



# **Future directions in supporting children with Intellectual Developmental Disabilities and their families. Will there be a brighter future?**

Dr. Dana Roth Ph.D.

Director of Research and Evaluation

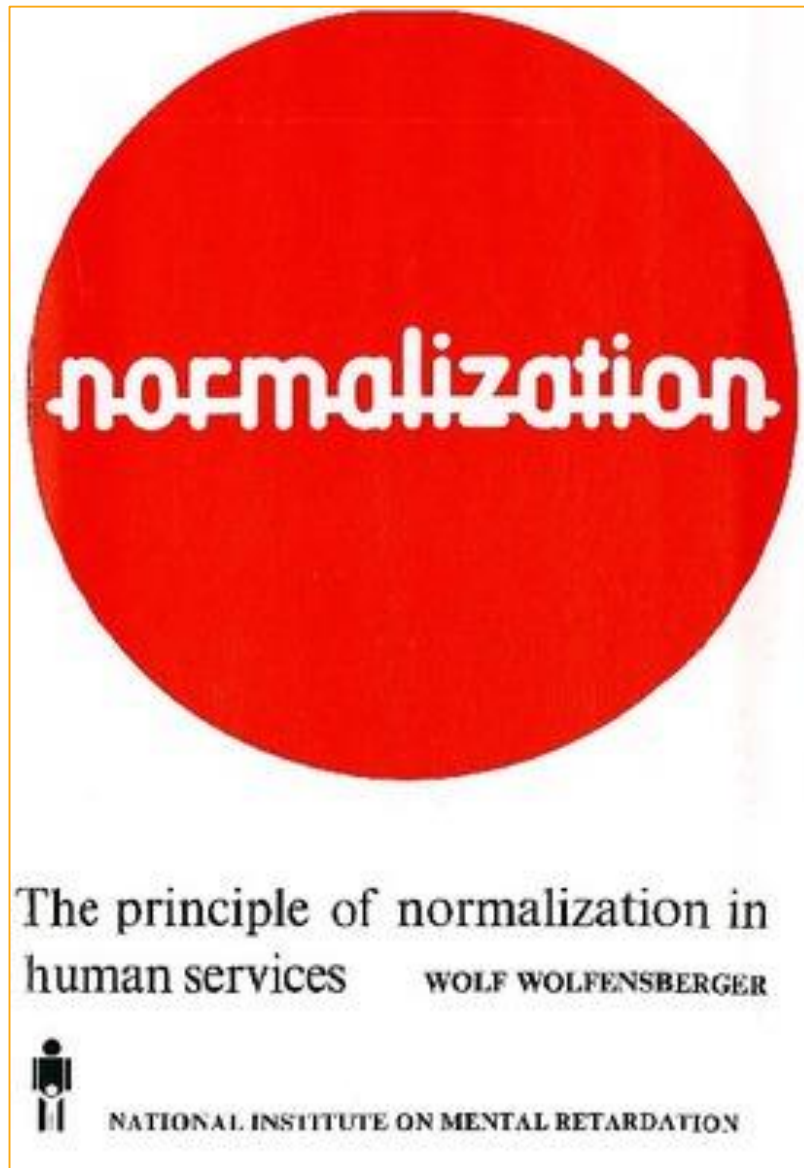
Beit Issie Shapiro, Israel



**Beit Issie Shapiro**

Changing the lives of people with disabilities

