



*Forster*

**AGE APPROPRIATENESS. ENABLER OR  
BARRIER TO A GOOD LIFE FOR PEOPLE  
WITH PROFOUND INTELLECTUAL &  
MULTIPLE DISABILITIES**



**Age-appropriateness: Enabler or  
barrier to a good life for people  
with profound intellectual and  
multiple disabilities?**

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## Breaking It Down

- Age-appropriateness
- Enabler to a good life
- Barrier to a good life
- People with profound intellectual and multiple disabilities

## People with Profound Intellectual & Multiple Disabilities (I)

- Profound intellectual disability
  - Problems with memory, concentration, problem solving
  - Cognitive age often <12mths
- Physical disability
- Sensory disability
- Health problems
- Require 24 hour care

## People with Profound Intellectual & Multiple Disabilities

- Not able to understand speech
- Not able to use symbols (speech, pictures)
- Can often express pleasure, displeasure
- May have limited alertness
- Rely on others to interpret
- Decisions usually made by others – best interest
- A growing group in services – invisible

## Christopher & Clive - CDDHV



## A Good Life for These People

- QOL-PMD *Petry et al*
  - Material wellbeing
  - Physical wellbeing
  - Social wellbeing
  - Communication and influence
  - Development
  - Activities

## Age-Appropriateness – What is it?

- Principle – big in AUS, UK, USA
- Rarely defined
- Activities and approaches commensurate with chronological age
  - Dress
  - Objects
  - Interactions
  - Activities

## Where Did It Come From?

- Normalisation
  - Nirje – “to be able and be allowed to be yourself among others”
  - Wolfensberger
    - Social Role Valorization
    - Need to avoid anything that could be perceived as child-like or sustaining the view of the person with a disability as an eternal child
- But is it consistent with person-centredness?

## Arguments for Age-Appropriateness

- Individual
  - To learn to behave in an adult fashion
  - As a sign of respect
- Community
  - To achieved community acceptance and engagement
- No support in research

## What Does Policy Say?

- ADHC –The **Life Choices Program** will provide people aged 25 - 54 with:
  - purposeful life-stage and age-appropriate daytime activities matched to skills and interests
  - leisure and recreation activities
  - healthy lifestyles
  - opportunities for community inclusion and participation
  - support to pursue individual interests and age-appropriate social relationships

## What Does Policy Say?

- Disability Act 2006 – no mention of AA
  - realise their individual capacity for physical, social, emotional and intellectual development;
  - access information and communicate in a manner appropriate to their communication and cultural needs
- Personal relationships, sexuality and sexual health policy and guidelines – not specifically AA
  - Encouraging appropriateness
  - “Support providers may need to offer information and advice”

## What Does Research Say?

- Lit search
  - 2010 – my opinion piece
  - 1993 – social perception – diff. Estimated IQ & reading level, not likeability & social distance
  - 1995 – children activity
  - 1990 – children being taught age appropriate restaurant skills
  - 1981 – teaching age appropriate darts game
  - 1979 - opinion

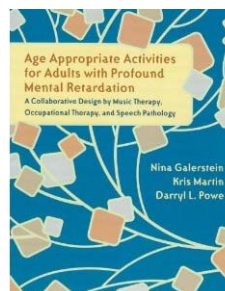
## What Does Research Say?

- Junko Abe's thesis
  - “In particular, when we examine the effects on individuals, the notion of ‘age-appropriateness’ frequently threatens to disempower people with an intellectual disability, rather than promote their rights and their quality of life”
  - “Doing so also placed power in the hands of professionals in the intellectual disability field. Professionals tend to restrict choice and autonomy of people with an intellectual disability by adopting a measure of age-appropriateness”
  - Reduction of age appropriateness in policy with rise of autonomy & choice

- “do we listen to individuals with ID (through the data they generate) or do we not?” (R. R. Saunders, personal communication, July 25, 2007).

## What Do Therapies Say?

- **Communication Interventions** – “Ideally, social closeness interactions for beginning communicators who are presymbolic would meet the following criteria: (I) be chronologically age appropriate...” Drager, Light, Parsons
- **Occupational Therapy** – Age Appropriate Activities for Adults with Profound Mental Retardation – Galerstein



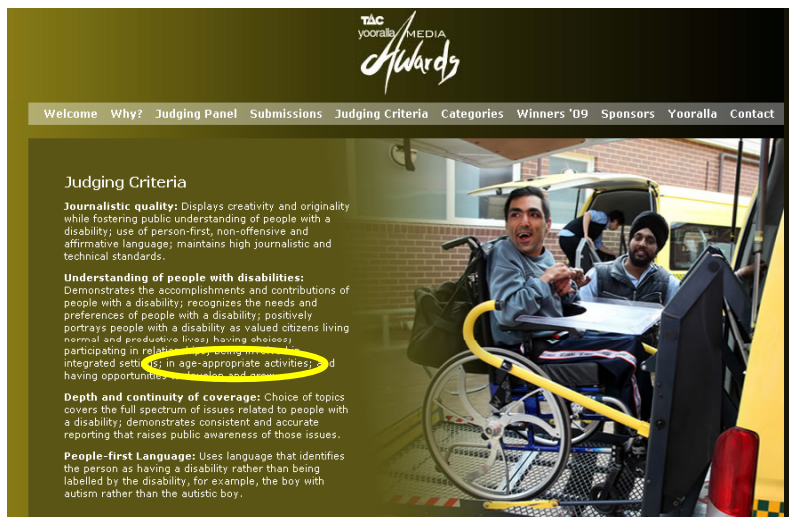
## What Do Therapies Say?

