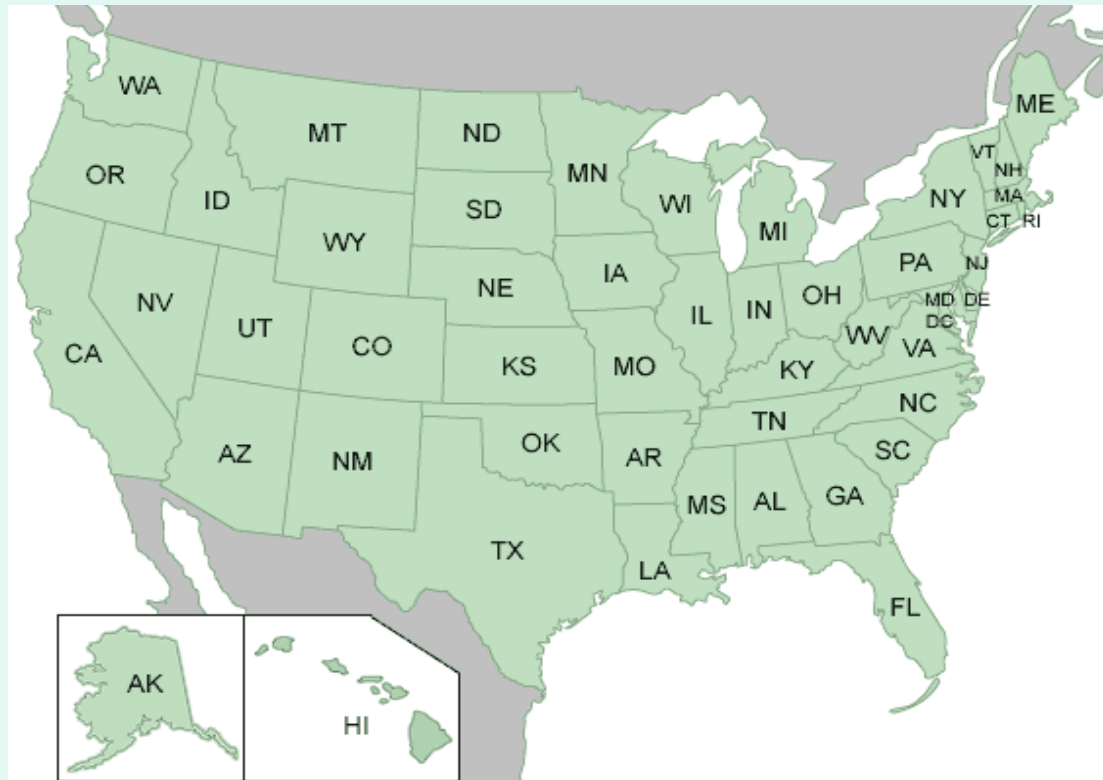


# The Principality of Wales



- 1 USA = many x Wales
- Just over 1 million people
- 6 sheep for every 1 human
- No-one in California has heard of it





*“Life, liberty, and the pursuit of alcohol”*

# Welsh places

- Aberystwyth
- Aberdaugleddyf
- Aberlleiniog
- Llanfihangelnantmelan
- Blaenauffestiniog
- Caerllionarwysg
- Cwmrhyddyceirw
- Dinbychypysgod
- Penrhyndeudraeth
- Pwllheli
- Bwlch
- Llanddewibrefi
- Llanfairpwllgwyngyllgogerywyrndrobwlllantysiliogogoch



# School-to-Adult Life: Transition for Individuals who are Deaf-Blind

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~cadbs](http://www.sfsu.edu/~cadbs)

# 2006 Regulations to IDEA 2004

## §300.320

(b) Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined by the IEP Team, and updated annually, thereafter, the IEP must include—

- (1) Appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and
- (2) The transition services (including courses of study) needed to assist the child in reaching these goals.

## National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives

Nearly one half of the youth left school without any formal communication system. Educational programs must provide services that promote communication development in students who are deaf-blind. These must include strategies for augmentative and alternative communication.

## National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives

Problematic and/or challenging behavior may affect an individual's ability to gain employment, engage in meaningful community activities, and have relationships. Approximately one-third of the youth involved in this study sometimes or frequently exhibited problematic behavior.

