

Behaviour & School Issues

AustCHARGE 2008
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What is special about CHARGE?

- Strong common characteristics BUT a very wide range of ability and function
- Large number of anomalies (up to 38?)
- True multi-sensory impairment
- Frequently high developmental potential plus features that normally suggest low developmental potential
- Brilliant adaptive abilities but also bewilderingly patchy development
- Sensory integration dysfunction that affects all areas of development, learning, and behavior
- Significant difficulties with self-regulation and with executive function
- Inherent high levels of stress

David Brown - Am.J.Med.Gen. 2005

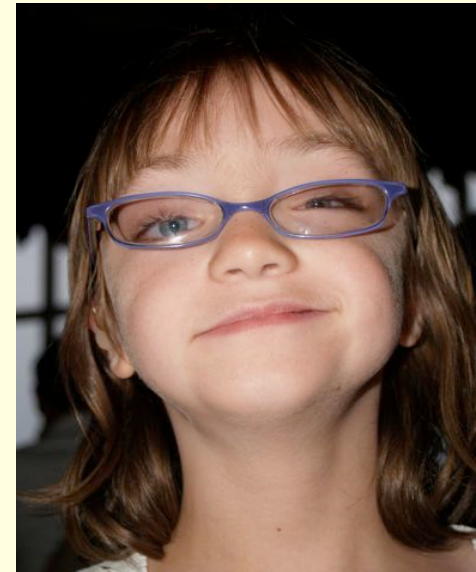
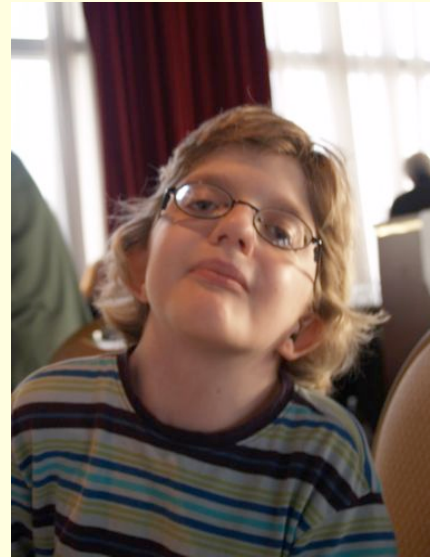
“Children with CHARGE syndrome are truly “multi-sensory impaired”, having difficulties not only with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control.”

David Brown - Am.J.Med.Gen. 2005

“....the immense difficulties that children with CHARGE face in almost everything that they do, and, as a consequence, the very high levels of stress with which they must live for much or even all of their lives. Time spent trying to reduce stress levels, and trying to give the children acceptable strategies for doing this for themselves, must be one of the most precious gifts we can offer them, and one of the biggest favors we can do ourselves as educators, therapists, and family members.”

Mental retardation? Or.....

- No balance sense
- Low muscle tone
- Visual impairment
- Hearing impairment
- Facial palsy
- Executive function deficit



Mental retardation? Or.....



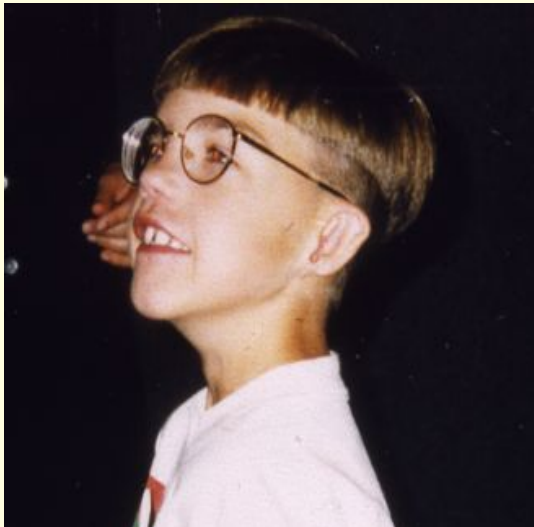
- Breathing difficulties
- Eating difficulties
- Illness, hospitalization
- Sensory defensiveness
- Inappropriate assessment

Individualization

I would argue that what people with an intellectual disability need more than anything else is to be accepted and respected ***as they are***. The aim of all of us who engage with them should be to support ***who they are***, to provide the supports so they can be ***who they are***, and to interact with them in such a way that ***their ways of being*** are appreciated and nurtured rather than undermined and dismissed. What this requires is stretching our rules of engagement and intimacy.

Jani Klotz

What might be needed? (1)



- 1-to-1 support
- Sensory Impairment Team (Services for Blind, Deaf, Deafblind, as appropriate)
- Physiotherapy, Occupational Therapy, & Speech Therapy support
- Sensory Integration program
- Adapted furniture
- Controlled or adapted environments
- Functional activities

What might be needed? (2)

- Individualized motivators
- Appropriate communication systems (possibly multi-modal, including a concrete system)
- Individualized pacing
- Facilities for safe rest periods
- Specific support for group sessions
- Nursing or paramedical support
- A teacher who has 'IT'