On the Willie & Celia Trump Campus

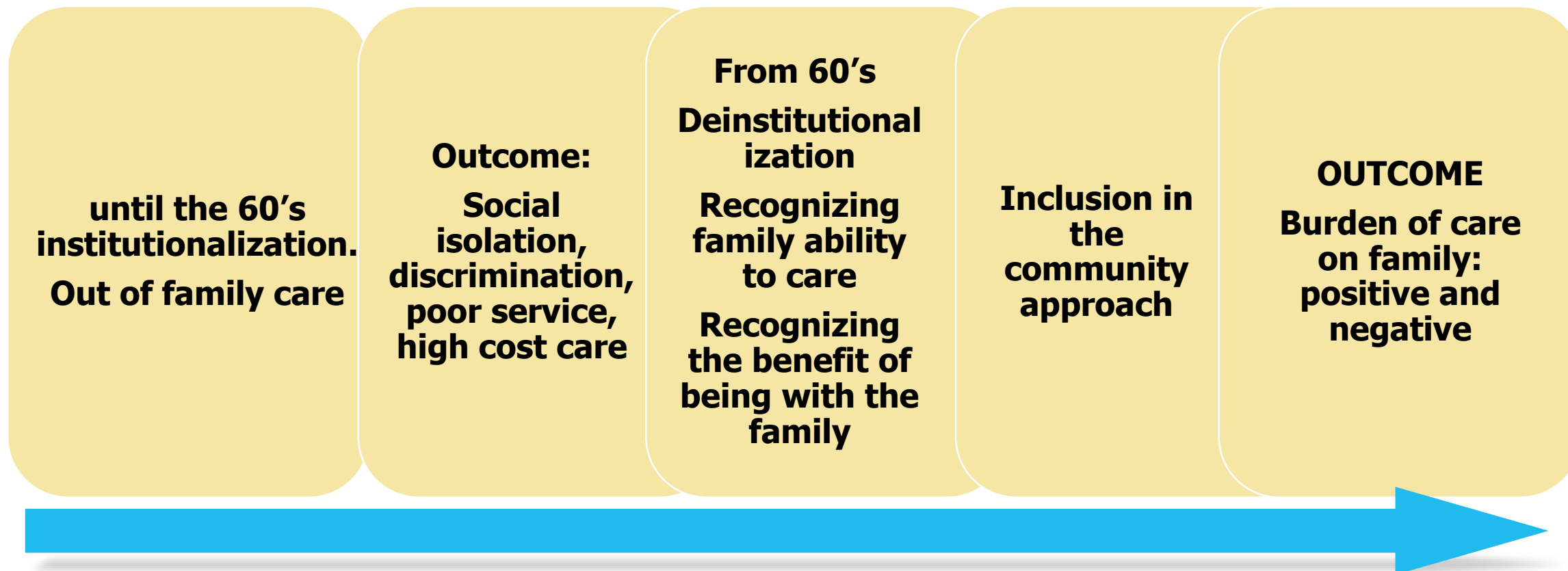


“making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society”.





# The Evolution of the Family with Respect to People with disabilities



Barns C. & Mercer G., 2003; Brown I. & Brown R.I., 2003 ; Werner S., Edwards M., Baum N., Brown I., Brown R.I. & Issacs E.J., 2009









