. Therapists are part of the multi disciplinary child development teams in the 3 Child Development Centres. Nevertheless there are limitations as a result of the level of resources available.

Learning disability and mental health

It is well documented that children with a learning disability are more likely to develop mental health difficulties. We recognize this in Worcestershire and have developed a pathway to improve the service available to children and young people with this dual diagnosis. The pathway will ensure that they get the assessment and support they need. The Challenging Behaviour Team in North Worcestershire provides assessment, support and training aimed at promoting the positive management of children and young people by carers where there are presenting challenging behaviours associated with learning disability. The county challenging Behaviour strategy is aimed at developing a countywide service for children and adults with a learning disability.

Extended services and Children's Centres

Health services are included in the range of services being delivered through Children's Centres in Worcestershire and an inclusive approach is expected for all our Children's Centres and Extended Services in schools.

Coordination and Key workers

One of the difficulties faced by children and young people and their parents/carers is the sheer multitude of professionals whom they meet and who provide services. Improved approaches are needed to co-ordinate health care appointments. Key workers will be introduced as part of the implementation of the Early Support programme

Short breaks

For over two hundred children and young people a range of short break services provides support to children and young people and families. In Worcestershire there is an integrated and coordinated approach to the provision of short breaks across social care, health, Barnardo's short breaks, the Early Years and Childcare service. A monthly panel considers community and residential resources available to meet assessed needs bearing in mind the preferences of families. A range of options includes childminding, after school clubs, family based overnight breaks, residential overnight breaks, buddies and support workers in the community and groupwork. Mainstream and specialist holiday playschemes are also available during school holidays. In summer 2007 219 children with disabilities were supported jointly by County Council/PCT funding in accessing specialist or mainstream playschemes.

To ensure that children and young people's health is promoted all staff are trained in meeting their individual health needs and some of our provision is very specialist to meet the very complex health needs of a small group of children and young people. A County Play strategy and the work of the Early Years and Childcare Inclusion team will also ensure opportunities for access to play and leisure

Housing

Housing adaptations support the health care of those children with the most severe physical disabilities and also provide a suitable environment for parents/ carers. Work is in progress to develop a more consistent approach across our 6 District councils.

Transition

Transition to adulthood is one of the most worrying times for children and young people and their parents/carers. In Worcestershire we have been making it a priority for development in the past 2-3 years. We have dedicated Transition social workers in Adult and Community Learning Disability and Physical Disability services with protocols in place between Adult and Children's Services. These staff work in partnership with schools, Connexions, Learning Skills Council and education services to support a planned and person centred approach. The use of the "Transition Pathway" is being supported in schools by the Transition Coordinator, following its launch in 2006. Our Valuing People Board also has a Transition sub group with a young people's group and a meeting of young people with professionals. A young adult is joint chairperson. Young people in transition are a priority group for the development of a Health Action Plan within the Adult Learning Disability Services.

Our priorities for change:

1. Early identification and intervention are provided through a thoroughly joined up assessment for all children and young people with significant disabilities/ complex health needs under 5 years, rolling this out to all children and young people with severe and enduring disabilities/complex needs within 3 years

Improvements we want to achieve

- Increased use of Early Support programme
- Key worker for children and young people with the most severe disabilities / complex health needs under 5 years
- Single joined up assessment and one Family Service plan for children with severe disability / complex health needs

2. Clear pathways are in place to ensure timely support and intervention

Improvements we want to make

- All Child Development Centres have a consistent Pathway approach
- Reduction in waiting times for therapies and mental health services
- Services are delivered in the child and young person's local community wherever possible
- Medical appointments to be streamlined wherever possible

- Learning Disability pathways are fully implemented across the county
- Transition to adulthood is experienced as seamless for children with severe disabilities and complex health needs

Both 1) and 2) can be helped by new ways of working as well as by additional resources identified as necessary.

Outcome 2: Children and young people are safe

What is it like in Worcestershire for children and young people with disabilities and/or complex health needs?