## National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives

The study shows that a large majority of youth who are deaf-blind are not working or are underemployed. They are living primarily with their parents with little hope for independent living in the near future and have a narrow span of participation in community activities. The most remarkable of these results show that half of these youth have few friends outside their families and/or people who are paid to be with them. Additionally, over 50% of these youths are living at home with their parents and a majority of these parents want them to remain living at home

# What I've learned over the years

- Importance of social skills
- Developing community—it's all about connections
- Time of life when students need to be at their best and families need the most energy
- The “readiness model” doesn't work
- Typical issues of high school/college

# Things to remember

- Adult services are not an entitlement
- Document everything
- Mind the gap; strike while the iron is hot
- All goals must lead to valued outcomes
- Some students look terrible on paper
- Know what families *really* want

**“Parents these days are spoiled.  
They’re not ready for the black  
hole of adult services.”**

Janette Peracchio, National Family Association  
of the Deaf-Blind, 2008

*“Life, liberty, and the pursuit of happiness”*

Is emotional competence ever an educational goal?

AustCHARGE 2008

Christchurch, New Zealand

David Brown

CDBS Education Specialist



# A worldwide community





## So what's wrong with the (education) world?

1. Too much focus on 'discrete skills & outcomes', and no focus on 'processes'.
2. Real individualization is rare.
3. People mistake compliance for emotional maturity.
4. "Our children are fires waiting to be lit, not vessels waiting to be filled" (Flo Longhorn).
5. Self-regulation issues are rarely on the agenda.
6. Separation of 'education' and 'therapy'.
7. Too much focus on the distance senses of vision & hearing, while other, more fundamentally important, sensory systems are largely unnoticed and ignored.

## Francis Fukuyama

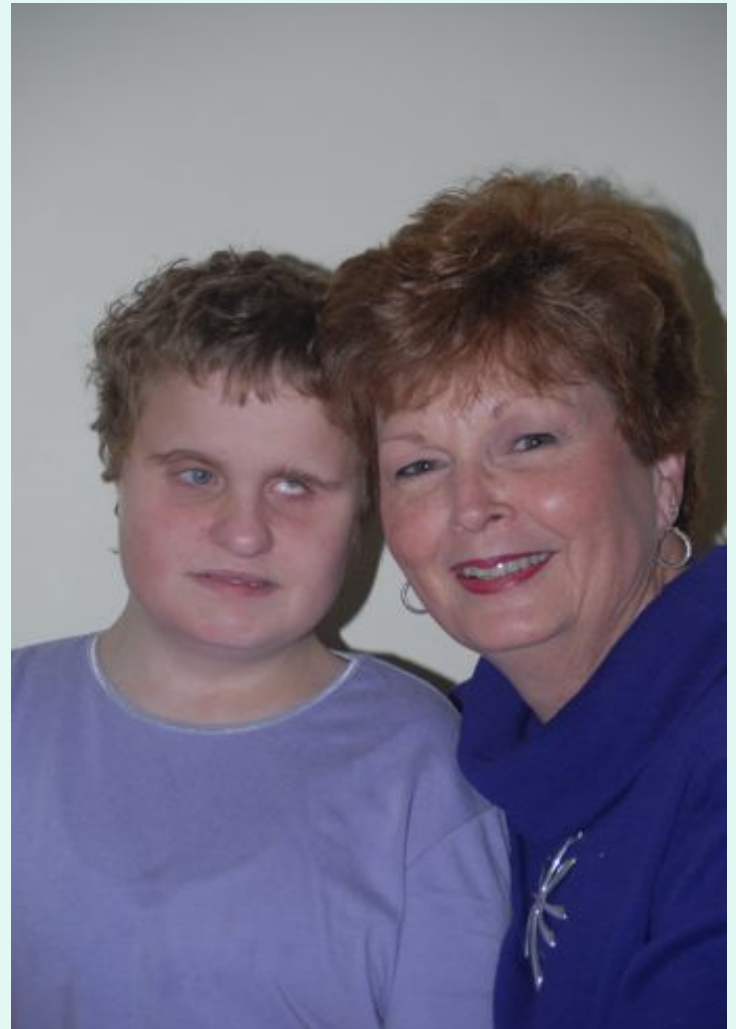
“While many would list human reason and human moral choice as the most important unique human characteristics that give our species dignity, I would argue that possession of the full human emotional gamut is at least as important, if not more so.”

