EVERY DISABLED CHILD MATTERS:

Charter promoted by the Council for Disabled Children

RBWM's preliminary assessment, January 2008



Introduction

The Council for Disabled Children, in conjunction with Contact a Family, Mencap and the Special Education Consortium, has opened a campaign to 'challenge politicians and policy-makers to make good on the Government's commitment that every child matters'. Local Authorities and Primary Care Trusts are invited to sign a Charter containing nine maxims affirming practical commitment to strategic planning of provision of services for disabled children. In return the Campaign offers practical support.

This paper is written at the request of the Overview and Scrutiny Panel. It is a initial assessment of the Royal Borough's progress towards the nine maxims.

The title of the Campaign is presumably drawn from the Government's initiative *Every Child Matters: Change for Children*. Stemming from a green paper with this title in 2003, far-reaching changes have been made in the legislative provisions for vulnerable children.² Many of the principles contained within the maxims exist as recommendations in various other places and in governmental guidance on the implementation of the *Every Child Matters* agenda.³

The focus of the Charter is upon disabled children. The meaning of the word 'disability' in this context is considered in Appendix 1. However, children excluded from school are also considered as a part of the Charter even though they may not have a disability. Many of the principles of the Charter apply to other vulnerable children; the local authority may consider it appropriate for these maxims to be extended to include a more comprehensive range of children with needs. For example, the Minister for Children, Young People and Families has recently written to local authorities reminding them, amongst other things, of the importance of strengthening 'the

² Related publications will be found at http://www.everychildmatters.gov.uk/publications/

¹ Its website will be found at http://www.edcm.org.uk

³ For example, in *Joint planning and commissioning framework for children, young people and maternity services*, Department for Education and Skills and Department of Health, 2006. In connection with the development of Children's Trusts, emphasis is placed here on the use of data to inform planning, followed by user participation in planning, commissioning and evaluating services.

⁴ A National Parent Partnership Network is run by the Council for Disabled Children, details of which will be found at http://www.parentpartnership.org.uk

influence of vulnerable young people and their families and communities and their ability to create positive change'. This is very much in the spirit of the maxims below.

Overview and general recommendations

The maxims are topical and practical. They form a summary of some of the principal features first put forward in the Every Child Matters green paper of 2003, mentioning such matters as improved information sharing, the introduction of a lead professional (or 'Keyworker'), and working in multi-disciplinary teams. Some were mentioned as desirable by RBWM parents of children with special educational needs at a Saturday conference in 2005, You Talk, We Listen. The May 2007 government publication Aiming high for disabled children: better support for families also takes up a number of these principles, stressing amongst other things the importance of engagement and participation by service users in service planning, and the importance of responsive and timely support. In short, these are all arrangements and services expected of local authorities by central government.

In the Royal Borough, a mixed picture emerges. On the one hand, many of the activities called for in the nine maxims are already happening to varying extents. On the other hand, with the notable exception of the arrangements for promoting principles of equality, there could be improvements in the coordination and consistency across the Royal Borough. Amongst issues that emerge are the following:

- 1. It would be helpful to have more far-reaching analysis of data from a range of sources about pre-school children with disabilities. (This is already touched upon as one of the recommendations arising from the 2007 Annual Performance Assessment).
- 2. Every excluded pupil would benefit from a Keyworker.
- 3. Parents' forums are not at present very representative.
- The involvement of children in planning, commissioning and monitoring is promising but should be more far-reaching to specifically include children with disabilities.

RBWM performance against individual maxims is discussed below, but three themes emerge as deserving of more immediate attention. In this respect it is recommended that:

⁶ As summarised, for instance, in *Every child matters: a summary*, Department for Education and Skills. 2003

⁵ Letter dated December 2007 from Beverley Hughes, Minister for Children, Young People and Families to Jim Gould, RBWM Corporate Director of Learning and Care

⁷ Aiming high for disabled children: better support for families, HM Treasury and Department for Education and Skills, May 2007. (Hereafter Aiming High.)

