

# Comunità in Rete:

## processi di inclusione tra scuola ed extrascuola

Casalgrande 21 novembre 2011

### Il Concetto di Transizione nell'approccio alle persone con Disabilità Intellettiva

Ciro Ruggerini  
Sumire Manzotti

# INDICE

- Nascita recente del concetto di Transizione riferito alle persone con Disabilità Intellettiva
- Implicazioni del concetto di Transizione

# INDICE

- **Nascita recente del concetto di Transizione riferito alle persone con Disabilità Intellettiva**
- Implicazioni del concetto di Transizione

# **Il concetto di transizione nell'arco della vita relativo alle persone con Disabilità Intellettiva**

7° Congresso Nazionale SIRM  
Bari, 28-30 aprile 2011

## **Consiglio Direttivo SIRM**



C. Ruggenerini, C. Porcelli,  
M. Bertelli, CM Cornaggia,  
G Albertini, E Aguglia, A  
Castellani, P Frilli, G  
Giambalvo del Ben, GP La  
Malfa, S Lassi, R Salvini

# Transizione

**Transitions occur throughout life and are faced by all young people as they progress, from childhood through puberty and adolescence to adulthood; from immaturity to maturity and from dependence to independence.**

In addition, some young people experience extra transitions as a result of other life events for example, bereavement, separation of parents, and being placed in care.

Diana Andrea Barron et al. ( 2006)

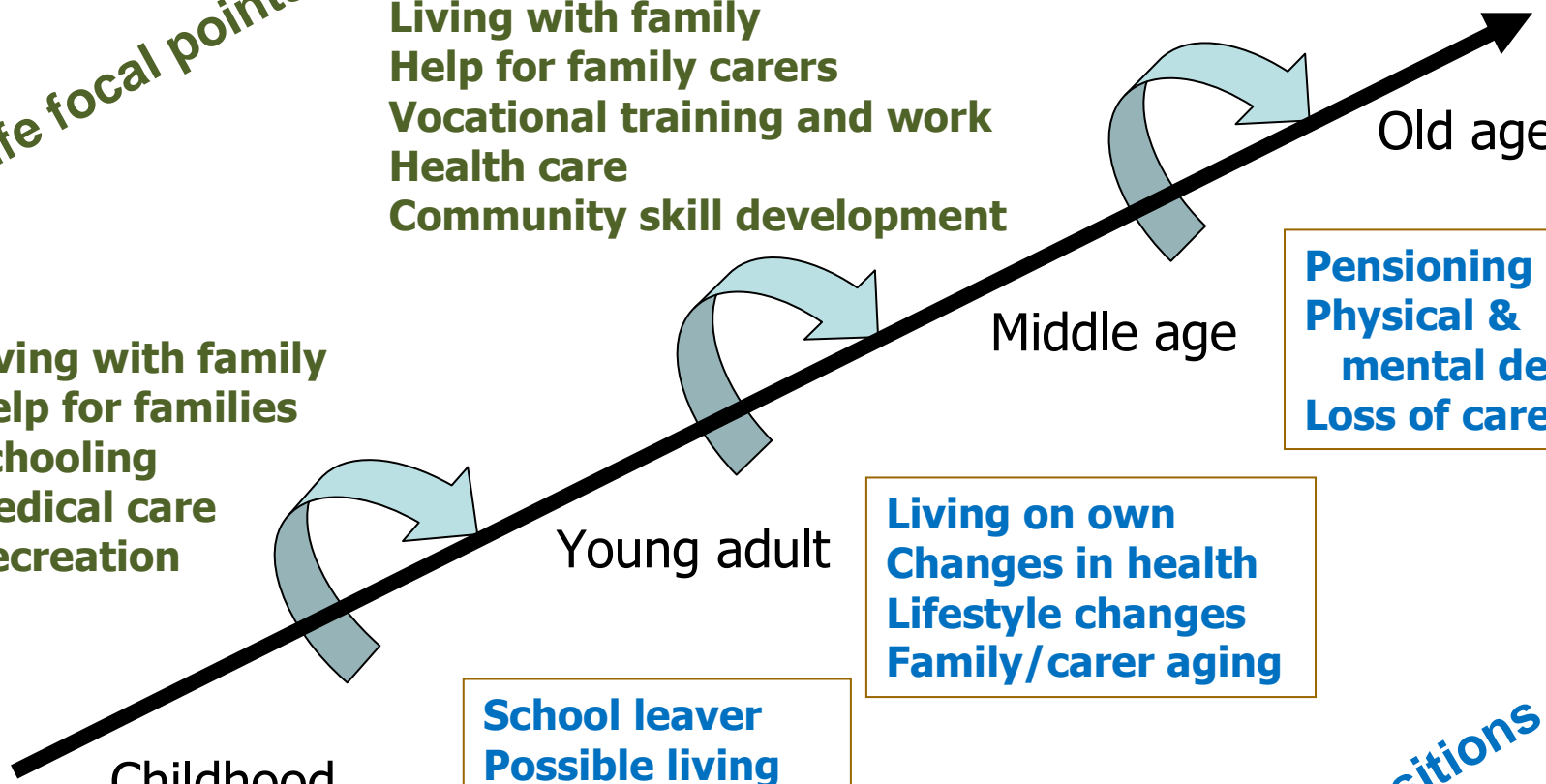
# Transitions and Life Focal Points for People with Intellectual Disabilities

*Life focal points*

Living with family  
Help for families  
Schooling  
Medical care  
Recreation

Living with family  
Help for family carers  
Vocational training and work  
Health care  
Community skill development

Living on own or with group  
Retirement  
Health care  
Community involvement



**School leaver**  
**Possible living on own**  
**Independent of family**

**Living on own**  
**Changes in health**  
**Lifestyle changes**  
**Family/carer aging**

**Pensioning**  
**Physical & mental decline**  
**Loss of carers**

*Transitions*

# Transizione: l'origine di un concetto

- The increased **longevity** of persons with intellectual disabilities in many of the world's nations is the *direct result of medical and social advances* which have also extended the longevity of the general population.
- Yet, the WHO is aware that people with intellectual disabilities are still generally regarded as a **devalued class** and often disadvantaged when attempting to access or secure social and health services.
- With this in mind, and recognizing that **scientific and medical advances can benefit** people with lifelong disabilities

# Transizione

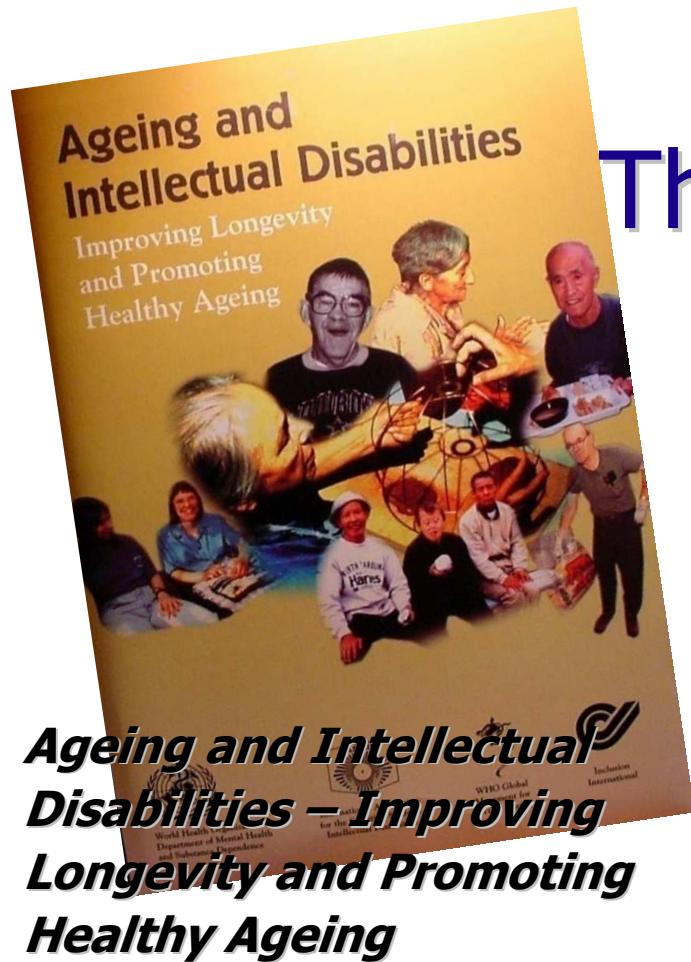
- Orizzonte Internazionale
  - Orizzonte Europeo
    - Altri Orizzonti
  - Orizzonte Italiano





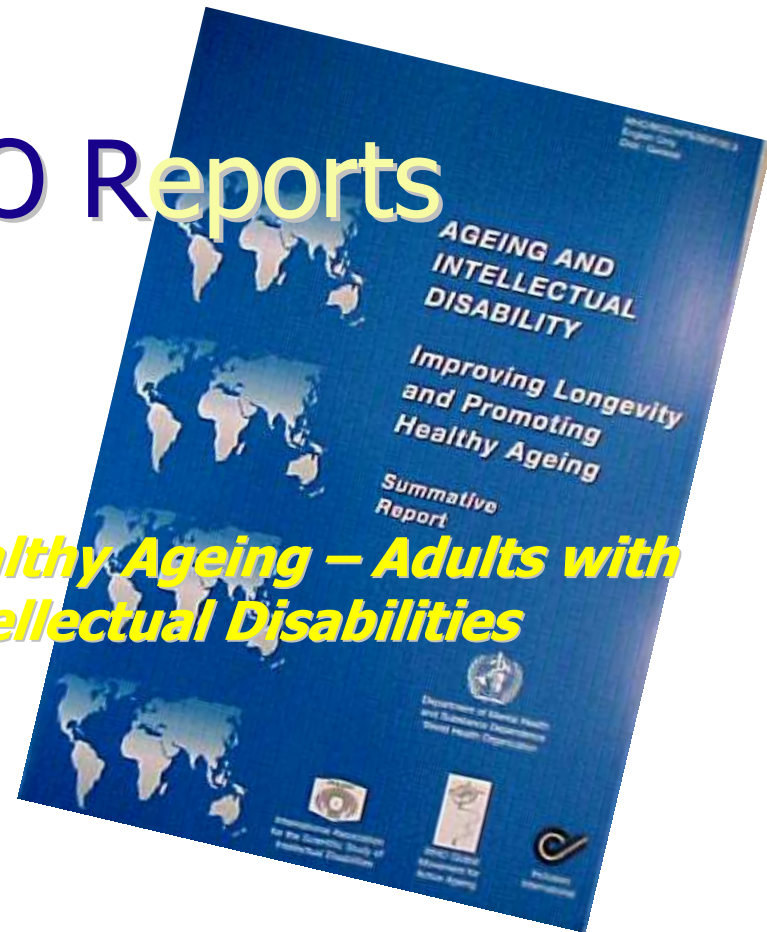
**Orizzonte Internazionale**

# The WHO Reports



**Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing**

*Journal of Applied Research in Intellectual Disabilities* (JARID), 2001, Vol. 14(3), 171-275