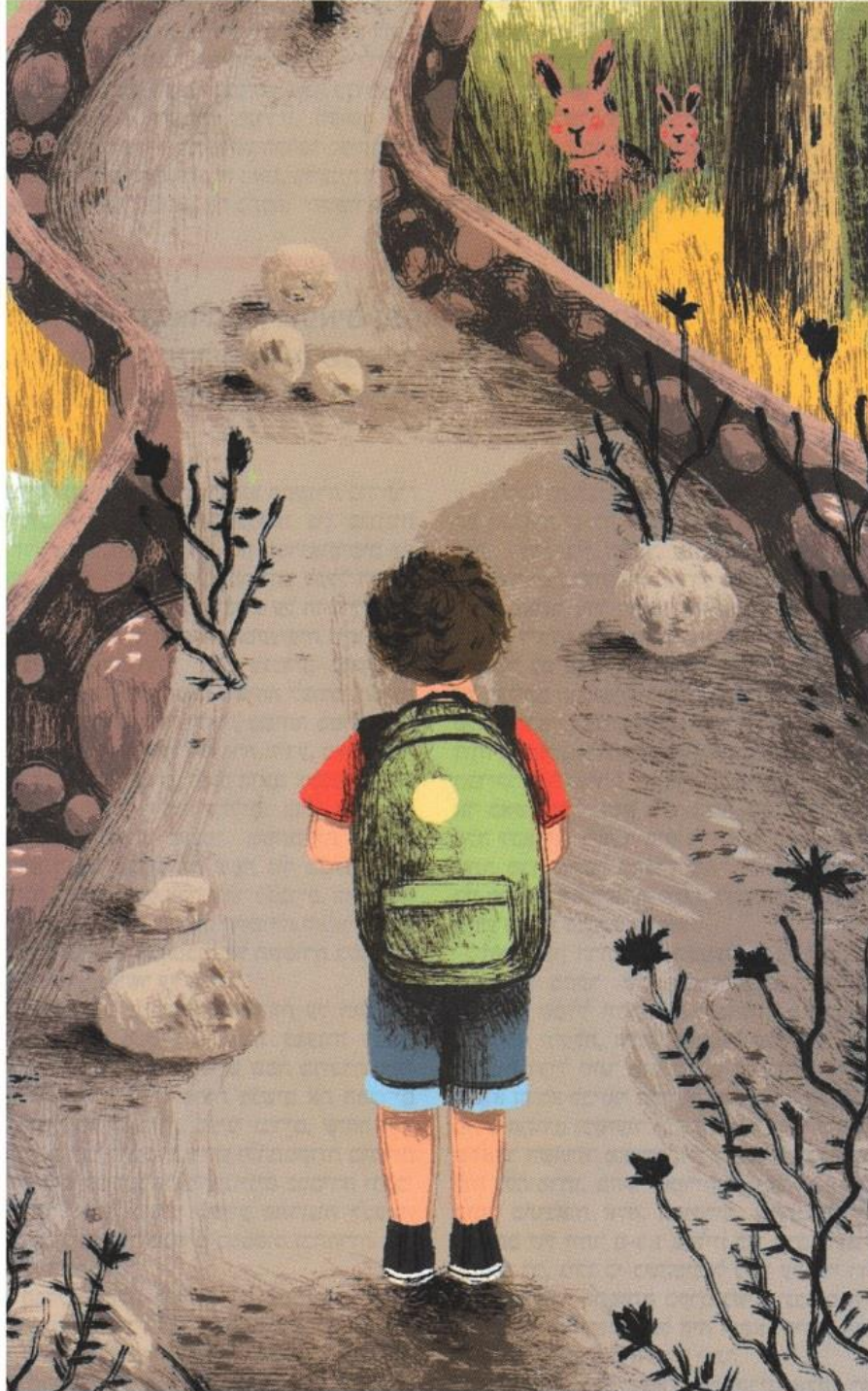


Illustration:  
Rotem Teplow

Physical development

Emotional development

Social development

Knowledge and skills

**Self** – self image, self esteem, self-concept, self actualization, self - determination.....

# Identity





# Basic psychological needs

## Relatedness

Initiating and maintaining relationships

## Autonomy

Free will, willing to stand up for oneself, making decisions

## Competence

Feeling effective in achieving valued outcomes

**Self-determination**



**Optimal wellbeing**





# The– United Nations Convention on the Rights of People with Disabilities The Key Principles



- Dignity
- Independence
- Freedom to make choices
- Non-discrimination
- Participation
- Inclusion
- Respect for difference
- Acceptance
- Equality of Opportunity
- Access



Article 3







# UNCRPD Articles Relating to children

- Article 7 : **Children with disabilities** - The best interests of the child must be a primary consideration in all actions concerning children with disability
- Article 9: **Accessibility** - People with disability have the right to access all aspects of society on an equal basis with others including the physical environment, transportation, information and communications, and other facilities and services provided to the public.
- Article 24: **Education** - People with disability have a right to education without discrimination. Countries must provide reasonable accommodation and individualized support to maximize academic and social development
- Article 30: **Participation in cultural life, recreation, leisure and sport** - People with disability have the right to take part in cultural life on an equal basis with others, including access to cultural materials, performances and services, and to recreational, leisure and sporting activities.