All children and young people need security and stability and to live in a safe and caring environment.

For parents/carers this can sometimes mean anxiety about trusting others with the complex needs of their children. However, this very complexity can lead to extra stresses and pressures which mean that taking a break from caring is very important. It is therefore a priority for agencies in Worcestershire that staff are skilled in the care they provide – in schools, in care settings for children Looked After and in short breaks provision. Child protection training, moving and handling training, anti bullying training are all important foundation courses for staff. All staff in `services which provide for health care needs are trained in meeting those needs appropriately.

Because of their dependency on adults, children with disabilities are vulnerable to abuse. In recognition of this the Worcestershire Safeguarding Board provides specific courses relating to child abuse and disability.

A small number of young people with a learning disability have difficulty managing sexually or have such challenging behavior that they present risks to other children.

Staff in schools and residential units are regularly trained in managing challenging behaviour by designated local authority trainers using nationally accredited programmes.

Housing adaptations for children with the most severe disabilities support safe care in the home. Appropriate lifting/hoisting and other equipment is available to meet the assessed needs of children who need these items in schools, at home, in care or short breaks settings. This promotes positive outcomes for children and young people and their parents/ carers.

All playworkers supporting children and young people in the holiday playschemes arranged by the council have received training in child protection, moving and handling. Feedback from children and young people using specialist schemes tells us that they feel happy and safe.

Children and young people who are disabled and/or have complex health needs report both bullying in school and “Hate Crime” in the community. The County has an anti bullying policy and so does every school, along with systems to consult children and young people on its effectiveness. Speak Easy, a self advocacy organisation for people with learning disabilities, is taking its awareness raising programme on “Hate crime” to schools in Worcestershire. District Councils are starting to adopt Hate Crime protocols using a Partnership approach.

Our priorities for change:

3. Children and young people are protected from bullying and hate crime.

Improvements we want to achieve:

- People are aware of how damaging these are and what they can do to help.
- Anti bullying policies in schools and settings are regularly reviewed to ensure their effectiveness.
- Support is provided to those who are affected by bullying or hate crime

4. Children and young people with disabilities/ complex health needs are protected from significant harm.

Improvements we want to achieve:

- All adults working with children and young people in a voluntary capacity are trained in child protection.
- Children and young people have access to support when they have been abused.
- Support is available to young people with a learning disability who have difficulty managing their sexuality and as a result are vulnerable to abuse or present risks to other children.

5. Children and young people have timely access to the equipment they need.

Improvements we want to achieve:

- An integrated approach to providing equipment is commissioned between the local authority and the primary care trust in conjunction with the Integrated County Equipment Service

Outcome 3: Children and young people enjoy and achieve

What is it like in Worcestershire for children and young people with disabilities and/or complex health needs?

All children and young people thrive on achievement and fun.

The families of children and young people who are disabled and/or have complex health needs and the children and young people themselves tell us that it can be really difficult to find places to go. For example, many people do not understand the behaviours of children and young people with a severe learning disability.

Although every building is required to comply with Disability legislation, access to some buildings and provision for those with mobility difficulties can be a problem.

More opportunities are being made available to support the inclusion of children with disabilities and/or complex health needs in mainstream provision at after school and holiday clubs. Specialist playschemes are also available provided by the voluntary sector, schools and funding from health and local authority Children's Services. Children's Fund grants have also enabled the development of increased play opportunities for children with disabilities. In addition, District Councils are part of a new County Strategy for play which will be fully inclusive in its approach.

Within the Youth Service some pioneering work has taken place in Wyre Forest developing opportunities for young people with learning disabilities to access youth club facilities and a local nightclub. The use of the Transition Pathway with young people in schools is supporting Person Centred Planning and promoting their independence.

Fun is also something which is very important to the experience of children and young people in their short breaks – whether it be going out into the community with a buddy or befriender, staying with a foster carer, attending a youth club or staying at one of our four short break units.