**Healthy Ageing – Adults with Intellectual Disabilities**

**Ageing & Intellectual Disability – Improving Longevity and Promoting Healthy Ageing – *Summative report* (WHO, 2000)**

# The WHO Reports (2000)

International Association for the Scientific  
Study of Intellectual Disabilities (**IASSID**  
**AGING SIRG**) – Matthew P Janicki -

Inclusion International (**II**) – Nancy Breitenbach -

Department of Mental Health and Substance  
Dependence (**WHO**)

# The WHO Reports (2000)

Key issues:

- There is generally a **lack** of organized public or private **sector system** designed to address the needs of persons with ID
- **Public attitudes** need to be modified ...
- There is a need for **supportive services, health surveillance and provision, and family assistance** for people with ID ...
- **Women** with ID often find themselves a disadvantaged class ...
- In some nations people with ID are **still not distinguished clearly from mental illnesses** ...
- Health practitioners generally fail to **recognize** special problems ...

# The WHO Reports (2000)

## Recommendations

Over their **life-span**, adults with intellectual disabilities should maintain the same array of preventive health habits and receive the **same protective health services as those offered to the general population ...**

To achieve this goal: →

# The WHO Reports (2000)

## Recommendations

- Health care providers should adopt a **life – span approach** ...
- Adults with DI and their carers need to receive appropriate and ongoing **education** regarding healthy living practices ...
- Ensure that there are sufficiently **educated and trained medical and health personnel** ...
- The distinctive health care needs ... of **women with ID should be recognized** ...



Orizzonte Europeo

# Carenza di strategie

“Non vi è alcuna **strategia coerente e basata sulle evidenze** per il **monitoraggio della salute delle persone con disabilità intellettiva negli Stati Europei.**”

Per questo non è possibile fare confronti tra questa popolazione e la popolazione generale nè confrontare la situazione in diversi Paesi. Senza una tale strategia, **verranno meno eventuali tentativi di implementare le politiche europee** e quindi di promuovere invecchiamento “sano” dei cittadini europei con disabilità intellettive”

p. 48

Walsh, P.N., Kerr, M., Van Schrojenstein Lantman-de Valk, H., (2003). Health indicators for people with intellectual disabilities. A European perspective. *European Journal of Public Health*, Vol 13, No 3, Supp 1, 47-50







# **Monitoraggio dello Stato di Salute degli Adulti con Disabilità Intellettiva in Europa**

**Coordinato da Patricia Noonan Walsh**  
Centro per gli Studi sulla disabilità, University College Dublin Ireland



<b><i>Pomona</i></b>	<b><i>2002-2004</i></b>
<b><i>Pomona-2</i></b>	<b><i>2005-2008</i></b>

# Orizzonte Europeo: Progetto POMONA



- **POMONA I (2002-2004)** aimed to identify a set of health indicators specific to people with intellectual disability resident in the European Union.  
The monitoring of these indicators on a longitudinal basis will provide a benchmark of health of people with intellectual disability over time thereby highlighting any reduction in the disparity of health status and access to health systems experienced by those with intellectual disability.
- Using a previously defined set of health indicators for the general population as a working framework, (the European Community Health Indicators: ECHI), POMONA project partners engaged in a consultation process in each participating Member State. People with intellectual disability, family & carers, advocates, health professionals, service providers, researchers, and policy makers all contributed to the identification of a draft set of eighteen health indicators for people with intellectual disability. An extensive review of evidence-based research was undertaken to validate this selection and potential operational and measurement definitions of these indicators were presented.

## THE POMONA 18 INDICATOR SET

### Demographics

- 1.1 Prevalence
- 1.2 Living arrangements
- 1.3 Daily Occupation
- 1.4 Income/Socio-Economic Status
- 1.5 Life Expectancy

### Health Status

- 2.1 Epilepsy
- 2.2 Oral health
- 2.3 Body Mass Index
- 2.4 Mental Health
- 2.5 Sensory
- 2.6 Mobility

### Determinants

- 3.1 Physical Activity
- 3.2 Challenging Behaviour
- 3.3 Medication

### Health System

- 4.1 Hospitalisation/Health Care
- 4.2 Health Check Ups
- 4.3 Health Promotion
- 4.4 Training Health Professionals

Orizzonte Europeo:  
**Progetto POMONA**



- **POMONA II, (2005-2008):**

The **over-arching aim** was to promote the **quality of life and health** of people with intellectual disabilities in Europe by the provision of accurate health information and knowledge regarding this population

Orizzonte Europeo:  
**Progetto POMONA**



**POMONA II, (2005-2008):**

aim:

pilot the **collection of data** on people with  
intellectual disability in thirteen Member States;  
interview with **1300 men and women with ID;**

# ***POMONA II (2005-2008)***

- **IRLANDA**  
*Prof. Patricia Noonan Walsh & Christine Linehan*
- **Austria**  
*Prof. Germain Weber & Dr Cecilia Heiss*
- **Belgio**  
*Prof. Geert van Hove*
- **Finlandia**  
*Dr. Tuomo Määttä*
- **Francia**  
*Dr. Bernard Azema*
- **Germania**  
*Prof. Meindert Haveman*
- **Italia**  
*Prof. Serafino Buono*
- **Lituania**  
*Dr. Arunas Germanavicius*
- **Paesi Bassi**  
*Dr. Henny van Schrojenstein Lantman-de Valk*
- **Norvegia**  
*Dr. Jan Tøssebro*
- **Romania**  
*Dr. Alexandra Carmen Căra*
- **Slovenia**  
*Dr. Daša Moravec Berger*
- **Spagna**  
*Prof. Luis Salvador*
- **Galles, Regno Unito**  
*Prof. Mike Kerr*

## SUMMARY

### Demographics

- 1.1 Prevalence
- 1.2 Living arrangements
- 1.3 Daily Occupation
- 1.4 Income/Socio-Economic Status
- 1.5 Life Expectancy

- 77% lived in the community
- over one-half said they had a job – of these, half earned money



## SUMMARY

### Health Status

2.1 Epilepsy

2.2 Oral health

2.3 Body Mass Index

2.4 Mental Health

2.5 Sensory

2.6 Mobility

- 28% of people reported epilepsy
- 21% reported having pain in their mouth

## SUMMARY

## Determinants

3.1 Physical Activity

3.2 Challenging Behaviour

3.3 Medication

- one-half of the people were either 'overweight' or 'obese'
- two-third of the participants took at least one kind of medication (most commonly used medication falls within the nervous system category)

## SUMMARY

## Health System

- 4.1 Hospitalisation/Health Care
- 4.2 Health Check Ups
- 4.3 Health Promotion
- 4.4 Training Health Professionals

- 83% had visited a doctor in the past year
  
- 17% had stayed in a hospital during the past year



**Altri Orizzonti**

# Altri paesi: atti, piani, ricerca...

<b>Paese</b>	<b>Anno</b>	<b>Documento</b>	<b>Concetti Chiave</b>
<b>Sweden</b>	1998	<b>Special-rights law</b>	the social role as a citizen; increased empowerment and influence over one's services; the same opportunities as other citizens
<b>AUSTRALIA (Melbourne)</b>	2005	<b>Canvassing the Issues</b>	
<b>Japan</b>	2006	<b>the Services and Supports for Persons with Disabilities Act</b>	Universal platform; User friendliness; Institution to community; Transparency and Clarification; Stable fiscal resources
<b>Singapore</b>	2006	<b>enabling Masterplan</b>	Heartware; City of possibilities; the opportunity to become equal, integral and contributing members of society
<b>UK</b>	2008	<b>Implementation of <i>Valuing People</i></b>	Mainstream public services as a key indicator of inclusion in Universal citizenship; New Public Management- critique of large public sector agencies, commitment to consumer choice between alternative providers, Market Management; enhancing choice for ID; participation to local partnership boards
<b>CANADA (Halifax, Nova Scotia)</b>	2008	<b>What about us? Aging with Disability and Dignity</b>	access to needed services; person centred supports; full-citizenship and inclusion; continued participation and living; age-friendly communities; inform key decision makers; best-practice standards

<b>Belgio</b>	2008	<b>Accommodation and Supports for the Aging of People with ID</b>	a person-centered philosophy; Aging in Place; Changing Capabilities and needs of aging people; Accessibility, Safety, Comfort, Independence, Social Interactions
<b>Clanda</b>	2009	<b>Care and Service trajectories: Defining Its Course and Determinants From the Client's Perspective</b>	transition from children's service to adult services; continuity, accessibility, availability, and flexibility of care and services; asking which criteria people with ID and their families value most when judging the quality of trajectories
<b>USA</b>	2010	<b>Health Surveillance System for People with ID in the US</b>	quality healthcare; multistage strategy; healthcare reform
<b>Ireland</b>	2010	<b>Transition from Special education into Postschool Services for Young Adults with ID: Parents' Experience</b>	vocational training and employment; the role of the parent; gaps between policy and service provision
<b>UK</b>	2011	<b>Transition for Teenagers With Intellectual Disability: Carers' Perspective</b>	the need for quality information and validated and standardized tools for transition planning; integrated referral systems for health and social care need; clear care pathways; monitoring of individual and systemic outcomes
<b>UK (Wales)</b>	2011	<b>Multi-agency Protocols in ID Transition Partnerships</b>	transition protocols; person-centered planning; involvement of young people and carers; inclusion of external agencies in transition planning

# Intellectual Disability and Ageing: Canvassing the Issues.

Leveratt et al. (2005)-

Australian Catholic University -

## Contents

### \* **Theoretical approaches to ageing and ID**

“... the whole focus of ‘**Normalisation approach**’ is on changing disabled people to make them more like “normal” people rather than challenging the idea of “normality” ...”