# Definition of Quality of Life (QOL)

**Bob Schalock – E-QUAL Congress , 2014**

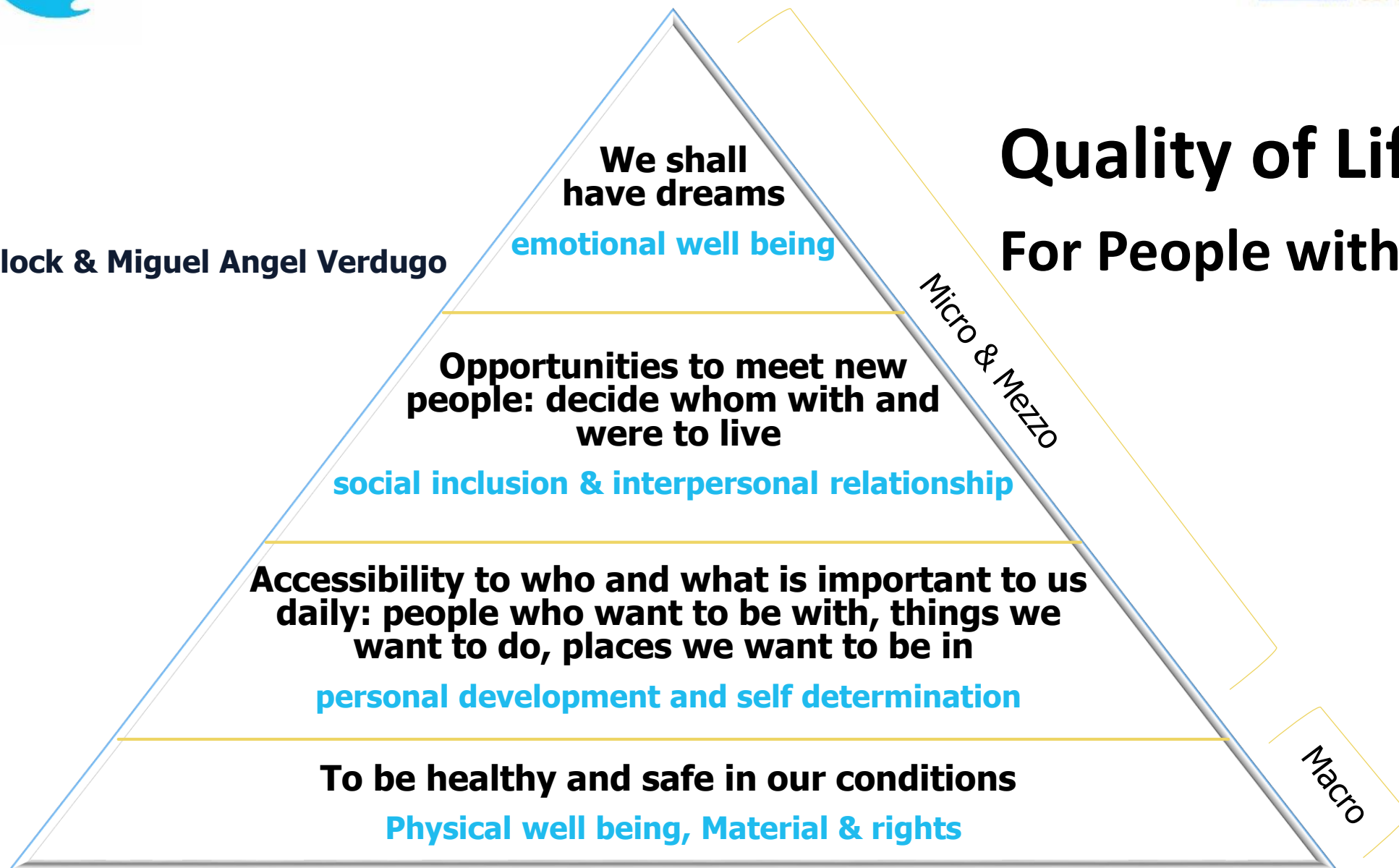
A multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance.