- 1. a working group be commissioned to plan a Keyworker Service for children with disabilities and also for children excluded from school
- consideration be given to the bringing together into a single body of knowledge, technical practice and expertise in the form of written policies and information. This is to provide consistency in the provision of
 - a. written information for parents, professional persons and the general public, whether on the website or in booklets or leaflets
 - b. information and advice disseminated in writing and by word of mouth by Keyworkers and other employees of the Royal Borough in individual cases
- as a matter for policy there should be representative involvement of young people in the planning, commissioning and monitoring of services.

The nine maxims are listed below in bold type.

1. We know how many disabled children live in our area and that all agencies in our area are planning services on the basis of this knowledge

Youngsters with disabilities will be known to the Primary Care Trust from birth, or from diagnosis of a disability. This information will usually be passed to RBWM social care staff as necessary. Sensory Impairments are reported immediately to the [pan-Berkshire] Sensory Care Consortium, which is hosted by RBWM. Pre-school multi-disciplinary meetings ensure that educational needs are discussed at an early stage, and where necessary referrals for statutory assessments under the Education Act 1996 are made. These meetings consider information supplied by the PCT.

However, it is unclear at present exactly how many disabled children live within RBWM. We can be confident that nearly all disabled children are all known to at least one service or school, but it is not possible at present to cross-reference names from a common database.

RBWM already makes use of several databases. The education arm of the Learning and Care Directorate make use of One (formerly Education Management Services). This contains school information about each child in the authority's schools. Information collected by the Early Years and Child Care Service is recorded to assist in assessing requirements for nursery funding.

In social care, the system PARIS is used for case recording and, referrals; parents give consent for its use with their child. A Disabled Children's Register exists, containing such information as the name of the worker, disabilities and diagnoses, and difficulties within the family etc. This interprets 'disabilities' in the same way as the PCT. However, it is a voluntary register, depending upon

being given by parents. Paper files contain records of all work undertaken by social care.

Connexions makes use of a database listing all children in secondary schools.

It is clear that many children at School Action Plus of the SEN Code of Practice will have a disability. School Action Plus is the name given to the level of support offered by a school with assistance from outside agencies such as the Educational Psychology Service, but stopping short of a statement of special educational need.⁸ Many of these children will not be known to other services, and it may be felt desirable to include these pupils in the reckoning. A survey undertaken at the end of December 2007 disclosed at least 518 children in the authority's schools at School Action Plus.

In addition, we know that some 12.5% of the total number of residents of all ages of the Borough declare themselves as having a 'limiting long-term illness, health problem or disability'.9

The picture described here almost certainly mirrors the national picture. This is acknowledged in *Aiming high*, where central government affirms that it will look to local authorities and PCTs jointly to collect data on the number of disabled children in their area for planning and service provision.¹⁰

As part of the Every Child Matters agenda, central government is developing a national database, called ContactPoint. This will contain general information about every child in the country to enable authorised users to ascertain which professional persons have had professional involvement with the child. This is expected to be available to RBWM in April 2009, and colleagues in the Workforce Development Team are currently looking into its implementation. However, it is unclear whether this will allow counting of numbers of children with disabilities to help ascertain overall demand for services.¹¹

It is recommended that as the proposals for ContactPoint become clearer, a working group be set up to determine how best to glean the necessary information from it for planning services.

2. There is a key worker service in our authority providing support to families who are accessing more than one specialist service

The word "Keyworker" in this context means a professional person to coordinate the work done for or on behalf of the individual child with a disability. This must be a person with the requisite general and specialist

⁸ Special Educational Needs Code of Practice, Department for Education and Skills, November 2001, p.37 and elsewhere

⁹ Reported in *Community Partnership: Comprehensive Equality Policy, December 2006 to December 2009*, RBWM, November 2006, p.4. (Hereafter *Comprehensive Equality Policy.*)

¹⁰ Aiming high, pp. 29-30

¹¹ Information about ContactPoint is at the website

http://www.everychildmatters.gov.uk/deliveringservices/contactpoint/

¹² This role may be described as that of a 'lead professional'. Such a role is described elsewhere as 'a person responsible for co-ordinating the actions identified in the assessment

knowledge, and with the status to require services to be provided or tasks to be done. This person will be the principal point of contact between the family and the authority, and it must be that person's job to maintain and ease the relationship between the two. The term 'authority' here should be taken to include the Primary Care Trust. The Keyworker might be taken from any of various professions providing the Team Around the Child: social care, the school (including Early Years Support Teachers), health, Portage and so forth.

