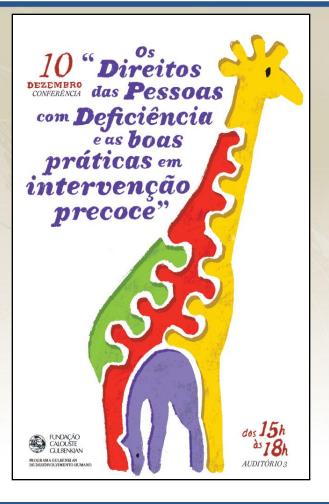


## **Reframing Disability in the** 21<sup>st</sup> Century

## Don Bailey, Ph.D. RTI International



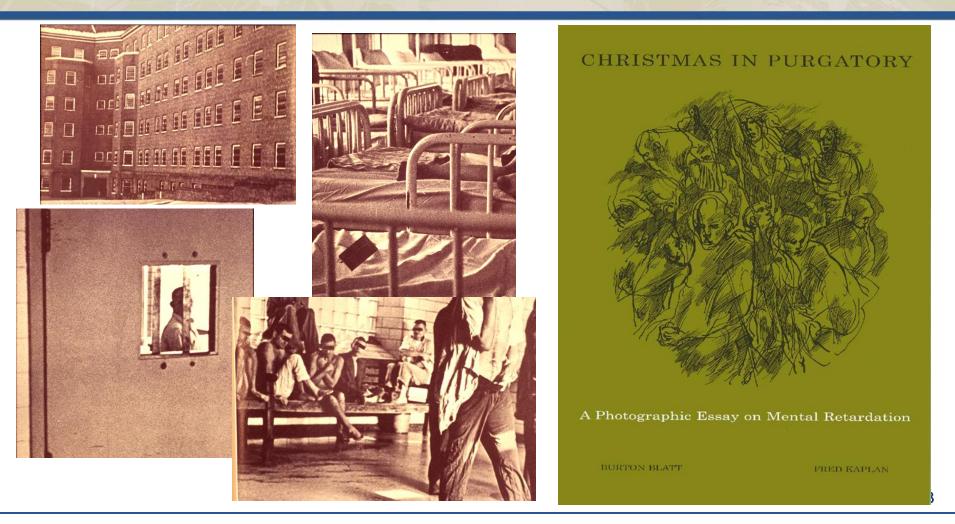
# U.N. Convention on the Rights of Persons with Disabilities

To promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity





## What a difference 40 years makes!





## What I learned working at Central State Hospital in 1971

### I SAW:

Unrealized potential as a result of no treatments or services



### I REALIZED:

- *Early intervention* could prevent or reduce limitations in function
- Complete exclusion from the "normal" world



- Inclusion and normalization of life experiences ought to be a fundamental goal
- Family members did not visit and rarely had any contact
- Supporting *positive family adaptation* is central to the success of people with disabilities



# The U.N. Convention forces us to think about disability from a completely different perspective













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 Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons





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- Non-discrimination
- Accessibility





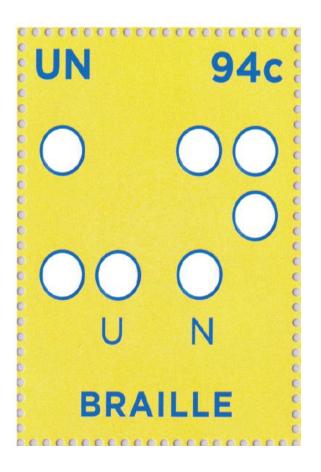
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 Full and effective participation and inclusion in society



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- Equality of opportunity
- Equality between men and women



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 Respect for the evolving capacities of children with disabilities and for the right of children with disabilities to preserve their identities





 Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity





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# How will we make the U.N. Convention a reality for people with disabilities?

- Meet the general and specific obligations for countries who ratify the convention, for example
  - Anti-discrimination legislation
  - Reasonable accommodations
  - Research and development
    - Universal design of goods, services, facilities, equipment
    - New technologies and assistive equipment
  - Accessible information
  - Staff training
  - Public awareness raising
  - Education, employment, citizenship, health, independent living, family life
  - Involve people with disabilities in decision-making and implementation
- Think about the full range of systems, community settings, and services that need to be involved and coordinated
- Start early, with continuity throughout the lifespan



# Today you will hear about a project studying good early intervention (EI) practices in Portugal

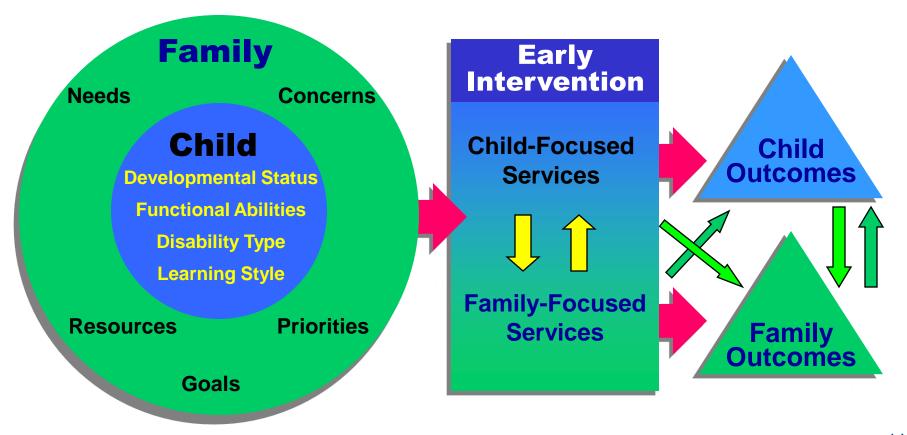
- Family-centered
- Parent-professional relationships
- Inclusion
- Community-based
- Public-private partnerships
- Interdisciplinary team
- Co-responsibility
- Staff development





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El is an individualized system of supports and services designed to help children and families





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# Family-centered principles provide the basic foundation for all EI services



#### **Family-Centered Principles**

- Shared philosophy
- Families as partners
- Focus on strengths
- Family choice of goals and services
- Collaboration and coordination of service
- Effective communication
- Flexibility
- Community-based



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 Represent a fundamental philosophy about the nature of the relationship between parents and professionals

• Say some important things about the ultimate goal of EI

 Have strong empirical support through multiple research studies



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# All program activities are affected by a family-centered approach

#### **Family-Centered Principles**

- Shared philosophy
- Families as partners
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- Collaboration and coordination of service
- Effective communication
- Flexibility
- Community-based

#### **Program Activities**

- Referral and intake
- Determining eligibility
- Child assessment
- Family assessment
- Team meetings and decision-making
- Service provision and coordination
- Parenting practices
- Community support



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# Using these principles and practices should lead to specific family outcomes

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#### Family Outcomes

- Understand child's abilities and special needs
- Know rights and advocate effectively
- Help child develop and learn
- Have support systems
- Access the community



# What threads tie the U.N. declaration and early intervention together?

- Both represent a philosophy and a set of principles
- Both force us to rethink the meaning of disability as part of the very fabric of family and society
- Both force us to think about what kind of service system and community would achieve the goals of EI and the convention
- Both emphasize the need to link philosophy, attitude, and practice across activities and settings





# Disability and early intervention in the 21<sup>st</sup> century



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