

Parent/Carer Questionnaire: Explanatory notes

Introduction

1.1 These notes and associated parent questionnaire are intended to help schools identify and respond to the needs of their disabled pupils. They were developed and tested through research projects and are being made available to others who may find them useful. Schools are under no obligation to use them.

1.2 The Disability Discrimination Act 2005 (DDA) is now incorporated into the Single Equality Act (2010) and together they require schools to:

- Promote equality of opportunity;
- Promote positive attitudes towards disabled people;
- Assess and monitor the impact of their activities on disabled people;
- Make reasonable adjustments to ensure disabled children are not disadvantaged;
- Improve outcomes for disabled people.

1.3 Schools in England are currently required to collect data on children with Special Educational Need (SEN), but this does not capture information about all disabled children and to date there has been no consistent way of identifying and categorising disabilities. Collecting this information should help policy and practice to respond to the needs of disabled children and their families in line with the Disability Equality Duty (DED) and Single Equality Schemes.

1.4 It is not always easy to know whether a child is disabled. Difficulties can vary over time and may depend in part on the specific environment or activities undertaken. The subjective experience of a disability can only be fully understood by asking parents and children themselves. This questionnaire was produced to help schools consult with parents, providing a useful *starting point* for follow up conversations with parents who indicate that their child is disabled. There are also a set of related 'flexible tools' that schools can use directly with children and young people to find out how they experience and understand difficulties themselves.

Benefits of the questionnaire

2.1 Schools consulted cited the following potential benefits of collecting robust and consistent disability information.

- identifying students' difficulties that had not been brought to attention already
- using the survey information to liaise with other professionals about health problems
- updating information without targeting students suspected of being disabled
- informing pastoral and SEN planning
- contributing to the School Development Plan and Disability Scheme
- informing possible Continuing Professional Development events
- using the information to review and update information on students' statements

- reviewing provision, and in particular consideration of whether additional support or intervention is needed
- reviewing accommodation
- allowing better sharing of information about pupil needs across the school
- reviewing needs assessment for educational visits

When is a child disabled?

3.1 The Equality Act states that someone is disabled if “*they have a mental or physical impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities*”.

3.2 There are 3 important features of this definition:

- The impairment itself
- Its effect on the person’s daily life
- Its duration - whether it lasts for a year or more.

3.3 There are an additional two groups of children covered by the Act. These children do not have to prove their condition has a substantial adverse effect:

- children whose treatment (excluding glasses) offset the effect of the condition e.g. children on medication for epilepsy which is necessary to control the fits.
- children with cancer, HIV infection, progressive conditions such as muscular dystrophy and multiple sclerosis at the point of diagnosis are all taken as meeting the criteria without proving an adverse effect, together with children with severe disfigurement

3.4 Disability is not the same as special educational needs (SEN). Almost half the children with an SEN do not meet the DDA definition of disability. Children with SEN experience difficulties in learning in school but may not have an impairment that impacts substantially on their daily life. Similarly, a significant proportion of disabled children do not have special educational needs, including those with health and mental health needs.

Using the Questionnaire

4.1 Questions 1 - 3 identify whether a child has a disability. A child is considered to have a disability if their parent indicates substantial and long term difficulties with one of the areas listed (Q1), OR that there would be difficulties without medication or supplements currently taken (Q3). Questions 4 – 6 then ask parents for more information on involvement of external agencies and nature of the disability. This should help ensure schools respond as effectively as possible.

4.2 The final part of the questionnaire recognises the sensitivity of this issue for parents. Parents are invited to request a follow up discussion with a member of staff and to identify anyone with whom parents would not wish information to be shared.

4.3 The questionnaire was produced as a *starting point*, from which some schools involved in the research said they may plan follow up conversations with parents who indicated that their child was disabled.

Who should complete the questionnaire and when?

4.4 It is important that all parents have the opportunity to complete the questionnaire and to update information as appropriate, since disability can occur at any time. For many schools, the admissions process may be the most appropriate time to collect the disability information initially. It could then be verified and updated during routine face to face meetings and key transition points.

Parents who may be hard to reach

4.5 The questionnaire has been developed to be easy to understand and complete. However, it may present difficulties for some parents for whom English is an additional language or who have limited literacy skills. It is also important to recognise that different social and cultural groups may understand and respond to disability in different ways. Those who have already experienced discrimination and prejudice may also lack trust in official institutions or be reluctant to disclose personal information.

4.6 Versions of the questionnaire translated into community languages will help to collect more comprehensive disability data. However, there may be a particular challenge in finding equivalent terms or concepts to use.

4.7 In some cases - and at the school's discretion - it may be helpful to offer parents the opportunity to complete the questionnaire individually with an appropriate member of staff, or to follow up with parents if it appears that information may have been omitted unintentionally.

Confidentiality

5.1 Parents will need to understand why the data is being sought and how it will be used. Parents in the research project were assured that there were appropriate procedures in place to protect sensitive data and that it would not be disclosed to a third party without their informed consent. Paragraphs relating to these confidentiality issues have been included on the standardised questionnaire, but schools may wish to reinforce them in any related correspondence or conversations.

What might a school consider if it identifies a disabled child whose difficulties they were unaware of?

6.1 Issues that schools might need to consider include:

- How should I follow up this information with the child and their parents?
- What more do I need to know so that I can ensure that the child's needs are met?
- Should I initiate a referral through the Common Assessment Framework?
- What action is needed in school?
- Do I need to share this information and with whom?