Robert Schalock & Miguel Angel Verdugo

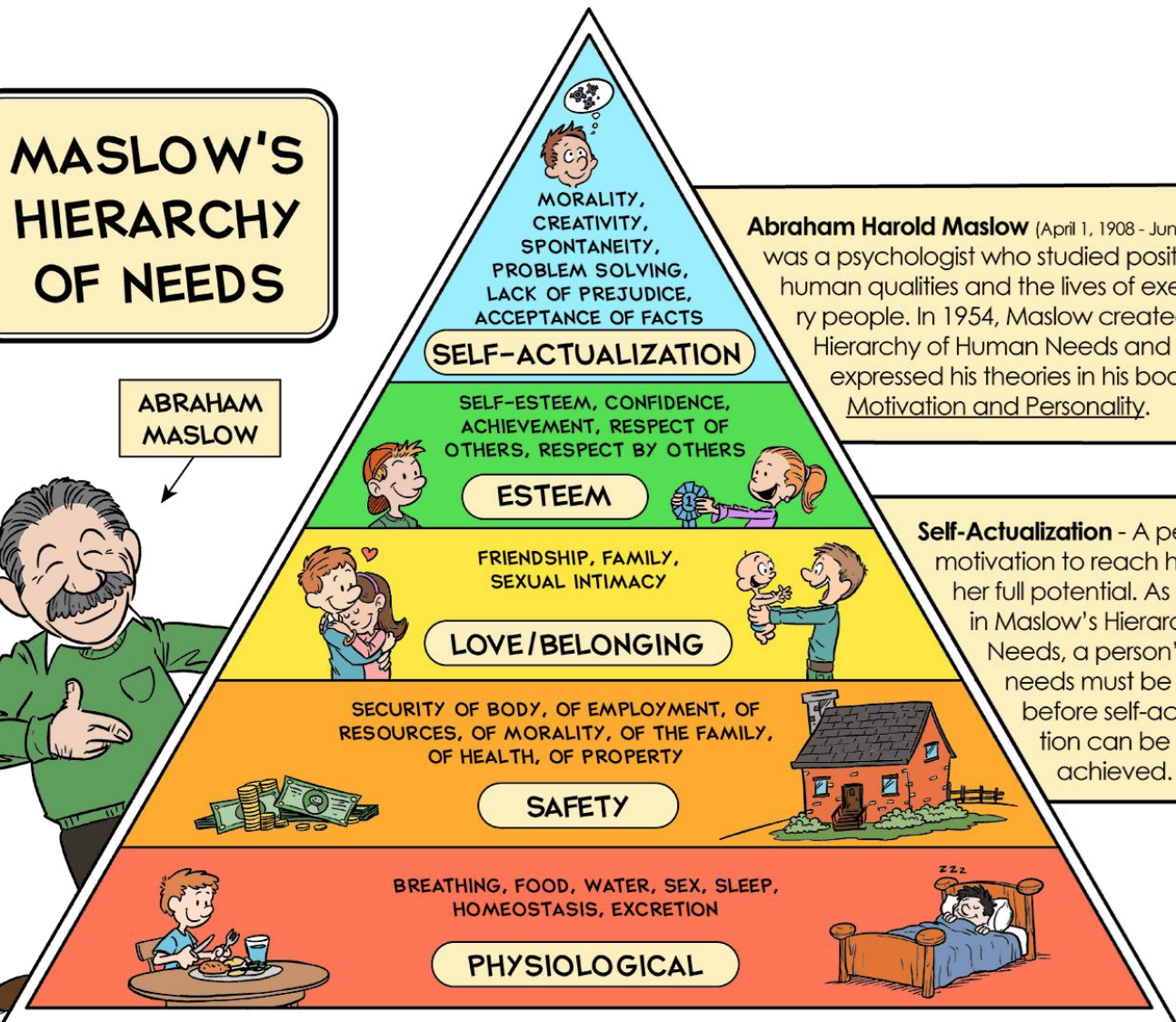
# Quality of Life For People with IDD





# MASLOW'S HIERARCHY OF NEEDS

ABRAHAM MASLOW



**Abraham Harold Maslow** (April 1, 1908 - June 8, 1970) was a psychologist who studied positive human qualities and the lives of exemplary people. In 1954, Maslow created the Hierarchy of Human Needs and expressed his theories in his book, *Motivation and Personality*.