Worcestershire Children's Services has a range of special schools and specialist resources within mainstream school settings to offer choice and equality of access for children and young people with disabilities. Nurture groups, Nursery Plus, Autism Resource centres, Language Units, Communication centres and Learning Resource centres are just some of the specialist resources available. Outreach teams for children and young people with physical disabilities, based in 2 Special schools, work with mainstream schools to support appropriate achievement and access. Specialist teachers for those with sensory impairments, autism and communication difficulties, as well as those with medical needs provide the individual assistance and/or equipment children and young people need. Specialist staff train others in order to promote positive outcomes for children and young people.

Whether in mainstream school or in specialist resources the emphasis is always on supporting children and young people to achieve to the best of their ability, to try out new things and to have fun.

Finally, transition planning, especially when the Transition Pathway is used, supports the likelihood of young people accessing the opportunities, which are available in further, and higher education, employment opportunities and an adult life which promotes independence and enjoyment.

Our priorities for change:-

6. Children and young people with disabilities and/or complex health needs have access to play and leisure activities appropriate to their ages/needs.

Improvements we want to achieve:

- Children and young people are able to access mainstream play and leisure opportunities when this is their choice.
- Parents and carers are supported in accessing a range of short break opportunities.
- Footpaths and public transport are accessible to wheelchairs.

7. Children and young people with disabilities and/or complex health needs receive the support they need to enjoy learning and achieve well within their local communities.

Improvements we want to achieve:

- The consistent provision of very good facilities for children and young people with disabilities/complex health needs through the implementation of the Special Educational Needs (SEN) Strategy in Worcestershire.
- Young people are fully involved in their Transition planning through the use of tools such as the Transition Pathway and Autism Pathway

8. Families are offered a range of appropriate family support services that are flexible and responsive to their needs.

Improvements we want to achieve:

- Support to siblings of children with disabilities and complex health needs.
- Creative use of direct payments to meet the assessed needs of children with severe and enduring disabilities.
- Access to support locally through Children's Centres and Extended services in schools as well as from specialist workers.

Outcome 4: Children and young people make a positive contribution.

What is it like in Worcestershire for children and young people with disabilities and/or complex health needs?

Children and young people with disabilities and/or complex health needs in Worcestershire are making a challenging and positive contribution to the agenda for change in the County.

The Child's Voice initiative has supported many in expressing their views, their experiences and their wishes to an audience of agency representatives and professionals whose work brings them into contact with children and young people who have additional needs. During conferences their voices have challenged and moved us and confirmed for us how much we need to have our stereotypes confronted and how valuable it is to know what is in their minds.

Many schools now have a School Council which supports children and young people in giving their views; this includes children with physical and/or learning disabilities. The views of children with a Statement of Special Educational Needs are included in their annual review. Schools are also encouraged to involve children, as appropriate, in meetings and discussions with parents and professionals.

Children who use communication in other forms than spoken language are supported by appropriate means of communication aids and equipment.

The views of children and young people who are Looked After are sought as part of their statutory review process and they are supported in attending their review, whenever possible, to be involved in decision making.

Worcestershire Youth Cabinet is making sure that the views of children and young people with disabilities and/or complex health needs are heard and taken into account.

Information about the choices available to children and young people and their families is improving through such means as SCROLL newsletter and handbook, Family Services Directory (Family Information Service), Carers pack, Autism pack (West Midlands Regional SEN Partnership), Branching Out pack (Young people with a learning disability), County Short Breaks leaflet (NHS Barnardo's and Worcestershire County Council), Integrated Service Specialist support service (ISSS) PCT, Parent Partnership, Connexions and other service leaflets and websites. The Contact a Family website is a national website which everyone can access for information. (www.cafamily.org.uk)

Our priorities for change:-

9. Children and young people and their parents/carers have the information they need so that they can make informed choices.