In practice, such work is already done unofficially by many persons involved with families. For instance, members of the Children with Disabilities Team, the Special Educational Needs Team, various health practitioners, and members of the Early Years and Child Care Service, to name just a few, will immediately recognise the role. Even so, parents are still required to 'tell their stories' many times, and the person offering advice does not have the authority to coordinate matters in an official way. Without a comprehensive body of knowledge on which to draw, differing messages can be given by various people, speaking more as a representative of their own service rather than as a Keyworker of the authority.

Angela Waterfall (Senior Educational Psychologist) has prepared a valuable report on a feasibility study into the benefits of a Keyworking Service in RBWM. Though confined to a small number of pre-school children, its findings are likely to be more widely applicable. In particular, she recommends that such a Service should be offered in all cases where a child has complex needs: that such a Service could be built from existing arrangements and frameworks; that the Service should be available all the year round; and that sufficient administrative support should exist for the Service. 13

One of the recommendations of the 2007 Annual Performance Assessment is that 'the Council and its partners should ensure that all assessed children with learning difficulties and disabilities have multi-agency care plans and an identified key worker co-ordinating their care'. The Children and Young People's Plan includes a commitment to a 'co-ordinated multi-agency approach' with regard to Early Intervention, and this is a principle that might also be built upon.¹⁴ In the light of the above, it is recommended that relevant advice and guidance be brought together and that a Keyworker Service be established. Children without disabilities excluded from school would also benefit from such a co-ordinated approach, as discussed below.

process and being a single point of contact for children with additional needs being supported by more than one practitioner'. (Common Assessment Framework for Children and Young People: Managers' Guide, Children's Workforce Development Council, 2006, p. 6.) ¹³ Educational Psychology Service, RBWM, The Family Support Keyworker in the Royal Borough of Windsor & Maidenhead, internal report, RBWM, [December 2007], pp.19-20 ¹⁴ Royal Borough of Windsor & Maidenhead Children and Young People's Strategic Partnership, Children & Young People's Plan 2006-8, RBWM, 2006, p.20. (Hereafter C&YPP Plan.)

3. Our parent partnership service is sufficiently resourced to provide advice, information and support to parents of disabled children and young people who have been excluded from school

Independent Parent Partnership Services are a legislative requirement upon local authorities. RBWM's Service consists of an officer who works term-time only, together with a small amount of administrative support: the total full-time equivalent establishment is 0.98 of a person. It is a service currently focused almost exclusively on special educational needs. Information about the Service is routinely sent to parents of children undergoing statutory assessments and at other times; it is also publicised in schools and elsewhere. It is unlikely that the Service as currently set up would be able to cope with any significantly increased workload arising from offering advice or advocacy for excluded pupils.

In practice, excluded pupils – whether deemed to have disabilities or not – and their families require two overlapping kinds of guidance or assistance. First, they require practical help in finding other schools and managing the time that the pupil is out of school. Second, they require advice as to their legal rights and sometimes advocacy in support. There are times when it is better for the two sources of advice to be separate, though in practice there can be much overlap. The first kind of advice is currently given by Area Teams or by the Special Educational Needs Department, and sometimes with the assistance of colleagues from social care. For the second kind of advice, parents are often referred to independent organisations such as the Advisory Centre for Education.¹⁵

It is recommended that the proposed Keyworking service should extend to children excluded from school for the first kind of advice mentioned above. Consideration might be given to establishing a more formal connection with a suitable independent organisation for the second kind of advice, such as the Advisory Centre for Education, the Council for Disabled Children, or even an individual arrangement with the Citizens' Advice Bureau.

4. Parents and cares in our area are getting accurate and timely information and advice on the full range of services available to them and their families

A wide range of information is available to parents and others, including , leaflets and booklets and websites. These tend to be specific to the individual service, and so may require to some extent prior knowledge of the existence and contact details of the particular service.

Mention should be made of three particularly successful multi-disciplinary sources of information in RBWM: *Signposts*, the Transition Information Pack and the web-based Children's Information Service.

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¹⁵ http://www.ace-ed.org.uk/

Signposts is published by the social care arm of RBWM Children's Services and lists various bodies and sources of information. It is currently being revised and reprinted.