**... le persone con DI  
devono diventare simili  
alle persone normali  
oppure bisogna  
cambiare il concetto di  
normalità? ...**

### \* **The interviews**

- Individuals and their families
- Disability service providers
- Aged care service provider
- Policy workers

# Possibilities for an Inclusive Society in Singapore: Becoming Inclusive Within. Lim (2009)- National Institute of Education -

... the needs for the possibilities of changes in society **toward inclusivity** of diverse others (e.g. persons with intellectual disabilities) therefore **lie within the individual** and imply that at the core of such change is **personal interior growth and transformation ...**

... **al centro di questo cambiamento c'è una crescita personale interiore e una trasformazione ...**

... **non si può dare ciò che non si ha ...**

... **in assenza di una profonda conoscenza di sé, di libertà interiore, di integrità e della capacità di amare, c'è uno spazio ridotto per includere, condividere, donare ...**

... this thinking honors and reflects the adage that **“one cannot give away what one does not possess within”**. Without the deepening of self-understanding, freedom, integrity, and the capacity to love, there is little within, as a basis, to include, share with, or give to others ...





**Orizzonte Italiano**

Istituto Sacra Famiglia,  
***La persona adulta con ritardo mentale  
nelle istituzioni: cura e riabilitazione.***

Giornate di studio, 30 Nov - 1 Dic 1995, Milano

# ***La persona adulta con ritardo mentale nelle istituzioni: cura e riabilitazione.*** Milano,

1995

Giorgio Moretti, "Divenire biopsichico del Ritardato Mentale"

“ ...se è vera la stima secondo la quale il Ritardo Mentale incide nella popolazione generale in misura dell'1.5% (stima che è, a mio avviso, piuttosto bassa), i soggetti ritardati in Italia si avvicinerebbero al milione, 600/700.000 dei quali sarebbero in età adulta. **Di tale rilevante popolazione ben poco sappiamo ...**

... può essere sconcertante , in un'epoca dominata dalla ricerca di precisione, scoprire che molte decine di migliaia di individui gravitano sul mondo medico ed assistenziale in modo assolutamente irrazionale, ricevendo perciò un'assistenza non guidata se non da una conoscenza approssimativa ...

... **ciò di cui si avverte il bisogno è un'ampia survey** capace di fornire delle direttive generali che possono declinarsi secondo tre assi principali: la situazione sociale, l'età, il grado di compromissione ...”

- Giorgio Moretti e don Giancarlo Pravettoni – dell'Opera Don Guanella - promossero nel 1995 questa survey - una ricerca che interessò 483 persone con DI in età adulta – di una età media di 36 anni - , che frequentavano 22 Residenze o Centri Diurni della Lombardia e del Lazio – (Ruggerini e coll. 2004).

# il Percorso della Survey proposta da Giorgio Moretti

- 1995: ideazione e proposta al Superiore e Consiglio generali della Congregazione dei Servi della Carità – Opera Don Guanella
- 1996: affidamento del coordinamento a Don Giancarlo Pravettoni
- 1997: messa a punto del metodo della ricerca (Questionario) e individuazione delle organizzazioni assistenziali disponibili per la collaborazione alla ricerca
- 1999: prima elaborazione statistica dei dati relativi a **483 Ritardati Mentali adulti**
- 2004: presentazione definitiva della “**La sfida tra sviluppo e Ritardo Mentale**” (Franco Angeli Editore).



**orizzonte italiano:  
Costituzione AIRIM nel 1996**



- ***L'Associazione Italiana per il Ritardo Mentale (AIRIM)***, costituitasi nel 1996, con lo scopo di promuovere il coordinamento di Operatori e Centri che si occupano di Ritardo Mentale, in particolare in età adulta, rispondendo ad un'esigenza, avvertita nel settore, di collegamento e di promozione e qualificazione delle attività.



**orizzonte italiano:  
Costituzione della SIRM nel 1996**

- Società Italiana per lo studio del Ritardo Mentale (SIRM), "Sezione Speciale" della Società Italiana di Psichiatria (SIP)

# “La Nuova Longevità’ della Disabilita’ Intellettiva”

Percorsi di cura dalla gestione alla relazione (Liguori Editore, 2008)

Tema: assistenza alle persone adulte con sindrome di Down che vanno incontro a Demenza

- Una riflessione più generale relativa ai ruoli sociali e alla qualità di vita nel percorso di nuova longevità di questa popolazione.
- L'analisi della relazione tra caregiver e persona accudita
- La capacità relazionale e la flessibilità del caregiver
- Descrizione di una esperienza iniziata nel 2005 presso il centro integrato "La Meridiana" ( ANFFAS, Trento), il primo, in Italia dedicato alla assistenza alle persone con Sindrome di Down e Demenza



**“La Promozione della Salute Mentale nella Disabilità Intellettiva”** Consenso multidisciplinare e intersocietario  
(Erickson, 2010)



*20 capitoli;  
prospettiva life-span e  
multidisciplinare;*





# Prospettive

- 1. Obiettivi**
- 2. Prassi di assistenza**
- 3. Ricerca**

# Prospettive

a. obiettivi

# Report on the State of Science on Health Risks and Aging in People with Intellectual Disabilities. (IASSID

Special Interest Research Group on Aging on ID)

Meindert Haveman et al (2009)

- Create a **healthy environment**
- Identify **health risk** early, including ageing itself
- Manage **illness** appropriately
- Prepare for appropriate palliative care and **end-of-life decision making**
- Call for effective training of health care **practitioners**

Prospettive

b. tipi di prassi operative

# Aging With Developmental Disabilities. An Overview.

Toby Long & Sarkis Kavarian (2008)

- **Person**-based
  - *Supporting the individual in such areas as nutrition, physical activity, preventive care, rest, management of stress*
- **Provider**-based
  - *Systematic inclusion of information on developmental disabilities within curricula for service providers (FORMAZIONE DELLA COMUNITA', ONU, 2006)*
- **Policy** -based
  - *Creating a system of care to improve coordination among agencies*

Prospettive

c. ricerca

# The transition to adulthood for youth with disabilities: Evidence from the literature. Debra Stewart et. al (2010)

## Inclusion Criteria

- Published in past 8 years (2000 – 2008) (Nº= 134)
- “Evidence based” references
- Population of interest is young people, ages 14 to 29 years of age with “disabilities”