**Self-Actualization** - A person's motivation to reach his or her full potential. As shown in Maslow's Hierarchy of Needs, a person's basic needs must be met before self-actualization can be achieved.

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**WiFi** **Internet Access**





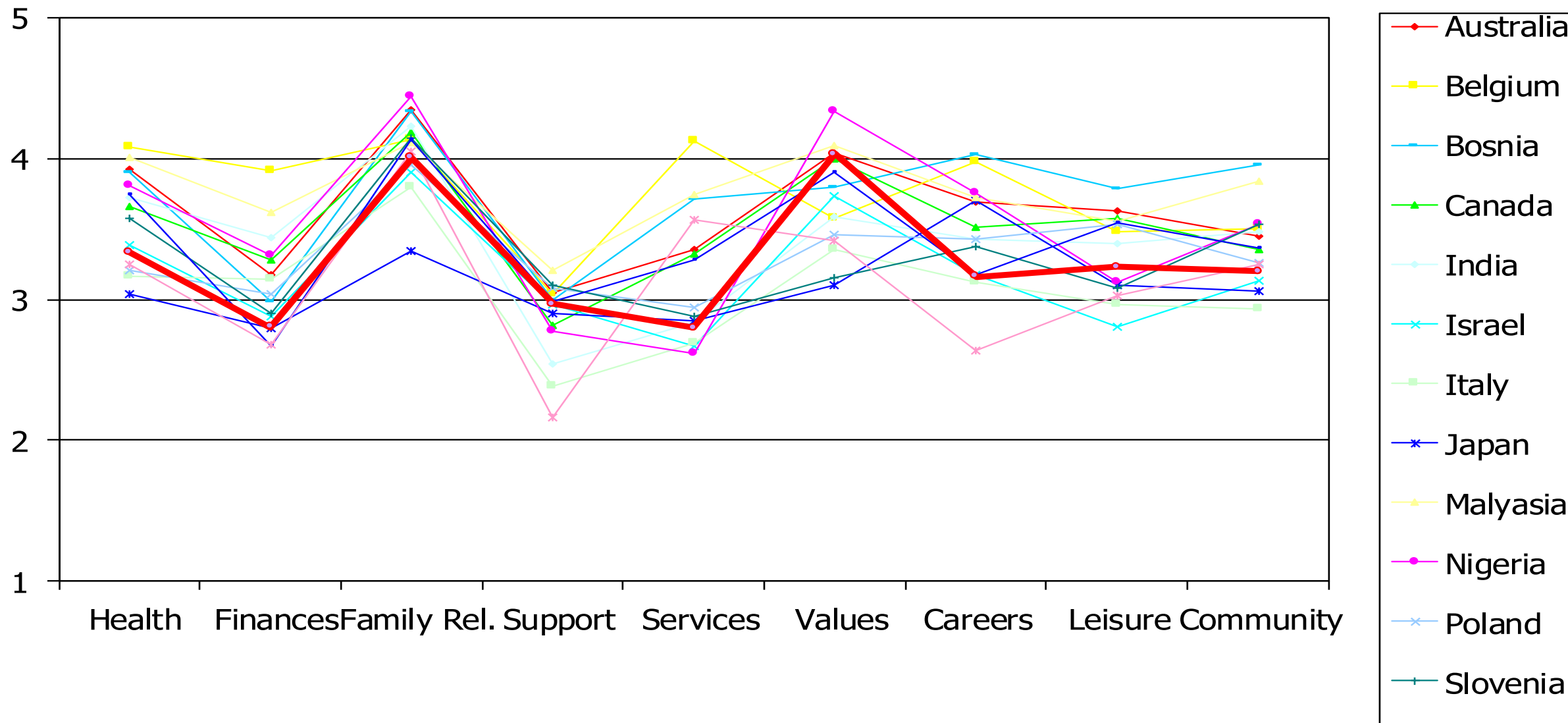


# **Family Quality of Life: in 14 Countries**





# Family Quality of Life





**Inclusion**



**Participation**



**Belonging**





# Quality Inclusive Education

A sense of belonging and membership,  
positive social relationships and friendships,  
development and learning which should  
promote successful outcomes of participation  
and belonging (Odom, 2012).







