

Seattle Growth Attenuation & Ethics Working Group

Recap for DEE-P Webinar on GA – May 2022

Evaluating Growth Attenuation in Children with Profound Disabilities: Interests of the Child, Family Decision-Making, and Community Concerns

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January 23, 2009

Shared Assumptions

- Many people and institutions in society do not positively value people with disabilities
- Improvements in medical and social services should be an ethical priority
- Important to encourage more welcoming attitudes about disability
- Parents who care for children with disabilities should be respected and afforded some deference in making decisions based on the unique needs of their child

Broad issues to be considered

- Potential benefits
 - Child
 - Family
- Potential harms
 - Child
 - Disability community
 - Society
- Respect for parental decision-making
- Respect for the community of people with disabilities

Where we ended up

- Some of working group members have strong views on either end of the spectrum
 - Generally acceptable, with a few caveats
 - Firmly against it
- By engaging in discussion and appreciating the validity of the contrasting views, most were willing to accept a moral compromise to reach a middle ground
- Most of the working group were somewhat uncomfortable with growth attenuation to varying degrees and for a variety of reasons, but willing to accept and support decisions by informed and loving parents with appropriate oversight
- All of the working group remains committed to improving the welfare of children with disabilities, their families, and all people with disabilities

Conclusions

- All believe that we need to work to improve the lives of children with profound disabilities, to support the decision-making of parents, and to acknowledge the community concerns
- We appreciate the validity of contrasting views
 - Why some think GA can be problematic
 - Why some think GA can be valuable
- We appreciate the need for moral compromise to accommodate these diverse perspectives

Our moral compromise

- Limited eligibility
 - Profound cognitive disability
 - Non ambulatory
- Robust informed consent
 - Realistic understanding of the benefits, risks and alternatives
 - Understanding the perspectives of parents who have considered growth attenuation
 - Understanding the disability perspective
- Recommend oversight
 - Of the clinical approach that would be used
 - To insure that the child meets criteria for GA
 - To scrutinize the understanding and expectations of the parents