Improvements we want to achieve

- Comprehensive information is available through the Family Service Directory.
- Information is accessible and available in a range of suitable formats and venues.
- SCROLL (Special Children's Roll) is integrated within the Family Information service to promote the effective provision of information to families.
- Parents of children 0-5 years are provided with materials from the Early Support Programme, appropriate to their needs.

12. Children, young people and their families are actively and routinely involved in making decisions that affect their lives at all ages and stages.

Improvements we want to achieve

- Children and young people with disabilities and complex health needs are routinely involved in, and supported in contributing their views to decisions and plans which affect their lives, especially at key points of transition, using a range of appropriate aids to communication where required.
- Children, young people and their families are involved in the planning and monitoring of the services we deliver.

11. Children and young people are engaged in community activities that enable them to give as well as receive support.

Outcome 5: Children and young people benefit from economic well being:

What is it like in Worcestershire for children and young people with disabilities and/or complex health needs?

Families with disabled children face additional costs and reduced income through barriers to work for parents. Additional costs range from more nappies a day than are available from services, to transport, to the purchase of chosen specialist therapies.

Although benefits are available many families find that they do not cover all costs.

When families struggle to access work their income relies on benefits. The major barrier to work for parents is access to appropriate childcare. Worcestershire Early Years and Childcare Inclusion service is promoting and developing inclusive childcare services with considerable success. Attached Kidz workers are proactively linking with parents and carers to make sure they have the information they need about services.

Obtaining suitable housing can be a challenge for some families. In Worcestershire local District Councils are working together to develop a consistent approach to the provision of adaptations. Information about suitable properties is sometimes shared across District Housing areas.

Advice on benefits and concessions is available through the local Community Hubs in Worcestershire, through Citizens Advice Bureau, the Family Services Directory. The CAF (Contact a Family) Directory is held by key professionals and accessible via the internet.

Nationally it has been found that disabled young adults are four times more likely to be unemployed or voluntarily out of work than non disabled children at age 26 years, and twice as likely not to be in education, employment or training (NEET) than their non disabled peers.

Schools and colleges in Worcestershire offer appropriately supported work experience and vocational training to young people with disabilities and actively promote employment tasters and access to college prior to children leaving school.

The adoption of the Transition Pathway in Worcestershire schools and in Adult and Children's Services will support improved planning for young people in all aspects of their future life as an adult, including where they live, training and employment opportunities, relationships, health, leisure, income and travel. Its use will support choice and support independence for young people.

The Connexions Service supports and advises young people with disabilities in planning for future employment and training.

Opportunities for supported living for young adults with a learning disability are improving and this promotes their independence.

Further Education/Higher Education (FE/HE) team within Children's Services acts for the Learning Skills Council in supporting the inclusion of young people with sensory impairments and autism into Further and Higher Education. The strategy for learners 14-19 years is inclusive of disabled young people and the related Learning group specifically focuses on provision for young people aged 13-25 years with a range of disabilities.

Priorities for change:-

12. Families caring for children and young people with disabilities /complex health needs are able to access appropriate childcare.

Improvements we want to achieve.

- Increase the numbers of child care settings in which staff are trained and skilled to care for children and young people with additional needs.

13. Young people with disabilities/complex health needs are supported to remain living within their local community and their independence, learning needs and employment opportunities are promoted.

Improvements we want to achieve

- Increase the number of young adults accessing supported living and supported places in employment and training.
- Increase the number of young adults using Direct Payments to promote their independence.

14. Families of children with disabilities/complex health needs have accommodation appropriate to their needs.

- A consistent approach to adaptations across Worcestershire
- A register of adapted properties in the county

Our Action Plan sets out details of how we will achieve all of these improvements.

How this Strategy fits with other Plans:

The overarching plan for children and young people is the “Worcestershire Children and Young People’s Plan”.

This strategy is one of the range of multi agency plans established as priority within the above plan.