# The transition to adulthood for youth with disabilities: Evidence from the literature. Debra Stewart et. al (2010)

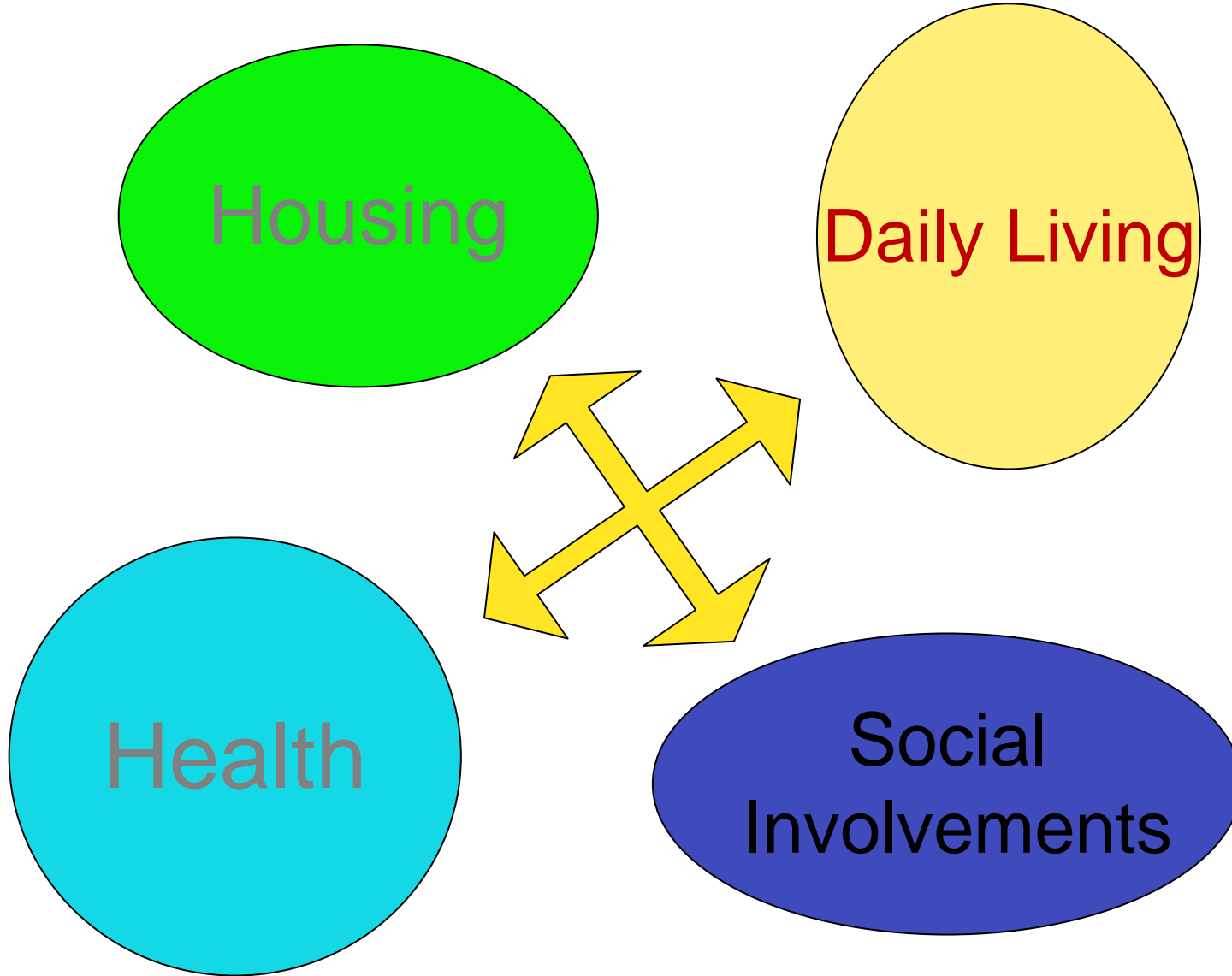
## Themes

1. Current Experiences and Outcomes (Youth, Parent, Service providers)
2. Different Types of Transition ( to and from services or systems; “developmental” or “lifecourse” transition)
3. Domains of Transition (Employment domain, Education domain, Living domain, Social and community life domain)
4. Factors that Influence Transition – Barriers and/or Supports (Youth factors – Risk factors/barriers; Supports and Facilitators -; Environmental Factors: Barriers and Supports)
5. Complexity



The transition to adulthood for youth with disabilities:  
Evidence from the literature. Debra Stewart et. al (2010)

- A. Transition to adulthood is now viewed as a complex phenomenon and **this is leading reserchers to study interactions of person and environment**, as well as dynamic processes, opportunities and other complexities
  
- B. It may be useful and cost effective to **connect “typical” transition frameworks and “disability” frameworks for future study**, to learn more about similarities and differences and promote an inclusive approach to research
  
- C. Researchers, organizations and services will **need to put aside the view that “our group is different/special”** and ... work together



## Issues related to

### Housing

- If living in family home
  - Supports for carers
  - Modifications to home if physical needs change
- If in non-family settings
  - Financial supports
  - “Aging in place” supports
  - Home sharing – finding housemates

## Issues related to

### Daily Living

- Aid with finding employment
- Enrolment in community “third age” activities
  - Learning community living skills
  - Self-advocacy for meeting needs
  - Help with shopping and other daily activities
  - Civic involvements

## Issues related to

### Health

- Stable affiliation with physician, clinic, or other health care center
- Periodic health screening for aging related conditions or diseases
- Dental care (oral health)
- Mental health care
- Specialty care for physical disability

## Issues related to

### Social Involvements

- Maintaining a network of friends
- Involvement in
  - community activities
  - neighborhood amenities
  - civic affairs
- Recreational outlets (active and passive)
- Self-initiated activities

# INDICE

- Nascita recente del concetto di Transizione riferito alle persone con Disabilità Intellettiva
- **Implicazioni del concetto di Transizione\*. Ambito:**
  - **educativo**
  - **attività sanitarie di riabilitazione**
  - **medico**

\*Ruggerini C et al.: La sfida tra sviluppo e ritardo mentale, Franco Angeli, Milano, 2004

# Implicazioni del concetto di Transizione. Ambito Educativo

Concezioni di base:

1. neurobiologia: **l'esperienza scolpisce il cervello** in tutto l'arco della vita (Shatz, 1992)
1. vi sono **più ambiti dell'apprendimento**: imparare a conoscere, imparare a fare, imparare a vivere insieme, imparare a essere (UNESCO, Delors, 2997)
1. le capacità intellettive, in assenza di patologie sopraggiunte, **umentano nell'arco intero della vita** (Albert, 1996) anche nelle persone con Disabilità intellettiva (Madle, 1990)

# Implicazioni del concetto di Transizione. Ambito Educativo

**Progetto di Vita** ( Progetto educativo individualizzato; Attività di Abilitazione sociale)

- alla persona con DI può accadere di essere considerata ... un eterno bambino ...
- ... una sorta di inimmaginabile trascuratezza rischia di avvolgere la condizione del disabile qualora varchi la soglia dei servizi di neuropsichiatria infantile ... mentre l'etichetta di disabile stabilizzato rischia di costituire la notte in cui tutte le vacche sono nere, **annullando il diritto di ognuno di vedersi riconoscere non solo una storia, ma anche un futuro**, il lavoro per progetti riafferma la cultura della differenza, insieme al diritto dei nostri ragazzi a coltivare il loro sogno personale ... (Franchini, 2002)

# Implicazioni del concetto di Transizione. Ambito Educativo

... è possibile ipotizzare **una scuola per adulti disabili**, che consideri quali percorsi siano ancora percorribili, quali conoscenze acquisibili e quale crescita individuale sia realizzabile. Una scuola dove si effettuino lezioni ad hoc finalizzate a una **consapevolezza cognitiva e non solo pragmatica delle loro esperienze**, incontri/discussioni relativi al proprio processo evolutivo (per esempio cosa riconoscono di aver imparato, cosa ritengono di voler imparare, etc ...) per una **consapevolezza di sé come soggetti ...**(Gava, 2001)

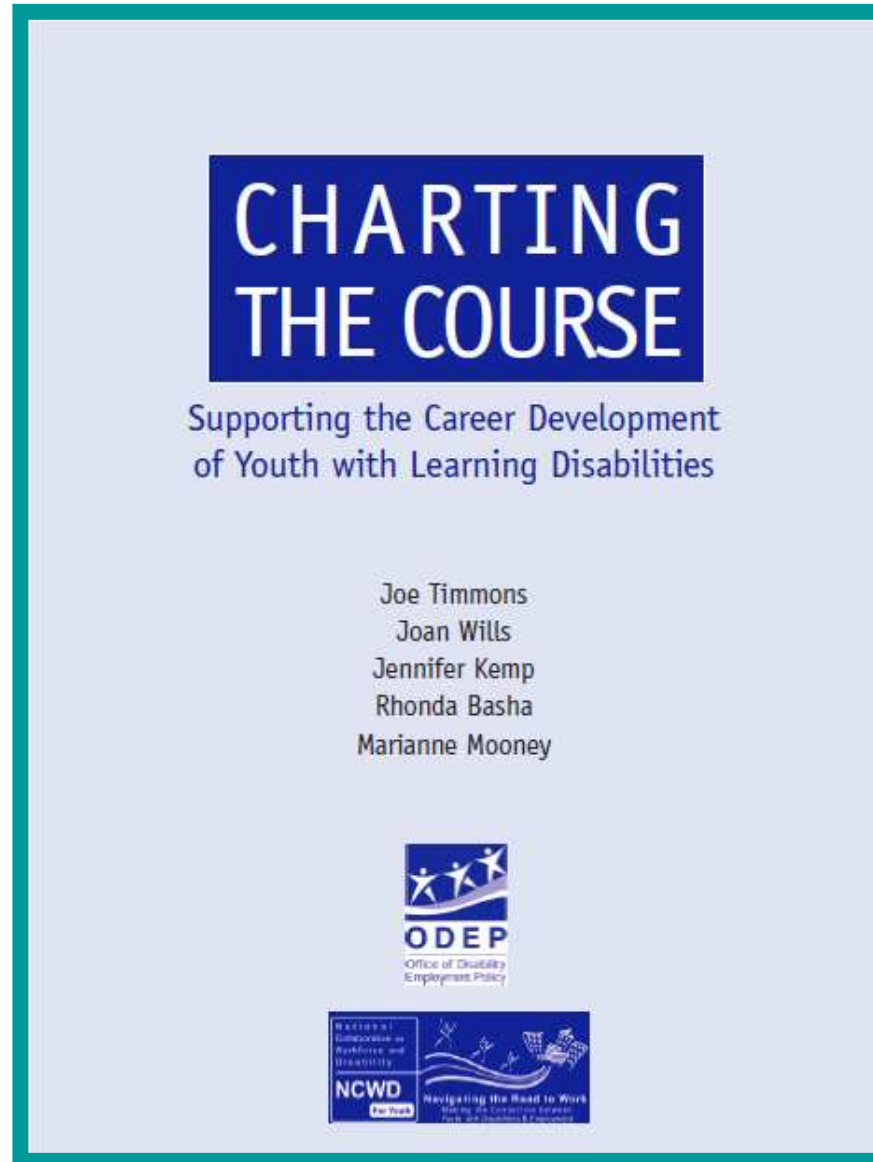
# Implicazioni del concetto di Transizione. Ambito Educativo

Una **nuova prospettiva** per la clinica e la  
pedagogia:

la valutazione (clinica) e l'insegnamento  
(pedagogia) dei **“fattori del successo”**



Cambiamento della paradigma: modello medico → sociale



# New perspectives on Supporting Individuals who have a Learning Disability

– Timmons et al., 2010 -

... Based on the current research, individuals with LD need to learn to develop “strategies for success” across the lifespan, and in multiple contexts... the field needs to evaluate its current position and emphasize the development of success attributes to the same degree that we do academic skills ...