The Transition Information Pack is a joint publication by Connexions Berkshire and the social care arm of RBWM Children's Services, and provides 'information for young persons with learning disabilities or additional needs and their families to help plan for the transition from school into adult life'. This is a wide-ranging and helpful publication.¹⁶

The Children's Information Service was originally set up at Windsor Library and managed by the Library Service. It is now managed by the Early Years and Childcare Service, and is based at Ellington School in Maidenhead. A new manager is due to start in January 2008. It is a service for parents and carers of children aged between 0 and 14, or 16 for children with special educational needs. Its details are available on the RBWM website. It covers a range of information, touching upon childcare, education, family help and support groups, and local activities and events. It expects to be able to offer advice by way of discussion and consultation with parents.¹⁷ The Children's Service Directory appears to be a web-based version of the same service: this is confusing and the two services should be amalgamated.¹⁸

In practice it falls to many individual practitioners to provide some advice to parents. As mentioned above, this can be akin to Keyworking advice. There is concern that this is overdependent at present on individual expertise, who may themselves have to acquire the necessary knowledge in a piecemeal fashion. Unsurprisingly, instances exist of conflicting or inaccurate advice having been given, however well-meant.

It is recommended that that in tandem with the Keyworking Service, the information given by the Children's Information Service should be based upon a single systematic and consistent written body of knowledge. This should in turn provide not only the basis of training for Keyworkers, but familiarity with and use of it should also be a requirement for all professional practitioners employed by RBWM. In addition, as mentioned above, for the sake of clarity, the Children's Information Service and the Children's Service Directory should be amalgamated.

 $^{^{\}rm 16}$ Transition Information Pack, RBWM Learning Disability Partnership Board in conjunction with the Connexions Service, October 2005

¹⁷ http://www.rbwm.gov.uk/web/cis.htm

¹⁸ http://www.rbwwm.gov.uk/search/csd

5. All staff have received both disability equality training and training to ensure that they have the core competencies to work with disabled children; relevant staff have received specialist training and other staff know how to contact them for information

The Disability Discrimination Act. (1995) was amended in 2005 by a new Disability Discrimination Act. Amongst other things, the 2005 Act placed a duty upon public authorities to eliminate discrimination and to promote equality of opportunity between disabled persons and other persons. The authority's Comprehensive Equality Policy commits the authority to highlighting and eliminating hidden discrimination and promoting equality of opportunity in everything that it does'. All members of staff are required to take part in Diversity and Equality training, and it forms a part of the authority's induction scheme. Emphasis is placed upon the use of Equality Impact Assessments to aid this, and existing members of staff have been required to attend training in the use of Equality Impact Assessments. Arrangements for monitoring the Policy, contained in a detailed Outcome Improvement Plan, include assessing the effectiveness of such plans.

Service-specific needs are covered in specialist training as necessary. Training may be conducted by RBWM staff or others as necessary. For instance, RBWM social care has recently contracted with a range of providers, including MENCAP to provide such training. In addition, social care expects its providers of care to have the necessary awareness of discrimination matters.²²

The wide-ranging nature of the *Comprehensive Equality Policy* makes it unnecessary to make any recommendations in connection with this maxim.

6. Disabled children are involved in drawing up our Disability Equality Scheme and also in monitoring its effectiveness in eliminating discrimination

Public authorities are under a duty to make a Disability Equality Scheme. This authority's Scheme and monitoring arrangements are contained within RBWM's *Comprehensive Equality Policy*.²³ The Scheme and Action Plan were considered by the authority's Access Advisory Forum, and by others within the Community Partnership. However, it appears that disabled children were not involved at this stage. The Action Plan nonetheless touches upon several important matters in improving services for disabled children: for instance, amongst the items to be monitored is the improvement in the educational opportunities and attainments of disabled pupils and students.²⁴

²¹ Comprehensive Equality Policy Outcome Improvement Plan, item no 4

¹⁹ Disability Discrimination Act 1995, s.2

²⁰ Comprehensive Equality Policy, p.6

²² Such things are also monitored by way of the *Comprehensive Equality Policy Outcome Improvement* Plan, item no. 16

²³ Comprehensive Equality Policy, pp.10-13

²⁴ Comprehensive Equality Policy Outcome Improvement Plan, item no. 13

In addition, the Scheme recognises the work of the Children's Services Accessibility Strategy, aiming to increase the accessibility of schools, including pupil referral units and nurseries, to disabled children and adults.²⁵

We note that the Plan for monitoring of the Scheme already includes wide consultation. It is therefore recommended that that consideration be given as to how to extend this specifically to include children's views.