The plans listed below all make reference to the needs of children with disabilities/complex health needs: -

- Extended Services in schools.
- Children’s Centre strategy
- CAMH Strategy (Child and Adolescent Mental Health)

- Safeguarding Children Plan
- 14 – 19 Strategy
- Connexions Plan
- Learning Skill Council Plans
- School Development Plan
- SEN Strategy
- Play Strategy
- Integrated Working Programme (Common Assessment Framework and Information Sharing).

How we will take the plan forward:

In order to improve outcomes for children and young people with disabilities and complex health needs we will:-

- Bring together champions for change from families and agencies as an Implementation Steering Group to make sure that we deliver our strategy.
- Advocate for children and young people and ensure that they can contribute to this group.
- Provide governance for the strategy through the Children and Young People's partnership
- Consult with Worcestershire Parent/Carers Council and other local groups.
- Continue to consult with Children and Young People.
- Take a Joint commissioning approach to service development. This means we will base development on our analysis and review of needs and resources, building on the work we have done so far with stakeholders and inviting agencies to share and pool resources wherever this will provide more effective services for children and young people.
- Develop our workforce through increased opportunities for multi agency training and other development opportunities.
- Define clear pathways for assessment and access to services, promoting joint assessment and so avoiding duplication so that service users tell their story only once.
- Bring together multi disciplinary teams in localities where our needs analysis and commissioning indicate that this will help us to achieve better outcomes

How the strategy meets the national agenda:

Valuing People: a new strategy for Learning Disability for the 21st Century 2001 DoH

Valuing people was the first white paper for people with Learning Disabilities for 30 years. It includes both children and their families and adults and is based on people having:-

- Their rights as citizens

- Inclusion in local communities
- Choice in daily life.
- Real chances to be independent, smooth transitions, family support, accessible childcare, early identification and intervention, holistic approaches, multi agencies, are all included in the document.

Together From the Start (DfES DoH 2003) paved the way to an integrated approach to early identification of needs and early intervention for disabled children. In Worcestershire our Child Development teams are working to support the implementation of a holistic pathway for children who receive a service from the multi disciplinary teams working together in localities.

Since it was introduced in 2003 the Toolkit of the Early Support Programme has also supported an integrated approach to meeting the needs of disabled children under 5 and their families, putting parents in the driving seat and promoting the use of key workers to co-ordinate the many professionals and services involved with children who have significant disabilities and/or health care needs.

We have raised awareness of the tools through a series of multi agency conferences culminating in larger events which attracted nearly 300 participants in February 2007. We are now putting into place a training programme for trainers followed by implementation of the Early Support programme in Worcestershire.

The Children Act (2004), has resulted in an ambitious and far reaching “Change for Children” agenda. All agencies are required to work towards the following 5 shared outcomes for all children and young people:-

- Being Healthy
- Staying Safe
- Enjoying and Achieving
- Making a positive contribution
- Achieving economic well being

Key services are also required to integrate around the needs of children and young people; being child and family centred rather than being limited by agency boundaries. Our strategy embraces this outcomes approach and its values reflect those of the “Change for Children” agenda

The Children Act 2004 also requests that consideration should be given to the use of Section 10 arrangements with health and partner agencies and to pooled budgets. Service development must involve children, young people and their families, as must monitoring and evaluation. Extended schools and services and Children’s Centre developments must be inclusive of the needs of disabled children and young people and their families.

All of these are important in Worcestershire’s proposals for service development across all sectors of Children’s services and through partnership arrangements.

From 2004 onwards there have been a large number of Government publications relating specifically to special needs and disabilities including :-

The National Service Framework (NSF) for Children and Young People and Maternity Services (2004) devotes a whole volume of its standards to disabled children and young people and those with complex health needs.

The 10 year programme sets a standard that “children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family centred services which are based on assessed needs, which promote social inclusion, and, where possible, which enable them and their families to live ordinary lives”. In Worcestershire we have undertaken a self audit against the Standards and will review the findings. Identified areas for development will be priorities within our action plan.

