



Factsheet 27

Guidance for Social Workers

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Working with parent/carers

Parents/carers of children with disabilities may never have encountered a social worker or social services prior to having a child with additional needs. As well as trying to deal emotionally and practically with their child's particular requirements, they are likely to have further anxieties about coming into contact with social workers. They may be feeling overwhelmed and frustrated. They may be worried about being misunderstood or judged as not coping and exasperated at having to explain everything repeatedly.

For a parent/carer of a child with CHARGE, this may be magnified as they may well be dealing with complex health problems, medical procedures, feeding difficulties, multi-sensory impairment – as well as the associated difficulties with communication and possible developmental delay.

Often, through necessity, parents/carers become experts on their child's needs and may be key sources of information for social workers. Social work assessments and contacts should therefore be offered sensitively and flexibly to fit in with parents/carers' schedules and needs.

Social work practice points

Here are some things to consider when working with children with CHARGE and their families:

- **Learn about CHARGE:** Unlike some disabilities, CHARGE is not well known or understood and this may be the first time a social worker has



actually come into contact with a child who has the condition. CHARGE is a particularly complex syndrome and care professionals need to make sure they develop their knowledge base and their professional networks so that they can support the family as much as possible.

- **Communication:** Developing an established form of communication for children with CHARGE is of paramount importance. The features of CHARGE, such as facial palsy and multi-sensory impairment, make communication a real challenge for these children. They may be very clear about what they want to communicate but not have the necessary ability or tools to do so. This can lead to frustration and the emergence of behaviours that appear 'naughty' or harmful.



A mutually agreed form of communication should be used consistently in the home, school and all other settings. This may require significant advanced preparation on the part of the social worker. For example, there is a need to ensure a non-verbal child has access to, and understanding of, relevant signs, pictures or symbols. It is also essential to involve a communication partner who the child has a secure relationship with.

- **Assessment:** Children with CHARGE should be assessed under the Framework for the Assessment of Children in Need and their Families (DoH, 2000). Under the Children Act 1989 they are entitled to an assessment as a 'Child in Need'. Alongside this, a specialist Deafblind Assessment (DoH, 2009) completed by a suitably qualified worker, can help to ensure a thorough assessment and clear plans for appropriate interventions and services in a social care setting.
- **An individual approach:** The intelligence of children with CHARGE is often underestimated due to their communication difficulties and they often surprise people with their abilities. A person-centred approach is therefore essential. It should be recognised that a child's needs may not fit either into mainstream or specialist services for children with disabilities, due to the implications of multi-sensory impairment.
- **Choosing the right services:** Many activities and respite services are very busy and noisy and this can be confusing and stressful for a child who has difficulty processing different sensory stimuli.

Putting the child and family in control through the provision of direct payments and individual budgets can enable them to choose how to provide more enjoyable and appropriate settings, such as one-to-one activities with a Personal Assistant (PA), or an Intervenor who has specific knowledge and communication skills. The hours provided could be used to try different social settings, to remain flexible and make sure that the child has as much choice as possible.

- **Creativity** in the use of resources is needed and is best achieved through working collaboratively with the child, their parents/carers and the team of people around them. For example, the provision of appropriate short break services for a child with CHARGE can be a particular challenge. Possibilities include: overnight respite with a child's own PA or Intervenor; flexibility in activities and routine in a fully adapted unit; or the option for a child to stay alone or with a friend.

- **Flexibility:** Whilst respite care may be aimed at giving parents/carers a much-needed break, they are likely only to get the full benefit of it if they know that their child is enjoying their time away and has appropriate support. Allocating a number of nights per week may not always be the best way to meet the family's needs. Frequent but longer breaks might enable a child to take part in the family events they would like to be part of.
- **Training staff:** Consider the experience, skills or training that any support staff will need. This might include: deafblind awareness or specialist intervenor training; sign language or alternative communication methods; and specialist training around any medical needs. This will need to be re-visited as staff move on. This is likely to mean an increase to the hourly rate normally offered for Direct Payments and a training budget may need to be agreed.
- **Inclusion:** Think about services and social activities that promote inclusion and friendship networks – such as out-of-school clubs and holidays, education and health services. Can a child access both specialist and mainstream services? Often children with particularly complex needs have to travel to schools outside of their community and having the opportunity to attend local activities can promote integration.
- **Support for carers:** It is the right of the carer to have an assessment (The Carers and Disabled Children's Act, 2000). However, it can be very difficult for a carer to step back from their own daily life and think about everything they are doing. Some may want to be left to think about and write notes themselves. Others might have a friend who could spend a day with them and write down what they observe.

A short 'Sharing Real Lives' documentary gives a useful illustration of 'A Day in the Life of Aidan and his Family' (Inspired Practice, 2009). The scope and impact of the caring role for a child or young person with CHARGE should not be underestimated – examples of the carer's responsibilities are illustrated in 'The Juggler: Caring for the child with CHARGE syndrome'.
- **Siblings** need one-to-one time with their parents/carers, which is much more difficult to get when their brother or sister needs constant care and attention. However, they may also want to do things with their sibling. Are there inclusive activities available that they can both attend and get something out of? Siblings' needs should be considered as part of the ongoing assessment processes and care package.



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