- Intensive Interaction
  - “Care-givers have intuitive abilities, triggered by their infants, to adjust themselves and their games to optimize the likelihood of the infants getting involved and interested. Intensive interaction attempts to learn from this, to release these abilities in practitioners and to explore the potential of combining innate abilities to interact with an intellectual analysis of the process. It would seem contradictory to this natural model to try to adapt the activities to be age-appropriate”
    - Hewett & Nind – In Whose Choice? Contentious issues for those working with people with learning disabilities

## What Does Human Rights Say?

- Property rights
- Freedom of expression
- Has proper consideration been given to an individual – blanket policy is not sufficient grounds for restricting rights

## What Does Your Organisation Say?



TAC  
Yooralla MEDIA  
*Awards*

Welcome Why? Judging Panel Submissions Judging Criteria Categories Winners '09 Sponsors Yooralla Contact

### Judging Criteria

**Journalistic quality:** Displays creativity and originality while fostering public understanding of people with a disability; use of person-first, non-offensive and affirmative language; maintains high journalistic and technical standards.

**Understanding of people with disabilities:** Demonstrates the accomplishments and contributions of people with a disability; recognizes the needs and preferences of people with a disability; positively portrays people with a disability as valued citizens living normal and productive lives; having choices; participating in relationships; being integrated into integrated settings, in age-appropriate activities, and having opportunities.

**Depth and continuity of coverage:** Choice of topics covers the full spectrum of issues related to people with a disability; demonstrates consistent and accurate reporting that raises public awareness of those issues.

**People-first Language:** Uses language that identifies the person as having a disability rather than being labelled by the disability, for example, the boy with autism rather than the autistic boy.

## What Does Your Organisation Say?



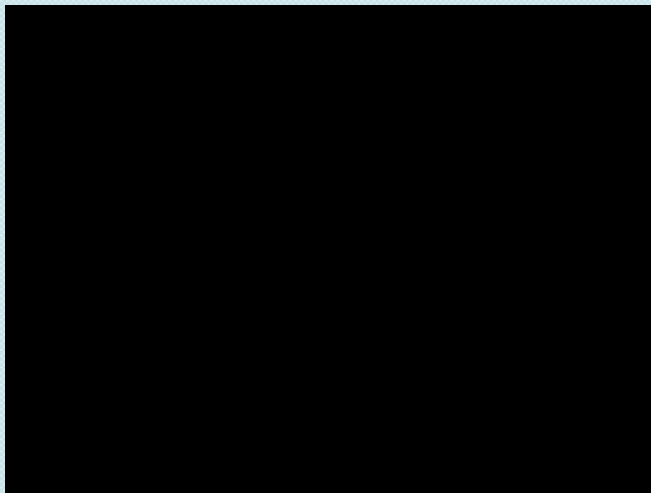
**What Does Your Team Say?**



**What Do You Think?**

## VICTORIA – RAISING OUR SIGHTS

Write down  
the things that  
**are** age  
appropriate  
and the things  
that **would  
not** be age  
appropriate...



[http://www.dh.gov.uk/en/MediaCentre/Media/DH\\_117967](http://www.dh.gov.uk/en/MediaCentre/Media/DH_117967)

## Victoria – Raising Our Sights



- Passions music, Mozart, and men
- Hair colour
- Nail polish
- Stereo
- No patterns on clothes
- Sharing a house
- Going to the market
- Peer aged around her
- Going to the pub



- Playing with a toy
- Playing with plastic
- Staff touching her nose
- Nail polish
- Hand to hand play
- Swiping at her cup of tea
- Being assisted
- Throwing a ball around
- “hello hello” tone
- Rocking a flapping her arm
- Other people making decisions
- Touching her face
- Playing with a hair brush
- Being called a “saucepot”

## Influencing the Use of Non-AA

- Practical needs
- Cognitive needs
- Sensory needs
- Social needs
- Learning needs – learning that has happened in the past, difficulty in learning new things
- Reinforcement needs
- Choice/preference
- MEANING NEEDS

## Scenario

- Toy taken away
- What might happen?

## The Language Game

- Pseudo AA
- Is brushing her hair okay?
- Is a single-switch computer game okay if we put pop stars on it?
- What about going shopping, but the person is not engaged?

## Can Age Appropriateness Be Harmful?

- “ Surely one of the most **disrespectful** things, which can be done to a person, is to **fail to communicate** with & thus fail effectively to relate to that person in a style which makes sense to him/her”
  - Hewett, Intensive Interaction newsletter

## A Middle Ground?

## An Individual Ground?

Determining what people with PIMD can and cannot do should not be assessed by the age-appropriateness of the activity, but be determined by what the person needs and responds to best. The interests of individuals with PIMD should be seen as more important than giving good facades. Forcing people to do meaningless activities in the name of passing for *normal* is not dignifying for the person, but rather can be construed as demeaning and tokenistic. I am not advocating for a return to indiscriminate infantilism. Adults with PIMD should not have their life experiences limited or be 'talked to just like babies', but each individual should be supported and spoken to in a way that is meaningful to them; and if that means using toys, animated facial expression, close contact, and short sentences, then this is what is most dignifying for the person. What I am calling for, consistent with Nirje's normalisation, is that age-appropriateness should only be used as a principle for opening up opportunity in a person's life, not for imposing limitations that, at best, make service systems feel good about themselves, and at worst deny people's psycho-social needs and their basic human right 'to be themselves among others'.

## For more information:

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- Forster, S. (2010). Age-appropriateness: Enabler or barrier to a good life for people with profound intellectual and multiple disabilities? *Journal of Intellectual and Developmental Disability*, 35, 129-131.