SEN (Special Education Needs) Strategy – **Removing Barriers to Achievement (DfES 2004)** – set out the Government’s long term vision for improving outcomes for children and young people with SEN. Worcestershire’s SEN Strategy and school development programme will build up the range of services to support children’s achievement, will improve the facilities for special schools and will support the inclusion of children and young people with identified additional needs, including those arising from disabilities or complex health needs. Children and young people as well as professional stakeholders and parents have been involved in visioning events.

Improving the life chances of disabled people (Prime Ministers Strategy unit 2005) sets the challenging goal of achieving substantial equality for disabled people by 2025. In relation to children and young people it focuses on improved early support for families with young disabled children and facilitating a smooth transition to adulthood. In Worcestershire we are actively promoting equality and providing the opportunity for more awareness raising of disability issues. The County is also looking to provide work opportunities for disabled people. Following a pilot scheme in special schools we are now extending the use of the Transition pathway in schools. The Pathway supports a person centred approach to transition planning with young people. A transition pack called “Branching out” is also available to young people with a learning disability. Transition social workers and Connexions personal advisers are actively involved in planning for adult support, further and higher education and services.

The Childcare Act (2006) places new duties on the council to secure sufficient child care places for children up to 14 (18 for disabled children) and to ensure parents have access to a full range of information. In Worcestershire the Early Years and Childcare service has set targets to improve the number of childcare places available for disabled children. The Children’s Information service holds information on services for disabled children and their families. The Children with Disabilities Register SCROLL coordinator is based within the service.

Aiming High for Disabled Children: Better Support for Families May 2007 HM Treasury/DCSF:

This report follows a policy review of children and young people established in 2006 and with the purpose of informing the Government's Spending Review. It focuses on raising the life chances and improving outcomes for disabled children in three priority areas: -

- Access and empowerment
- Responsive sessions and timely support
- Improving quality and capacity.

To support delivery of improvements a total of £340 million has been promised for the period 2008-2011. Key areas for funding to local authorities and PCT's are Short Breaks, Transition, Accessible Childcare, Community Equipment and Wheelchair Provision, Workforce Development and the development of parent carer forums

Worcestershire has expressed an interest in being a pilot authority for short breaks development.

I just want to feel normal, not different.

The support at my first school was very good, except that I couldn't go out on trips. I couldn't go unless my Mum came. I didn't want my Mum to come - no one else had their Mum or Dad there.

It's very different here - I have friends - they understand what's the matter with me. If I was at any other school I'd feel left out. Sometimes people can't understand what I say so I type it and people can read it and hear it.

He came here for work experience and he was so good we kept him on. He is part of the team. At first he was very quiet but not now.

We did a survey of local shops - you couldn't get around the whole shop. Sometimes the toilets were horrible and there wasn't always a counter. Staff didn't acknowledge you or anything.

1. Early identification and intervention are provided through a thoroughly joined up assessment for all disabled children/children with complex health needs under 5 years, rolling this out to all children with severe and enduring disabilities/complex needs within 3 years.
2. Clear pathways are in place to ensure timely support and intervention.

3. Children and young people are protected from bullying and hate crime.
4. Children and young people with disabilities/complex health needs are protected from significant harm.
5. Children and young people have timely access to the equipment they need.

6. Children and young people with disabilities/complex health needs have access to play and leisure opportunities.
7. Children and young people with disabilities/complex health needs receive the support they need to enjoy learning and achieve well within their local communities.
8. Families are offered a range of appropriate family support services that are flexible and responsive to their needs.

9. Children, young people and their families have the information they need so that they can make informed choices.
10. Children, young people and their families are actively and routinely involved in decisions that affect their lives at all ages and stages.
11. Children and young people are engaged in community activities that enable them to give as well as receive support.

12. Families caring for children with disabilities/complex health needs are able to access appropriate childcare.
13. Young people with disabilities/complex health needs are supported to remain living within their local community and their independence, learning needs and employment opportunities are promoted.
14. Families of children with disabilities/complex health needs have accommodation appropriate to their needs.

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