- Success attributes:
  - Self-awareness/self-acceptance of their learning disability
  - Proactivity
  - Perseverance
  - Emotional stability
  - Appropriate goal setting
  - Presence and use of effective social support systems

## Implicazioni del concetto di Transizione.

### Attività sanitarie di riabilitazione

(Trattamento dei Disturbi di linguaggio e del Movimento)

- La Prospettiva dell'arco della vita introduce la necessità di **considerare**

... l'utilità dei Trattamenti in età infantile e adolescenziale alla luce dei reali vantaggi funzionali o di prevenzione che essi sono in grado di indurre nelle età successive...

## **Implicazioni del concetto di Transizione. Attività strettamente medico**

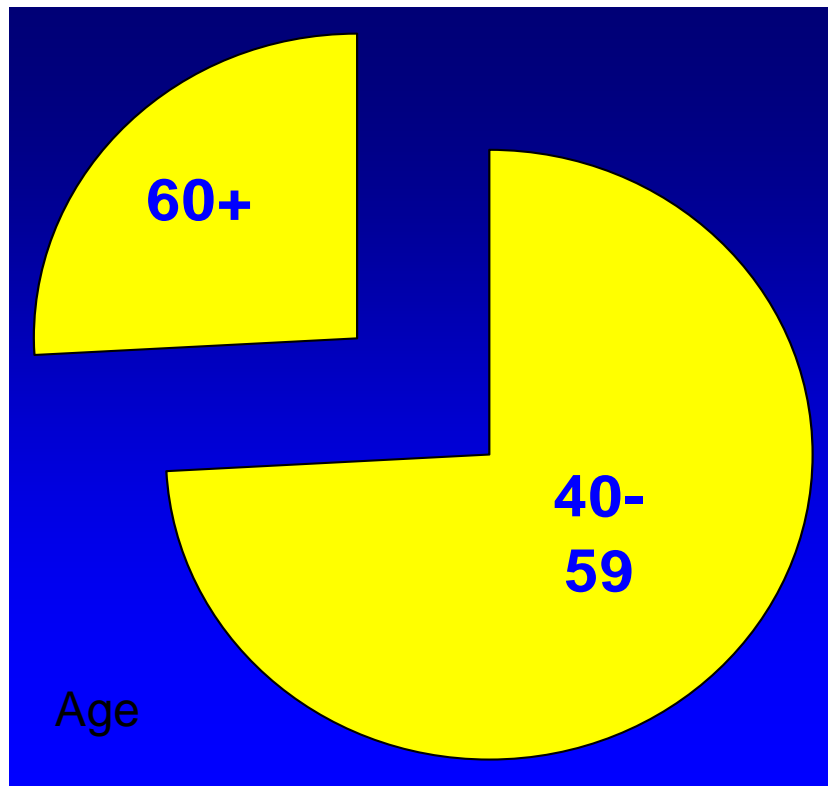
Introduzione di una cultura della “adulità”  
impone:

... la attuazione delle stesse pratiche di  
prevenzione sanitaria di tutta la  
popolazione ( es.:prevenzione dei tumori  
etc ...)

Grazie per l'Attenzione



## Proportion of older population of adults with intellectual disabilities



- Currently about **75%** of all older adults with intellectual disabilities are in the **40-to-60 age group**
- Expectations are that the 60+ age group will increase over the next years

# What is contributing to longevity?

- **Available and effective health care** (medical training in disabilities, better nutrition, disease prevention)
- **Research about growing older** (richer medical and social science literature enabling better services)
- **Cohort differences** (40-year-olds born in the 1960s – different life experiences)
- **Public policy attention** (governmental financing of services, laws, regulations)
- **Education** (academic interest in gerontology and greater awareness among administrators, educators, and professionals)



# The WHO Reports (2000)

## Main issues

Physical Health Concerns

Biobehavioral and Mental Concerns

Women's Health Concerns

Service Concern

# Physical health concerns

- Alzheimer's disease and related dementias
- Physical deconditioning and loss of stamina
- Obesity-related diseases
- Sensory impairments
- Poly-pharmacy and adverse medication reactions
- Mobility impediments
- Tobacco or second-hand smoke
- Exposure to toxicity in work place
- Contagious diseases
- Abuse and violence
- Poor nutrition (lack of availability or by choice)
- Non-medical drug use
- Passive lifestyle

[Source: Prasher, V., & Janicki, M.P. (2002). *Physical health and adults with intellectual disabilities*. Oxford: Blackwell Science]

Janicki



# Mental health concerns

- Misunderstanding of differences between mental illness and intellectual/cognitive disability
- Biological vs. social factors causing mental illnesses or psychiatric conditions
- Psychiatric diagnostic inadequacies
- Bias toward institutionalization – or the lack of adequate community supports
- Life-course stressors
- Loss of family or friends (reactive depression)
- Medical condition affecting mental health
- Psychiatric condition affecting physical health
- Social unrest – life disruption - violence
- Not understanding age-related c
- Discordance c
- Older age role expectations

[Source: Davidson, P.W., Prasher, V., & Janicki, M.P. (2003). *Mental health, intellectual disabilities, and the aging process*. Oxford: Blackwell Science]



# Health concerns of women with disabilities

- Discrimination against women with disabilities – denial of services & devalued status
- Abuse and neglect
- Variability of health care
- Lack of screening for age-associated conditions due to disability
- Inadequate research & education

[Source: Walsh, P.N., & Heller, T. (2002). Health of women with intellectual disabilities. Oxford: Blackwell Science]



# Service Concerns

- Countries vary in their models of care provision ...
- **Outcomes** that serve as basis for demonstrating the social value of intellectual disability services may include:

*practical, leisure or life enhancing skills ...;*

*improved or maintained dietary and general health status ...;*

*a varied rhythm of life;*

*recognition that challenge and productivity must continue through old age;*

*an increased and well-established social network;*

*participation on a regular basis in the general life of the*

# WHO – ‘Promoting Healthy Aging’

## >> the Barriers <<

### Barriers to ‘Longevity’

- Disease/malnutrition/pove rty in childhood
- Lack of (or deficient) health services
- Poor population health status
- Poor nutrition and hygiene
- Lack of employment or activities
- Unavailable rehabilitation supports

[Source: WHO. (2000). Ageing & Intellectual Disability – Improving Longevity and Promoting Healthy Ageing – Summative report. Geneva: World Health Organization]

- Inadequate housing

### Impediments to ‘healthy aging’

- Myths and stigma associated with disability
- Poor general or national health status
- Specialty health systems lacking for persons with disabilities
- Poorly organized state mechanisms for supports to persons with disabilities

- Scant information c research



# Factors affecting quality of life and the aging process of people with disabilities

- Uncertainties related to aging of parents } Parents age – they may retire, become ill or infirm, die, move
- Dysfunctional dependency } Some adults with ID have unnatural over-dependency; some parents foster over-dependency
- Role-reversal with adult with a disability assuming carer responsibilities } How effective an advocate can a son/daughter be? How to support them as carers?
- Challenging behaviors } Behaviors that irritate may evolve for varying reasons (chronicity, pain, lack of attention, etc.)
- Cognitive impairment or decline (pre-dementia) } Judgment and other decision making, taking care of oneself, being able to be left alone

# What lifelong factors help produce an healthier old age?

- Exercise and fitness
- Nutrition and diet
- Disease prevention
- Social involvement
- Early medical attention
- Periodic screenings and immunizations

[Source: WHO. (2000). Ageing & Intellectual Disability – Improving Longevity and Promoting Healthy Ageing – Summative report. Geneva: World Health Organization]





# A Five-Country Comparative Review of Accommodation Support Policies for Older People With Intellectual Disability

Policy and older people with intellectual disability

	UK	Australia	Canada	U.S.	Ireland
Mention of older people with ID in aged-care policy documents	<i>National Service Framework for Older People</i> identified issues for older people with ID, such as premature aging and different needs to be taken into account in developing services; singles out partnerships with mental health services in particular and the importance of specific health problems being addressed locally (DoH, 2001a)	<i>National Strategy for an Aging Australia</i> identified people with ID as one of the groups facing particular barriers to obtaining the level and type of services they need; suggests they will require specific or special arrangements to meet needs (Andrews, 2001).	<i>National Advisory Committee in Aging</i> identified aging with ID as an issue and commissioned a paper on aging and developmental disabilities as one of series on "Seniors on Margins" (Government of Canada National Advisory Council on Aging, 2004).	Early recognition of age-related issues: Many U.S. states developed state activity plans targeting older clientele with ID during 1980s (Janicki, Ackerman, & Jacobson, 1986); 1987 amendments to Older Americans Act enabled older adults with developmental disabilities to receive mainstream aging services, enable funding of specialist services, encourage state units on aging and area agencies on aging and state and community ID agencies to jointly plan and develop services for older adults with ID; amendments to the Nursing Home Reform Act 1987 addressed inappropriate placements through procedures to restrict admission and provided for specialized services for those who remained (Janicki, 1999; Janicki & Dalton, 2000)	<i>Action Plan for Services for Older Persons 1999–2008</i> (Eastern Health Board) recognized challenges posed by people with Down syndrome and dementia; action plan for dementia recommended specially designed care for people with Down syndrome and dementia delivered in ID system, with training facilitated by old-age psychiatry or geriatric medicine (McCarron & Lawlor, 2003; O'Shea & O'Reilly 1999).
Mention of issues for older people with ID in national ID policy frameworks	National policy mentions the need to address aging issues, notes older people may be "misplaced" in "aged care"; suggests partnerships between different care sectors (such as ID, mental health, and older people); suggests age-related health issues can be tackled through person-centered planning (DoH, 2001b). Suggests the need for flexible design and provision of accommodation support (Scottish Executive, 2000).	State and federal disability legislation has no upper age limit; two of the 19 priorities in the 2002–07 Commonwealth/State agreements relate to aging and aim to strengthen access to generic services and improve cross sector linkages; envisaged that links between sectors would improve access health other services and improve collaborative work (Australian Health Care Associates, 2006).	No mention at national policy level.	National advocacy by and documents of concern issued from President's Committee on Mental Retardation; Developmental Disabilities Assistance and Bill of Rights Act and other legislative framework mandated sharing ID planning and partnerships with "aged-care" sector dating back to mid-1980s (Ansello & Rose, 1989).	Attention drawn to aging in reports of National Intellectual Disability Database.; joint report by National Council Aging and National Disability Authority 2006 identified ID and aging as priority needs (Conroy & Mangan, 2006).