“Human nature is very plastic ... But it is not infinitely malleable, and the elements that remain constant, particularly our species-typical gamut of emotional responses, constitute a safe harbor that allows us to connect, potentially, with all other human beings.”



Without emotions there can be no joy, no values, no motivation. Emotions are very powerful tools for learning. The heart goes out of teaching when we become more concerned with where we're going than where we and the children are.

*Rob Long, Times Educational Supplement 1999*



# CHARGE & mental health

THE FUSCO BROTHERS *J.C. Duffy*



# EMOTIONAL INTELLIGENCE



- Identifying emotions
- Understanding emotions
- Managing emotions
- Using emotions

*Paula Ford-Martin 2002*

# Social and Emotional competence

(Adapted from Jean Brunelli, RN)

## SOCIAL COMPETENCE

Behaviors that enable a person to develop and participate in positive interactions with others



## EMOTIONAL COMPETENCE

The ability to effectively regulate emotions to accomplish your goals



# Assessing social and emotional development



- There is a sequence to development in both areas
- Development in both is shown by similar activities
- Social development is related to functioning with other people
- Emotional development is internal and is demonstrated in self-regulation, focus, and the initiation of both new and familiar activities

[Self-regulation]... “is defined as the capacity to manage one’s thoughts, feelings and actions in adaptive and flexible ways across a range of contexts”

Jude Nicholas, CHARGE Accounts, Summer 2007

# The 9 levels of arousal

(Carolina Record of Individual Behavior)

- Uncontrollable agitation
- Mild agitation
- Fussy awake
- Active awake
- Quiet awake
- Drowsy
- Active sleep
- Quiet sleep
- Deep sleep

# Key concepts in understanding social and emotional development

- Feeling safe, secure, and understood makes successful learning possible
- The adult-child relationship is the key to the child's resilience
- Physiological, emotional, and behavioral resilience is the key to development
- Nurturing care-giving provides genuine dialogue for the development of attachment & mastery of self-regulation
- Brain research shows that lack of "goodness of fit" may lead a child to be prone to distress and to increased regulation problems

# “Goodness of fit” (1)

It is critical to brain development, secure attachment, and eventual self-regulation of emotions and behavior



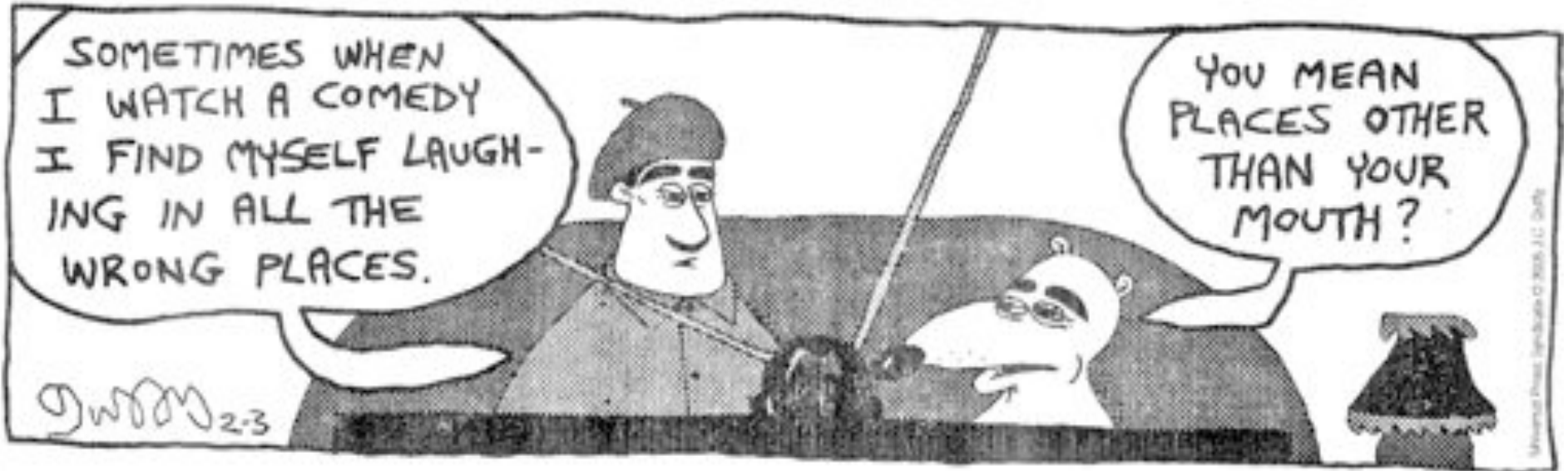
## “Goodness of fit” (2)



The child can demonstrate their physiological and emotional needs, and familiar people can note and respond to these needs.