# Social Inclusion with Children

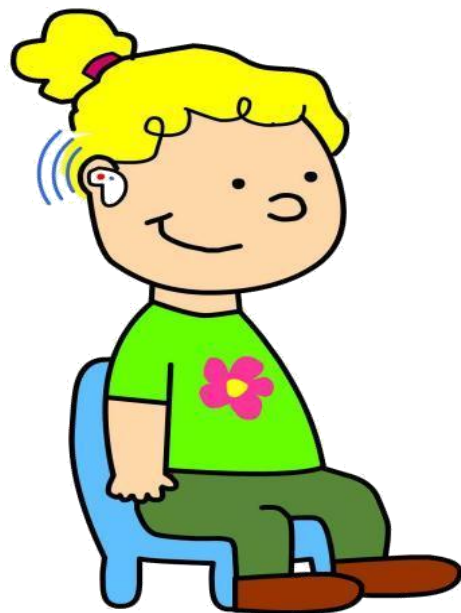
- Extensive evidence indicates that children with disabilities are at increased risk of being isolated, or bullied, compared to non-disabled kids – and that kids with disabilities experience more social exclusion (Donna Koller, Morgane Le Pouesard Joanna Anneke Rummens, 2018)
- Segregated settings may benefit PWIDD by offering a sense of belonging, friendship and safety (Hall,2010; Millner & Kelly, 2009)



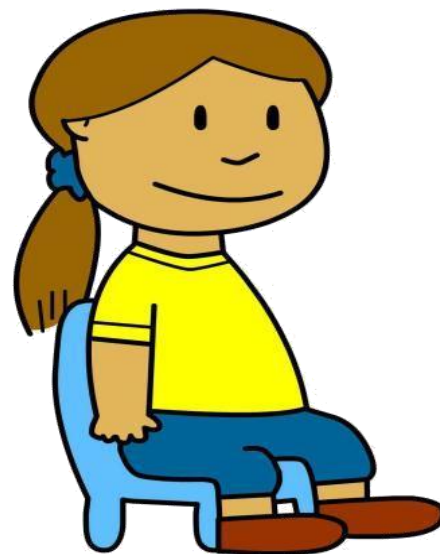


# Children's attitudes toward children with and without disabilities,

Werner, S., Roth, D. & Peretz, H. (2015). Early Childhood Research Quarterly 33, 98-107