	UK	Australia	Canada	U.S.	Ireland
Examples of strategies used to implement policy directions on aging	Specific funding for housing initiatives as part of "Extra Care Housing" (King, 2004); the Foundation for People with Learning Disabilities (2002) through its GOLD project funded a range of innovative projects between 1998–2002 that provided a series of program exemplars as well as, in some cases, leading to longer term service development (e.g., the Birmingham Psychological Service for Older Adults).	Action to restrict entry to residential "aged care" for younger people with disabilities, particularly those age less than 50 and not the least restrictive option; entry to residential "aged care" must be assessed and approved by Aged Care Assessment Service; national pilot initiatives examined interface of disability and "aged care," pilot "top up" model of aging in place, assessing those as eligible for residential "aged care" (AIHW, 2006).	Various collaborations between agencies, for example, the Ontario Partnership on Aging and Developmental Disabilities, (2005).	U.S. Administration on Developmental Disabilities in the 1980s funded a number of University Affiliated Programs (UAPs) to include training on aging issues; NIDDR funded Rehabilitation Research and Training Center on aging and developmental disabilities at University of Illinois at Chicago; the Administration on Aging and the Center for Medicare and Medicaid Services jointly funded 24 state units on aging to develop Aging and Disability Resource Centers as the single point of entry for all "consumers," including individuals with developmental disabilities, seeking long-term care services (Sutton et al., 1993; Bigby, 2004).	Development of specialist memory clinic for people with Down syndrome, agency specific responses, by for example, Sisters of Charity and St. Michael's House, (McCarron & Lawlor, 2003; McCausland et al., 2006).
Place of residence of younger people with intellectual disability	70% in family home 30% in supported accommodation age 20–24 years (Emerson, Hatton, Felce, & Murphy, 2001)	51% in group homes all ages and 29 % in institutions (all ages) (AIHW, 2005).	n.a.	40% in family home (age under 40); 35% in family home (age 41–49) (Braddock, 1999).	63.9% in family home (all ages); 27% in disability accommodation (age 20–34 years); 55.1% in disability accommodation (age 35–54 years) (Kelly et al., 2007).
Place of residence of older people with intellectual disability	30% in family and 70% in supported accommodation for adults age 55+ years (Emerson et al., 2001); less than 15% within family age 60+ years (King, 2004).	Victoria study of age 62+ adults found 26% living with family or independently, and 74% using formal services (64% in residential aged care and 10% in group homes) (Bigby, 1998).	n.a.	25% with family (age 60+) (Braddock, 1999); 8% of those in out-of-home care are in residential "aged-care" facilities with significant variation among states, e.g., Kansas has less than 1%, Georgia has 24% (Rizzolo, 2004).	75.4% in disability accommodation (age 55+ years); 0.6% in nursing care (Kelly et al., 2007).

## Commentary on policy implementation progress

Aging in place	UK	Australia	Canada	U.S.	Ireland
Characterization and commentary on approach and progress	<p><i>Ad hoc</i> wide variation across regions in models of service development; little evidence of local systematic planning; few partnerships boards have developed plans to address the needs of older people, they are marginalized from benefits of strategic planning; dislocated from policy intent (Forbat, 2006). Reactive, and no underpinning principles or framework; "service provision characterized by fragmentation and limited choice of resources and specialist care" (Hatzidimitriadou &amp; Milne, 2005). Scotland lacks specialist policy and aims are variously met (Fitzgerald, 1998).</p>	<p>Still at stage of scoping, examining changing needs and expectations and developing framework to guide the development of provision of services (Australian Health Care Associates, 2006). <i>Ad hoc</i> pilot initiatives not funded programmatically or recurrently (AIHW, 2006). Limited effectiveness in dealing with cross-portfolio issues, particularly the interface of aging and disability; problem in dealing with federal government where responsibilities cut across another government (NSW Government, 2007).</p>	<p>Survey of agencies in Toronto, Ontario, area in 2000 found 54% believed services inadequate to meet needs of older people with developmental disabilities (Sparks &amp; Temple, 2000).</p>	<p>Seen to be leading the way in 1980s and 1990s by UK researchers (Robertson et al., 1996; Walker &amp; Walker, 1998), but impetus not continued. "Challenges noted but few attempts to sort out issues lying at the heart of these" (Putnam, 2004). National survey of state units on aging and developmental disability systems found older people with intellectual disabilities were often ignored by these service systems, and few state developmental disability agencies had policies on dementia care or assessment (Janicki, 1996; Coogle, Ansello, Wood &amp; Cotter, 1997, cited in Janicki &amp; Ansello, 2000). Aging not a hot issue for either system, service systems were reactive, to specific problems and noisy advocacy issues, rather than taking proactive stances (Ansello, 2004).</p>	<p>Joint working is rare between the "aged-care" and disability systems, with little evidence of an integrated approach, and this population is regarded as a homogenous group (Conroy &amp; Mangan, 2006).</p>
Research on policy in action	<p>Qualitative study of six facilities, most common model is "referral-out" for residents with dementia; no access to external resources to assist organizations to support aging in place; staff committed to keeping an older person in place (Wilkinson, Kerr, Cunningham, &amp; Rae, 2004). National survey of residential "aged care" found older people with ID placed in residential "aged care" but not due to own needs; they were significantly younger than other residents and placed earlier than age 65 (Thompson et al., 2004). Cost differential found—disability shared supported accommodation cost approx. UK£43 and residential "aged-care" cost approx UK£14–20 (Thompson et al., 2004). Disproportionately high number of older people in residential aged care; estimated as 1 in 10 of those in out-of-home care in Scotland (Scottish Executive, 2002—cited in Thompson et al., 2004). Staff assumption is that a move from shared supported accommodation will occur (Bland et al., 2003; Hatzidimitriadou &amp; Milne, 2005).</p> <p>Multi-national study of group homes in 5 countries, including U.S., found no increase in funding to organizations to take account of increased support needs of people with dementia, residents were able to age in place by <i>ad hoc</i> actions of organizations using their own resources, which cannot be sustained for large numbers predicted in the future (Janicki et al., 2005)</p>	<p>National study of group homes found staff want to retain and let adults with ID age in disability system; only 3.4% of residents aged 50+ years moved to residential "aged care" over 2 years; 30% of respondents thought such a move inevitable; respondents reported difficulty in accessing "aged care" services or additional resources to support changing needs of aging residents; agencies absorbed increased costs from own organizational resources (Fyffe et al., 2007). Large disability organizations are absorbing costs associated with aging (<i>The Age</i>, Feb. 13, 2007). Victoria survey of people with intellectual disability in residential aged care found 40% had at least one person with ID; these residents were younger, stayed longer and were less likely to have dementia than other residents; half had moved from home (Bigby et al., 2008); cost differential found residential "aged care" costs \$44,000, disability housing costs \$84,000 (Senate Community Affairs Reference Committee, 2005).</p>	<p>Older people seen as at-risk of moving to long term residential "aged care" and numbers in this type of care are increasing (Pedlar, Hutchinson, Arai, &amp; Dunn, 2000; Roeber Institute, 2000). Group home residents often relocated to long term care settings (and sometimes to special care units) when dementia begins to present care management difficulties (Chaput, 2002).</p>	<p>When home care no longer viable for adults in mid- to late stage dementia the most common solution is transfer to long-term care facilities or specialist care units (Janicki &amp; Dalton, 2000). No infusion of new resources to pay for dementia care or programmatic or environmental adaptations; more time and staff resources need to be budgeted (Janicki et al., 2002). Most states do not take into account increased needs for 24h staffing for residents who have retired or for aging in place, as system expects either static or continued development; staff tolerance and threshold for moving has shifted up upward over time (Janicki &amp; Dalton, 2000). Many older families are forced to seek admission to nursing facilities, as there are no other alternatives; residents with ID in residential "aged care" are younger than other residents, average age is 64 years compared to other residents' average age of 80 years; less likely to be diagnosed with Alzheimer's disease (Rizzolo, 2004)</p>	<p>Anecdotal evidence that people with ID and dementia go to generic memory clinics; may be more likely to be referred to institutional care due to the lack of experience of staff with this group (McCarron &amp; Lawlor, 2003). 15% of adults with ID in group homes predicted they would have a change of accommodation, while over 50% of carers thought a change would be necessary as people aged (O'Rourke, Grey, Fuller, &amp; McClean, 2004).</p>

Aging in place	UK	Australia	Canada	U.S.	Ireland
Advocacy and policy position taken by the non government or informal sectors	<p>Foundation for Learning Disabilities' GOLD project funded range of research, service development and training initiatives. Positions taken by major national organizations, such as Mencap and BILD. Training materials produced by BILD.</p> <p>Down Syndrome Association of Scotland undertook advocacy stance, policy information, and training.</p>	<p>Major national industry body (NDS)'s national committee on aging and disability instrumental in building cross sector coalition of provider organizations and a securing memorandum of understanding on aging issues (Fyffe et al., 2007).</p> <p>Recommendation by Senate Community Affairs Reference Committee, 2005 on Quality and Equity in Aged Care and Senate Community Affairs Reference Committee (2007) on Commonwealth State/Territory Funding Agreement for aging in place and joint funding by disability and "aged-care" system.</p>	<p>Strongly articulated positions on aging in place, the need for clarity and clarity of policy from families and providers involved people with ID (Crawford, 2004). Strong policy position on aging in place, and need development of national principles and policy framework to inform program guidelines in British Columbia by Association for Community Living (2009b).</p>	<p>The Arc of the United States' position statement on aging. Political forces, such as The Arc of the United States, the Joseph P. Kennedy, Jr. Foundation, and the former AAMR, attempts to keep support for aging alive at federal level and push agenda with states (Janicki &amp; Dalton, 2000). National organization—the AAIDD—has produced information and guidelines for care of older people.</p>	<p>Commission on Nursing Report (Government of Ireland, 1998) pointed to gap in services for aging people with ID and urged the nursing discipline to respond.</p>

AAMR, American Association on Mental Retardation; AAIDD, American Association on Intellectual and Developmental Disabilities; BILD, British Institute on Learning Disabilities; ID, intellectual disabilities; n.a., not available; n.d., no date.