7. Our Children and Young People's Plan explains how we will provide specialist services and also make all universal services including extended schools and children's centres accessible to disabled children

The local authority's current Children and Young People's Plan is a wide-ranging document, prepared by a number of different organisations. It was prepared under the auspices of the Children and Young People's Strategic Partnership. It was signed not only by the then Leader of the Council and the Chief Executive, but also by leaders of the then local Primary Care Trust, Berkshire Connexions, Family Friends (a voluntary organisation), Thames Valley Police, and the Learning and Skills Council. It was developed after consultation with a variety of partners, including children and young people themselves, and their comments are included in detail.

Comments are included both from children attending the *Flying High Play Scheme* and from parents of pupils with special educational needs attending the 2005 Borough's Parents' Conferences *You Talk, We Listen*.²⁶

The Plan's central feature is the list of 14 Strategic Priorities. It is remarkable that all these Priorities touch to a greater or lesser extent upon the maxims contained in the *Every Disabled Child Matters* Charter. This Plan is strategic rather than operational. It is questionable that this Plan is the appropriate place for the detail suggested by the maxim above. Other, more closely focused plans – such as the Accessibility Strategy – are better placed to go into such detail. Nonetheless it is encouraging to see that the appropriateness of the Plan is confirmed by the maxims of the Charter.

At the time of writing, a new Plan is being consulted upon and is due to be written in the first quarter of 2008. It is recommended that that the maxims in this Charter be borne in mind when considering the details of the new Plan.

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²⁵ Accessibility Strategy, 2006-2009, RBWM, 2006

²⁶ C&PP Plan, pp.7-8. This includes the parents' comments foreshadowing some of the maxims of the *Every Disabled Child Matters* Charter.

8. Our Local Area Agreement includes targets for the level of service to be delivered to families with a disabled child

The Local Area Agreement is a statutory requirement, outlining an agreement with central government as to the challenges and local priorities facing the Borough. It is written by the Royal Borough's Community Partnership (which is to say, the Local Strategic Partnership within the Borough). Its overall aim is to improve services to local residents, through joint working and greater accountability between central government, local public service organisations businesses and other partners. The priorities for children in the current Local Area Agreement derive in turn from the Children and Young People's Plan, as mentioned above. The authority's Local Area Agreement was completed in April 2007.²⁷ It is now being revised, and a new three-year plan is being prepared for April 2008.²⁸

Targets for the level of service to be delivered to families with a disabled child are not included in the current Agreement. However, consideration should be given to this as part of the new Local Area Agreement. In writing the new Agreement, the authority will be required to choose up to 35 priority targets from a total of 198 proposed by central government.²⁹ One of the indicators from which the authority must choose is 'services for disabled children'.³⁰

Again, it is recommended that that the maxims in this Charter be borne in mind when considering the details of the new Agreement.

9. Disabled children and families are involved in the planning, commission and monitoring of services in our area, including both specialist and universal services

It is clear that individual children and their families take a strong part in the planning and review of services provided individually for them. For instance, children and their families take an integral part in reviews held by social care, and attend annual reviews of statements of special educational need.

A consultative group exists for parents of children with special educational needs, Parents in Partnership. This meets three times a year, with a steering group meeting beforehand. However, regular membership is low (fewer than 25) as a proportion of over 600 children with statements of special educational need and at least as many more at School Action Plus. A perception exists that this is not an entirely representative group of families of children with disabilities. Nonetheless, suggestions and comments from this Parents in

²⁷ Royal Borough of Windsor and Maidenhead's Local Area Agreement: Improving the quality of life through partnership working, RBWM, March 2007. (Hereafter, Local Area Agreement.) ²⁸ Delivering improved outcomes for children, young people and their families: the crucial role of the new local performance framework, Department for Communities and Local Government, 2007, p.3

²⁹ The New Performance Framework for Local Authorities & Local Authority Partnerships: Single Set of National Indicators, Department for Communities and Local Government, October 2007. (Hereafter New Performance Framework.)