**Karen has a hearing aid**



**Dana is a typical child**



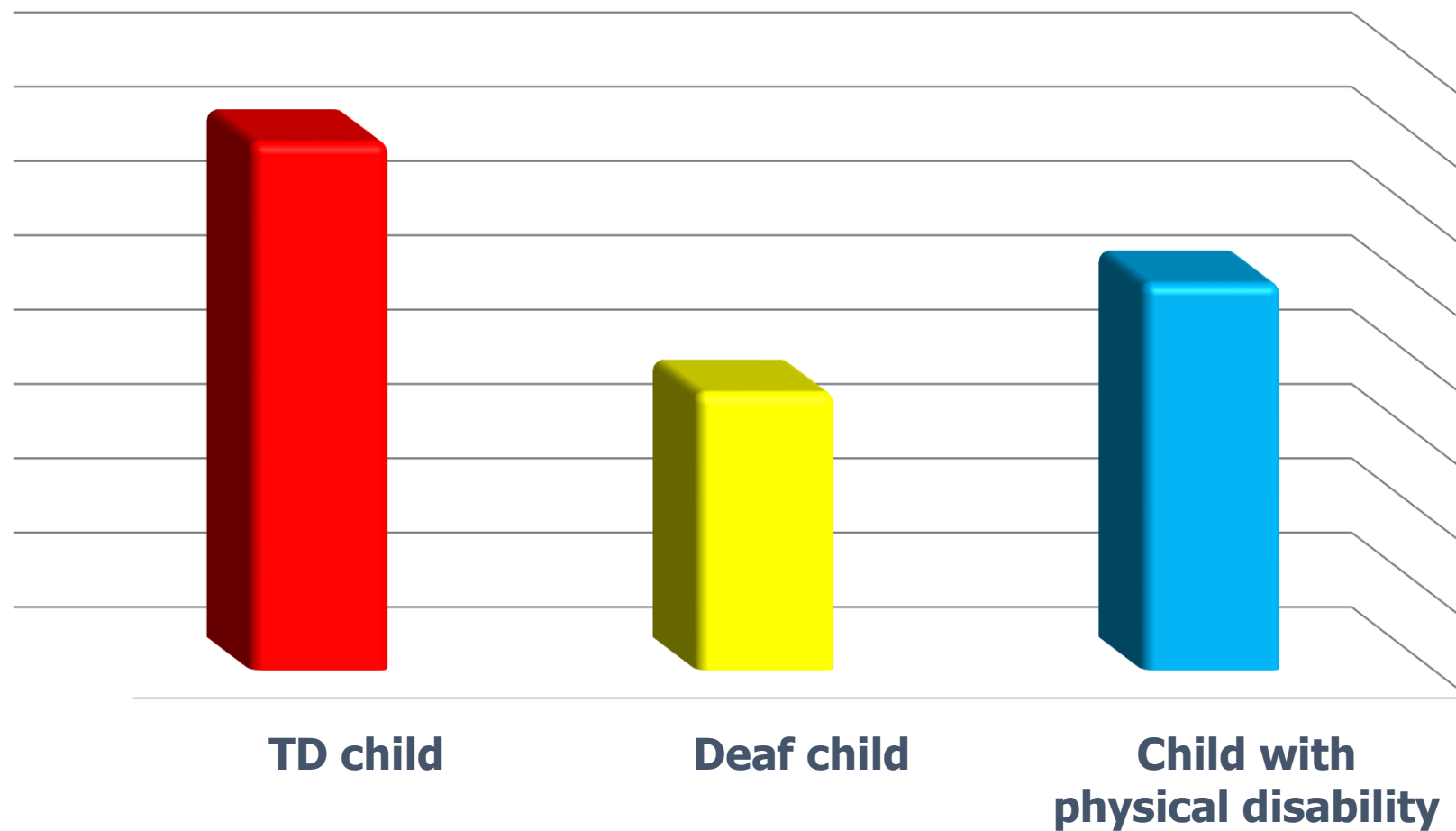
**May uses a wheelchair**





# General Findings – Cognitive, Affective and behavioral Measures combined

Statistically significant  $p < 0.01$







**Social Inclusion**



**Digital Inclusion**







**Family Member**

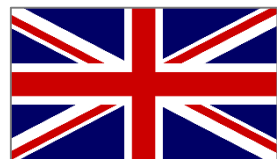


**People with disability**

**Professionals**

**Policy Makers & academicians**

**N=25**





## **What will be The future for kids with disabilities?**

1. What does the future hold for kids with disability?
2. What will be the supports and resources that will be necessary and/or available to them?
3. Will things remain the same, get better, get worse?
4. What will be the demands from professionals, families, support resources, systems?
5. What will be the major issues, challenges and concerns in 10 years to come that will need to be addressed?





## Main themes looking at the future



**Laws, Rights, Regulation**

**Burden on family**

**Technology**

**Social awareness**



**Budgets**

**Inclusion**

**Bureaucracy**

**Synchronization**

**Personalized model**

**Teams & Professionals**

**Advocacy & Leadership**



**Accessibility**





# My hope for the future



There are those who imagine a world where everyone is equal and similar. I hope for a world where there is a difference among people there is a diversity, but each has a place, a space and all have opportunities and access to happiness and fulfillment.



**Diversity & Belonging**







“Happiness Means

喜

someone to Love, Something

to be engaged in and

something to aspire to”



**Anffas 60 anni di futuro**  
**Le nuove frontiere delle disabilità intellettive e  
disturbi del neurosviluppo**



**Beit Issie Shapiro**  
Changing the lives of people with disabilities  
On the Willie & Celia Trump Campus

**THANK YOU!**

***Grazie Mille***

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