Abbiamo considerato tre situazioni:

- adolescenti con DI in cammino verso l'adulità
- adolescenti con DI i cui vi è co-occorrenza di un Disturbo Mentale
- adolescenti con DI, Disturbo Mentale e altri Bisogni, in situazione di Vulnerabilità estrema

adolescenti in cammino verso  
l'adulità

adolescenti in cammino verso l'adulità:

## Contenuti:

- **adolescenza:**  
transizione biologica  
e psicosociale
- **fioritura e problemi : i  
dati**
- **ill or psychosocial  
problem?**
- **favorire la fioritura:**  
i modelli della :  
psicopatologia  
dello sviluppo e del  
developmental  
approach
- **transition: evidence**

adolescenza: transizione biologica  
e psicosociale



# Adolescenza: transizione biologica e psicosociale

La **direzione** della Transizione

Effects of puberty on behaviour :

- altered social interaction with peers
- sometimes conflicts with parents
- behaviours characterised by sensation-seeking and risk taking

Such cross-species conservation of adolescent typical behaviours suggests their relevance for **reproductive success**, perhaps by facilitating migration away from genetically related adults and **building a social network to support offspring**.

Fonte: Moore (1992): Dispersal, nepotism and primate social behaviour.

# Adolescenza: transizione biologica e psicosociale

Il **supporto** della Transizione: aspetti neuro -biologici

- Adolescent **cortical changes** include shifts in gray/white matter, continued myelination, shifts in dopamine and serotonin production, and synaptic pruning, particularly in the prefrontal cortex (Spear, 2004, 2007; O'Brien, 2007)
- These structural and functional changes likely contribute to normative changes in **cognitive** (Casey, Giedd,&Thomas, 2000) and **emotional** processes (Dahl, 2001), but also to the onset/progression of **risky behavior and psychopathology** (O'Brien, 2007)

Fonte. Steinberg (2007). Risk taking in adolescence: New perspectives from brain and behavioral science

## Adolescenza: transizione biologica e psicosociale

### Il **supporto** della Transizione: aspetti sociali

- ... no other species shows the complexity of changes in brain seen in humans nor the repertoire of behavioural changes. These behavioural changes are in turn greatly affected by the socio-cultural and economic milieu in which humans mature ...
- ...it is now clear that **broader social processes define adolescence**, not least because its form varies so widely across societies and cultures ...

Fonte. Patton (2007): Pubertal transition in health.

## W Adolescent Health 1

### Pubertal transitions in health

George C Patton, Russell Viner

- **mismatch** tra:
  - cambiamenti maturativi biologici
  - sviluppo psico-sociale
  - “problemi di comportamento”
- **sviluppo Tipico**: lungo periodo di costruzione attiva di un ruolo sociale (istruzione, preparazione professionale) – un problema di **tempo** ...-
- **sviluppo Atipico**: lungo periodo per il riconoscimento di un ruolo sociale – un problema di **tempo e di cultura** -

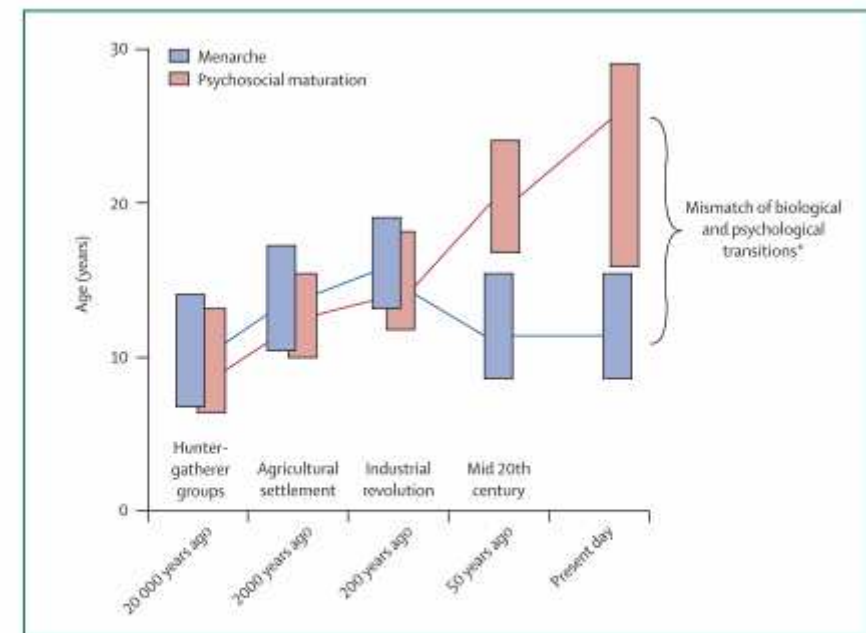


Figure 2: Changing relation between probable range of menarcheal age and psychosocial transitions into adulthood

Adapted from Gluckman and Hanson.<sup>10</sup> \*Psychosocial transitions range from first sexual activity through to marriage and parenthood

## Adolescenza: transizione biologica e psicosociale

La **meta** della Transizione: identity, purpose, mission

- identity VS role confusion
- Identity in relation to the ongoing interaction with others
- self as a being with a purpose and meaning in any given situation
- self with a mission; mission implies action. Mission implies self in motion

Fonte. Harvey( 2009): Positive Identity Development. An alternative treatment approach for individual with mild and moderate intellectual disabilities

## Adolescenza: transizione biologica e psicosociale

La meta ultima della Transizione: mission

... I believe that **all people**, not only people with normal IQs, are, in some form or another, **seeking to embrace a mission**, the activation of their purpose for living. Once that mission is discovered people can make **startling changes** in their behavior without obvious external contingencies in place ...

Fonte. Harvey( 2009): Positive Identity Development. An alternative treatment approach for individual with mild and moderate intellectual disabilities

**thriving & problems: some data**

# thriving & problems: some data

## thriving

... pensiero (astratto); **scelte** relative al **futuro**

... partecipazione attiva e **responsabile** alla vita familiare

... impegno in relazioni **interpersonali** profonde

... **empowerment** personale e sociale



# thriving & problems: some data

## problems

- a psychological component in > 26% of consultations with patients aged under 18
- an overall 18% prevalence of selected psychiatric disorders in a secondary school population  
(dysthymic disorder -4.9%-; major depression – 4.0-; generalized anxiety - 3.7%-; obsessive-compulsive disorder -1.9%- etc...)

Fonti:

- Bailey et. al (1978): How much child psychiatry does a GP do?
- Whitaker et al. (1990): Uncommon troubles in young people: prevalence estimates of selected psychiatric disorders in a nonreferred adolescent population
- Jacobson et al. (2002): Tackling teenage turmoil: primary care recognition and management of mental ill health during adolescence.

# thriving & problems: some data

## problemi

- 7% of males and 19 % of females aged 16 – 19 years living at home have a neurotic disorder;
- 9% have alcohol dependency and 7% drug dependency

Fonte: Meltzer e coll. (1995): OPCS Surveys of Psychiatric Morbidity. The Prevalence of Psychiatric Morbidity on Great Britain.

# Transition: evidence

A. process of transition from child to adult status

B. transition between services

# Transition: evidence THE CURRENT SITUATION

Fonti:

abbiamo utilizzato:

- due review ([May, 2001](#); [Beresford, 2004](#))
- Il prodotto di un [Focus Group](#) di un gruppo di genitori ([Ruggerini et al., 2010](#))

Beresford B. (2004): On the road to nowhere? Young disabled people and transition. *Child: Care, Health & Development*, 30,6, 581-587

Ruggerini C et al (2010): Application (2003-2008) of the “Innovative Care for Chronic Conditions “ framework to Intellectual Disability: a research project and its results  
(Focus Group: rafforzamento del self management nelle famiglie di persone con DI).  
*Psichiatria dell’Infanzia e dell’Adolescenza*, 77: 193-210

Transition: evidence  
THE CURRENT SITUATION (Beresford, 2004)

Transition from child to adult status

unhappy picture of the experience of leaving school:

- time of loneliness (minimal contact with peers)
- few opportunities to enjoy meaningful activities
- few opportunities to further develop skills and abilities
- less likely than young non disabled people to have achieved employment

Transition: evidence  
THE CURRENT SITUATION (May D, 2001)

Transition from child to adult status

**employment** Becoming Adult. School leaving, Jobs and the Transition to Adult Life. In David May (ed.), Transition and change in the lives of people with intellectual disabilities. Jessica Kingsley Publishers, London and Philadelphia)

in the three decades following World War II young people with ID – somewhere between one-half and four-fifths – could expect to find work on leaving school

in 1983 the proportion of young people moving into full-time jobs on school leaving had fallen to 42 per cent, down from 72 per cent in the late 1970

by 1987 it had fallen further, to 26 per cent

Transition: evidence  
**THE CURRENT SITUATION (May D, 2001):**

Transition from child to adult status

**employment** Becoming Adult. School leaving, Jobs and the Transition to Adult Life. In David May (ed.), Transition and change in the lives of people with intellectual disabilities. Jessica Kingsley Publishers, London and Philadelphia)

circa 1/3 dei giovani con DI è impiegato stabilmente nel mercato del lavoro

yet despite all this, the aspirations of the majority of young people and their parents remain fixed on work

