



## Factsheet 22

# The role of the Intervenor

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Henderson and Killoran (1995) wrote:

"An Intervenor acts as the eyes and ears of the individual who is deafblind, making him or her aware of what is occurring and attaching meaning to all experiences. An Intervenor intercedes between the individual who is deafblind and the environment in such a way so as to minimise the effects of multi sensory deprivation and to empower the individual to have control over his or her life." (p. 3)

Children and young people with CHARGE syndrome may be considered truly multi-sensory impaired. The condition can affect not only their vision and hearing but all their senses and is often associated with health difficulties. This can make day-to-day learning very difficult to access. Due to their complex multi-sensory needs, most children will have a range of practitioners offering advice on development and education. Whilst this is very helpful, it can mean life is very complicated for the child, family and those providing support.

### Building the relationship

The role of the Intervenor in minimising the effects of CHARGE is crucial. Children with CHARGE may find it difficult to build relationships especially when so many people are involved. The child may have behaviours necessary to regulate their senses; reduced and distorted use of vision and hearing; health difficulties and be sensitive to touch. All of these are a potential barrier to learning.

The trained Intervenor builds a relationship with a child and always works closely with them. They will pick up on the child's often subtle attempts to communicate and be aware of what sense the child is using. They will also interpret information for



the child, and look out for information the child might have missed to ensure best access to learning and development.

### Support at home

Parents of children with CHARGE can become overwhelmed by advice from helpful practitioners and may feel guilty if they have not had the chance to implement suggestions to help with their child's development. A home-based Intervenor can work with practitioners and support the various physiotherapy, speech and language therapy, visual and hearing training, Portage and sensory integration programmes devised for the child.

An Intervenor can give the parent the much-needed time to be a parent, a partner and to run a household. They can free the parent to enjoy their child and not to have to be a full time therapist.



## Support at school

Children with CHARGE are likely to be placed in an inclusive setting, a special or mainstream school that is not designed to meet their multi-sensory needs. The Intervenor can work with the teacher to ensure that the curriculum is adapted and individualised to enable equal access with their peers.

They can provide support for individual learning. If the child experiences sensory overload and needs some time away from the usual bustle of classroom life, the Intervenor can offer this. They can also provide the time necessary for the child to explore and find out about the environment around them. When moving down the corridor, for example, the Intervenor can ensure the child touches, hears, smells and sees landmarks to familiarise themselves with where they are – and so increase their independence and orientation and mobility skills.

The Intervenor can promote interaction with peers – a vital part of social development. This can help to increase self-esteem and limiting behaviours that may challenge the child and others.

Most importantly, the role of the Intervenor is to give the child TIME – time to process information and formulate their response. Time can be in short supply in busy homes and schools.

An Intervenor's observations of the child's use of hearing and vision can be beneficial to audiologists, ophthalmologists and specialist sensory impairment teachers to provide additional information about how the child functions in the environment.

## The Intervenor as Communication Partner

Paul Hart (2004) states:-

“Communication is always about partnership and if this is correct it asks us to reconsider what we mean by communication impairment. It can't really be one person's problem. If an impairment exists it must lie at the partnership level and right away that makes it at least two people's problem”.

The Intervenor is the child's Communication Partner, ensuring effective communication at all times using a Total Communication approach. This may involve using different modes in response to the child's changing needs.

An example:

*Vision is Tom's dominant sense and he uses symbols to communicate. However, it is the afternoon and his nystagmus (rapid eye movement) has increased. The Intervenor may reduce the amount of visual aids*

*used and introduce more tactile modes such as an object of reference.*

Many children with CHARGE use a hand-under-hand approach to communication. This helps a child to not only receive a sign that may not be accessible visually, but also to understand the proprioceptive aspect which is needed in order for the child to be able to express the sign.

A child's expressive sign language may not be an exact imitation of the British Sign Language (BSL) sign as their perception of the sign may vary. This does not mean the child has got it 'wrong' but it is how they believe the sign is expressed. The Intervenor will interpret the signs and ensure that others are familiar with the child's individual approach to signing.

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## GLOSSARY

**Communication Partner:** a person interacting with the child to share experiences and emotions.

**Proprioception:** the sensory information that we receive from our joints and muscles telling us about the position, movement, force, and direction needed for activities.

**Total Communication:** an educational approach that aims to make use of a number of modes of communication such as signed, oral, auditory, written and visual aids, depending on the particular needs and abilities of the child.

## REFERENCES

Hart, P. (2004) *Quality Communication: Maximising opportunities for people with Multi-Sensory Impairment*. Presentation at EMSEN Special Needs Regional Partnership Conference.

Henderson, P. and Killoran, J. (1995) Utah enhances services for children who are deaf-blind. *Deaf-blind Perspectives*. 3(1), pp. 3–6.