³⁰ New Performance Framework, p.6, no.54.

Partnership accord with opinions expressed nationally, and helpful comments have been made about services. As mentioned above, two Saturday conferences entitled *You Talk, We Listen* have also taken place, and comments from this body have fed directly into the development of the vision and values statement of the Children and Young people's Plan. Mention has also been made of successful consultation over the Flying High Play Scheme.

The Children and Young People's Strategic Partnership stresses the importance of views of children, young people and their families. Mention is made of consultation of various groups, notably the Youth Forum, which is a sub-group of the Children and Young People's Strategic Partnership, and through schools.³¹ A medium term aim of the Local Area Agreement is the building of 'a culture of participation in which children, young people and families have a say in planning local services'.³²

Consultation with parents is clearly a well-established feature of planning within this authority, but it may be that greater efforts are needed to engage the young people themselves. It is less clear that families are consulted on the monitoring of existing services. It is recommended therefore that as a matter of policy, young persons with disabilities should routinely be consulted during planning, commissioning and monitoring of new services, and that more generally, service users should be engaged in the monitoring of existing services.

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³¹ Local Area Agreement, p.41.

³² Local Area Agreement, p.63

Appendix 1 – Definitions of 'disability'

Different understandings exist of the term 'disabilities' in this context.

Educational understandings often stem from the principles and legislation surrounding Special Educational Needs. These were notably discussed in the so-called 'Warnock Report' of 1978, chaired by Mrs H M (later Baroness) Warnock. Her report introduced the phrase 'children with learning difficulties' and proposed the system of recording needs of children judged to require provision 'not generally available in ordinary schools'. 33 Her recommendations brought about the concept of the statutory assessment of needs requiring special provision. This concept was first enacted by way of the Education Act 1981, and its provisions have been subject to revision since that time. The current understanding is that a child has special educational needs 'if he has a learning difficulty which calls for special educational provision to be made for him.' A learning difficulty is defined as 'a significantly greater learning difficulty than the majority of children of his age', or 'a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the are of the local education authority'.34

The Disability Discrimination Act 1995 takes a broader view for its particular purposes, defining a disabled person as one who has 'a physical or mental impairment which has a substantial and long-term adverse effect on his [or her] ability to carry out normal day-to-day activities'. The Special Educational Needs and Disability Act 2001 extended the Disability Discrimination Act 1995 to cover the provision of education. The special Education and Disability Discrimination Act 1995 to cover the provision of education.

The term 'child' is taken by the Education Act 1996 in this context to mean a person who has not reached his or her 19th birthday, and, if aged over 16, is attending a school (not further or higher education or in employment).³⁷ The Disability Discrimination Act is again broader, talking of 'persons'. Despite these differences, broad agreement existed in discussion that the term 'child' extended at least to 18 and probably beyond, possibly to 21 or 25.

It is likely that nearly all the children who hold statements of special educational need will be regarded as disabled by other agencies, but there will be some disabled children who will not hold a statement. Social care colleagues would not at present regard as disabled a pupil with Attention-Deficit Hyperactivity Disorder or dyslexia on the grounds that neither might be taken to be a permanent and 'incurable' disorder.

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³³ Report of the Committee of Enquiry into the Education of Handicapped Children and Young People, HMSO, May 1978, p.338

³⁴ Education Act 1996, s.312 (1) and (2)

³⁵ Disability Discrimination Act 1995, s.1 (1)

³⁶ Special Educational Needs and Disability Act 2001, 1995, Part 2

³⁷ Education Act 1996, s.312(5)

Appendix 2 - Consultees

This report is written with particular help of RBWM colleagues, whose participation is gratefully acknowledged:

- Julie Alobaidi, Integrated Working Project Manager
- Sonia Binge, Team Manager, Disabled Children's Team
- Linda Chandler, Head of Community and Youth Services
- Anita Cleare, Children's Trust Development Manager
- Judy Coulson, Parent Partnership Coordinator
- Kathryn Rickman, Early Years Inclusion Officer
- Cliff Turner, Head of Children and Young People

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