“this is not simply the triumph of hope over experience, but rather speaks directly to the question of identity”

Transition: evidence  
THE CURRENT SITUATION (Focus Group 2010)

Transition from child to adult status

- ... la preadolescenza e l'adolescenza sono periodi di intensi cambiamenti psico-fisici. I ragazzi diventano più consapevoli di se stessi, sono ipersensibili agli atteggiamenti dei coetanei nei loro confronti...
- ... nei confronti dei ragazzi con ritardo mentale a volte i coetanei sono fortemente discriminanti poiché anche loro sono insicuri e temono di essere rifiutati dal gruppo...
- ... ***così gli inviti si diradano, il telefonino non squilla e gli eventuali interventi dei genitori sortiscono effetti ancora peggiori. Il pomeriggio è vuoto ...***
- ... i ragazzi e i giovani con disabilità dovrebbero poter partecipare a pieno diritto, come gli altri, a centri di aggregazione giovanile sul territorio affiancati da educatori del Comune della AUSI o da volontari



# Transition between services

What works? The evidence

Beresford B. (2004)

# Transition between services

Il principio generale è:

The purpose of transition planning and transition services is seen as a way to enable and support a young person to move toward and onto a new life stage

- not seen as a means by which an individual is moved from one service to another –

# Transition between services

As a result:

- -planning for transition needs to be person-centered (with the young person's preference, goals and aspirations taking centre stage)
- young people, their parents and other advocates have to play a central role in planning and decision-making
- it is necessary they are supported in this process by skilled staff with informed and realistic expectations

# Transition between services

As a result:

- things that young people most want in their future lives - friendships, social life, work, independent housing - cannot be fully achieved through the provision of a single agency

→ a multi-agency approach is necessary

# Transition between services

As a result:

- a flexible, long term view is required with sufficient time given to planning, information gathering, experiencing possible options before transition
- transition is not achieved in a single step but rather must be in tune with a young person's individual abilities and needs

# Transition between services

As a result:

-services, facilities and opportunity for young disabled people need to be in place and available

→the lack of post – school options for young person mean there is no choice to make

# Transition between services

What works? I desideri dei genitori

Focus Group (2010)

# Transition between services

- continuità del percorso assistenziale nell'area sociale e sanitari ( principle of the Connexions service)
- collaborazione tra istituzione scolastica e mondo del lavoro; progetti di inserimento lavorativo fin dalla scuola superiore (role of the Connexions Personal Advisor)
- utilità della partecipazione a gruppi nel tempo libero dove il “ragazzo va sollecitato, come gli altri, a divenire protagonista ed ideatore del proprio tempo, pensato come luogo di libertà e di promozione di se stesso in un interscambio reale con i suoi coetanei”; in questi luoghi è affiancato da educatori ... ( → parole chiave: protagonista & ideatore; scelta)
- coinvolgere la comunità nell'insegnamento dell'uso del denaro con accordi con i commercianti di un determinato quartiere (“negozianti amici”) (→ riabilitazione su base comunitaria)
- “riflettere tra genitori, educatori e psicologi sulle esperienze dei genitori, mettendoli in parallelo con quelle dei figli, per scoprire “gli interruttori” del cambiamento e maturare insieme” :  
(SI POTREBBE TRADURRE CON: - chiedere ai tecnici dei servizi – psicologi e servizi sociali – di tenere conto della esperienza dei genitori nel formulare programmi e proporre metodi di sostegno)
- utilità di gruppi di disabili con DI



# INDICE

- Nascita recente del concetto di Transizione riferito alle persone con Disabilità Intellettiva
- **Evidenze sul passaggio età adolescenziale/età adulta**
- Implicazioni del concetto di Transizione

**3rd IASSID-Europe Congress  
October 20-22, 2010  
Rome, Italy**

# **Transition from adolescence to adulthood for people with ID**

Ciro Ruggerini, Sumire Manzotti, Valentina Moretti

- Società Italiana per lo Studio del Ritardo Mentale (SIRM)
- Scuole di Specializzazione Università di Modena e Reggio Emilia
  - ASP Charitas (Modena)
- Cooperativa Sociale L'Arcobaleno (Reggio Emilia)
  - Minamiyachimata Hospital, Chiba (Japan)

## Nozione di eterogeneità

“ ... Nonostante sia incluso nelle sindromi dei manuali diagnostici psichiatrici, il ritardo mentale, altrove più spesso definito “disabilità intellettiva”(DI), non sembra semplicemente riconducibile ad un disturbo o ad una malattia, né ad una condizione univoca di disabilità. Esso sembra più correttamente definibile come un **raggruppamento metasindromico che include un'ampia gamma di percorsi evolutivi e quadri esistenziali sostanzialmente diversi** per etiologia, disabilità fisica, psicopatologia associata e funzionamento generale ...

...i criteri diagnostici rispondono senz'altro ad imprescindibili necessità di codifica e trasmissibilità tra professionisti, ma inevitabilmente impoveriscono e semplificano la complessità delle realtà individuali finendo per perdere validità ...”

Bertelli, Scuticchio, Ferrandi, Ciavatta, La Malfa, Mango, Porcelli, Monchieri (Giorn Ital Psicopat, 2010)

# Nozione di eterogeneità

La nozione di eterogeneità è adeguata, ovviamente, anche per i ragazzi adolescenti con DI.

Abbiamo rappresentato questo concetto nell'immagine di un ragazzo con lo zaino.

Lo zaino indica il viaggio (il percorso che il ragazzo si appresta a compiere); la dimensione dello zaino indica il carico di bisogni che il ragazzo porta con sé; lo zaino può avere dimensioni relativamente piccole oppure molto grandi.

**Adolescenti  
Con  
Disabilita' Intellettiva**

**Adolescenti  
Con  
Disabilita' Intellettiva  
e  
Disturbo Mentale**

**Adolescenti  
Con  
Disabilita' Intellettiva  
Disturbo Mentale  
ed altri Bisogni  
(Vulnerabilità Estrema)**



# Conclusione 1:

## adolescenti in cammino verso l'adulità

### Sviluppo Tipico

... we have to highlight the issue of teenage turmoil; it is imperative that there is no "overmedicalization" of the transition from childhood to adulthood

... a major gap at present is of **awareness**

... the **notion of teenage turmoil indicating potential mental ill health should be made more of a priority** for recognition and management by primary care ...

Jacobson et al.(2002): Tackling teenage turmoil: primary care recognition and management of mental ill health during adolescence

### Sviluppo Atipico

Nella DI vale la stessa considerazione, con una necessità, probabilmente, ancora maggiore.

*Nell'adolescente con DI il rischio di una semplificazione della lettura dei comportamenti è, infatti, maggiore.*

# Conclusione 2:

adolescenti in cammino verso l'adulità

## Sviluppo Tipico

Nella adolescenza si osservano con frequenza “**problemi di comportamento**” – condotta antisociale, uso di sostanze -; sono necessari interventi di prevenzione; due filosofie di fondo: **la eliminazione dei fattori di vulnerabilità, la promozione dei fattori della salute**

## Sviluppo Atipico

Valgono le stesse considerazioni per le azioni di prevenzione; **la promozione della salute comincia ad articolarsi in programmi codificati (es.: Positive Identity Development)**

# Conclusione 3:

adolescenti in cammino verso l'adulità

Sviluppo Atipico  
(particolarità dei fattori  
connessi allo sviluppo)

Lo schema di Guralnick  
indica che fattori come  
l'informazione fornita  
dagli operatori e  
l'empowerment dei  
familiari possano essere  
fattori chiave.

L' **assessment** che  
accompagna l'individuo  
nel suo percorso con le  
agenzie di educazione e  
di cura è quindi cruciale.

Essa **orienta sia la  
percezione che l'individuo  
ha di sé che le  
opportunità  
effettivamente offerte.**



**“La Promozione della Salute Mentale nella Disabilità Intellettiva”** Consenso multidisciplinare e intersocietario  
(Erickson, 2010)

*Società Scientifiche partecipanti*

hanno partecipato ai lavori specialisti scelti dai direttivi delle seguenti società scientifiche:

**SINPIA** (Società Italiana di Neuropsichiatria dell'Infanzia e dell'Adolescenza); **SIRM** (Società Italiana dello Studio di Ritardo Mentale); **AISQV** (Associazione Italiana della Qualità di Vita); **AIP** (Associazione Italiana di Psicogeriatria); **SIP** (Società Italiana di Pediatria); **SIAF** (Società Italiana di Audiologia e Foniatria); **ACP** (Associazione Culturale Pediatri); ai lavori ha partecipato una rappresentanza della **FISH** (Federazione Italiana per il Superamento dell'Handicap).

# “La Promozione della Salute Mentale nella Disabilità Intellettiva” Consenso multidisciplinare e intersocietario (Erickson, 2010)

## INDICE:

1. Premessa Metodologica
2. Linee Guide Esistenti
3. La concezione del Ritardo Mentale
4. Documenti Internazionali di Riferimento
5. Epidemiologia
6. La Generazione Dimenticata (RM Lieve e Condizione Limite)
7. Eziologia
8. Assessment Diagnostico
9. La Comunicazione della Diagnosi
10. **Aiuti allo Sviluppo**
11. Trattamento delle difficoltà di comunicazione
12. Fattori di Vulnerabilità
13. Disturbi Mentali e Comportamenti di Sfida;
14. Terapia delle Condizioni Mediche Associate
15. Servizi
16. Formazione del personale addetto alla assistenza
17. Il Ruolo delle Associazioni dei Disabili
18. **Il Concetto di Qualità della Vita nelle Varie Età**
19. **I Ruoli Sociali in Età Adulta e Senile:** Relazioni Affettive, Lavoro e Tempo Libero
20. Qualità di Vita e Qualità di Assistenza nei Centri Diurni e nelle Residenze