## “Goodness of fit” (3)

THE FUSCO BROTHERS J.C. Duffy



Occurs easily if the adult has learned to read and respond to the infant's cues, and if the adult's current life circumstances are not overwhelming and provide the necessary social, emotional, and economic support

# Risk factors

- The child's temperament is intense, cues are sporadic, resistant, or inconsistent
- The above may lead to increased sensitivity, proneness to distress, and self-regulation issues
- Neurological and sensory difficulties may interfere with attachment
- Multiple issues result in altered social and behavioral competencies in both infant and adult
- Social and environmental issues impinge on the infant-adult duo's ability to interact in typical ways

## 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.”

# Cameron's questions

What are I Down when I was born?	Why I got nose bleeds?
Why are you white I was died when I was born?	Why are I be dead?
Why are I way naughty at school?	Why are I grand my teeth?
Why are I play with my hair?	Why are I hurt people?

Does poor sensory perception (ie. poor or delayed or fragmented feedback) explain...?

- Need/preference for strong inputs
- Apparent sudden and extreme reactions to pain (I had no idea I was hurting until I was in agony)
- Apparent sudden and explosive changes in emotional state (I had no idea I was angry until I was furious/ I had no idea I was scared until I was terrified)
- Apparent executive function problems
- And is impulsivity an outcome of all of the above - or sometimes a functional solution?

“Emotional development involves mastery” Lilli Nielsen



van Dijk & Nelson  
“Principles of Assessment” (2001)

“The foundation of the assessment is the establishment of a relationship with the child and the creation of a secure base that begins with the child’s interests and successes, and it is the responsibility of the assessor to adjust his/her emotions, cognitive level and communications to those of the child.” pp 4-5

“Pre-assessment planning begins by talking with the child’s parents...to obtain information about the child’s history, interests, preferences, motivators ... Information is gathered about the child’s preferred learning channels...as well as what the child likes and dislikes” pp 5-6

## van Dijk & Nelson “Principles of Assessment” (2001)

- “The child’s interests guide the process: therefore, the assessment begins by following the child’s interests and movements.” p6
- “It is our hope that by carefully following the lead and interests of children... educators will come to know and understand the children and how they learn, communicate, socialize, and solve problems.” p25



## David Wiley “Where is there joy in this IEP?”

*([www.tsbvi.edu/Outreach/seehear/fall04/joy.htm](http://www.tsbvi.edu/Outreach/seehear/fall04/joy.htm))*

- ✓ Find out what is motivating to the student
- ✓ Assess to see if the student is enjoying the day at school
- ✓ Plan activities that incorporate motivating elements for the student
- ✓ Alternate less motivating activities with ones that create joy
- ✓ Teach language using highly motivating topics
- ✓ Teach literacy using highly motivating topics

The limits of my  
language are  
the limits of my  
world.

Ludwig Wittgenstein



van Dijk & Nelson  
“Principles of Assessment” (2001)

- Make the child at ease
- Determine the child’s bio-behavioral state
- Determine the child’s interest
- Follow the child’s interest

## Jean Ayres' theory



That the environment has a crucial impact on brain development, that the brain changes in response to external stimuli, and that experiences resulting from sensory inputs and the child's responses to them affect brain development.

# Key principles of S.I. therapy



- The Just Right Challenge
- The Adaptive Response
- Active Engagement
- Child Directed

In my work with children with CHARGE I am always thinking about their “sensory comfort” and their “sensory confidence.”



# Comfortable Shoes



“Yes, but are they happy love?”  
(Mother Brown)



# **SESAME** - Steps and **Excellent Strategies** for **Achieving Maturity** that is **Emotional**

- Be aware of the emotional state of the child - observe, interpret, intervene appropriately, and educate others
- Consider Social Competence & Emotional Competence inseparable - mastery of skills/ planning & choices/ relationships/ communication
- Consider and deal with the barriers to emotional maturity that are inherent in deaf-blindness
- Explore links between sensory perception and self-awareness of emotional state; consider a Sensory Integration perspective and/or other therapies
- Use communication & language that includes a focus on emotional states right from the start
- Provide appropriate and on-going support for those most involved with the child