# I MARTEDì DELL'ORDINE

*7 GIUGNO 2016*

# IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

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# SINTESI

1) Definizione
2) Perché discuterne ?
3) Gli ostacoli
4) Che fare ?

# SINTESI

1) **Definizione**
2) **Perché discuterne ?**
3) **Gli ostacoli**
4) **Che fare ?**

# DEFINIZIONE

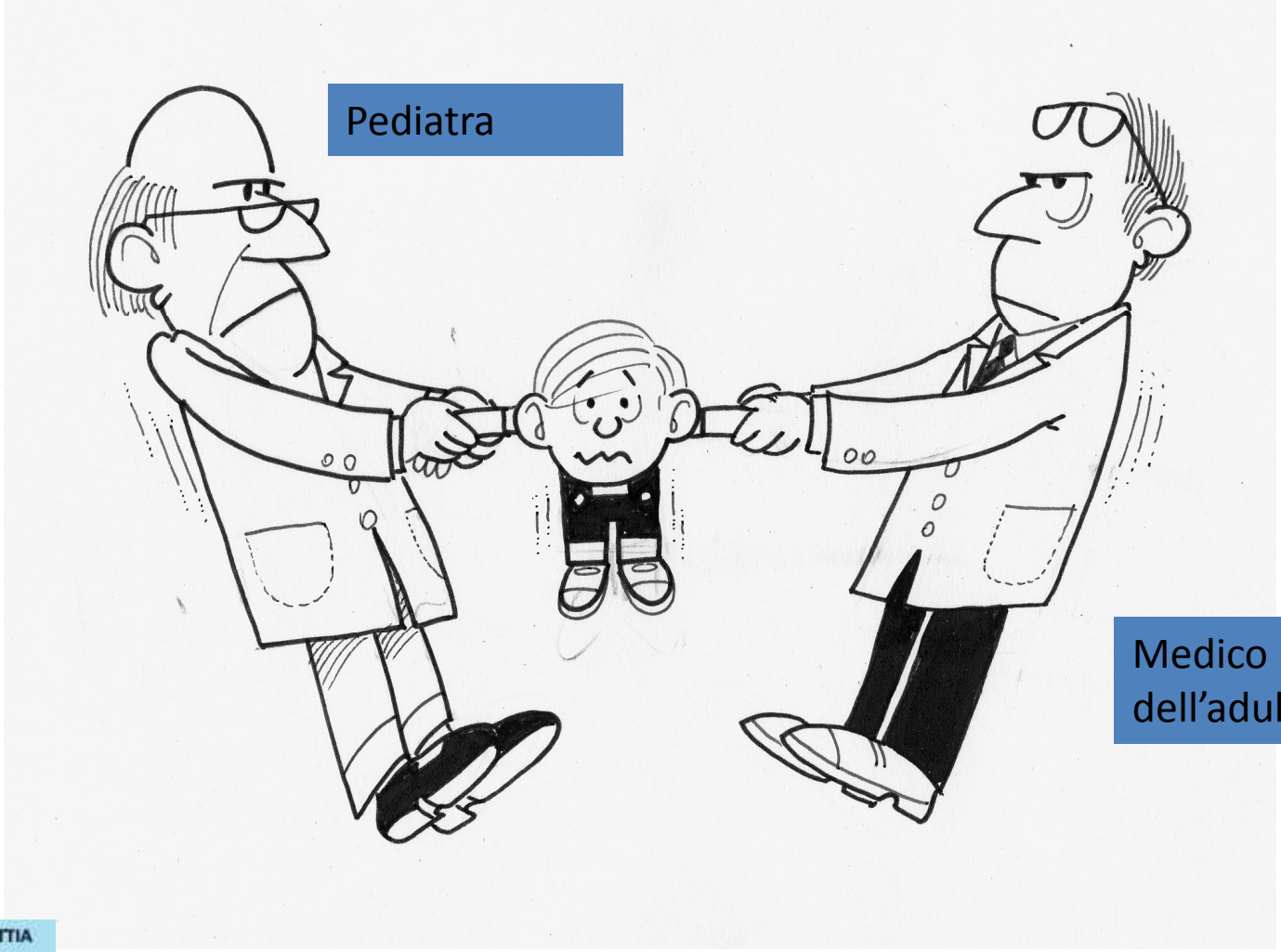
**…Transition is defined as "the purposeful, planned movements of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems"…**

**Society for Adolescent Medicine**

# SINTESI

1) Definizione
2) **Perché discuterne ?**
3) Gli ostacoli
4) Che fare ?

# Perché discuterne ?



# SINTESI

1) Definizione

2) **Perché discuterne ?**

   **- aumento e aumentata sopravvivenza**

   **malattie croniche**

# Current Issues in Transitioning from Pediatric to Adult-Based Care for Youth with Chronic Health Care Needs

Albert C. Hergenroeder, MD[1], Constance M. Wiemann, PhD[1], and Mitchell B. Cohen, MD[2]

THE JOURNAL OF PEDIATRICS

Vol. 167, No. 6 2015

**(I)**

Chronic disease in 6- to 21-year-olds affects approximately 1 in 5 US families.[1]

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

# Transition to adult services

*Arch Dis Child Educ Pract Ed* 2012;**97**:86–92.

Data from the Office of National Statistics and the General Household Survey in 2000 show that the prevalence of disability or long standing illness in children and young people up to the age of 19 was 17–19%.[10] A model applied to chronic conditions[11] indicates the population requiring transitional care can be divided into three levels of need: complex needs accounting for around 5% of this population; complex chronic conditions accounting for around 25%; and other chronic conditions, with good control, accounting for around 70%.

# Current Issues in Transitioning from Pediatric to Adult-Based Care for Youth with Chronic Health Care Needs

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Vol. 167, No. 6 2015

**(II)**

Advances in medicine have improved the outcome for children with chronic illnesses; in the US, 90% of children and youth with special health care needs of a physical nature will enter adulthood, numbering one-half million annually.

# Cystic fibrosis mortality and survival in the UK: 1947–2003

J.A. Dodge*, P.A. Lewis#, M. Stanton# and J. Wilsher#

Eur Respir J 2007; 29: 522–526

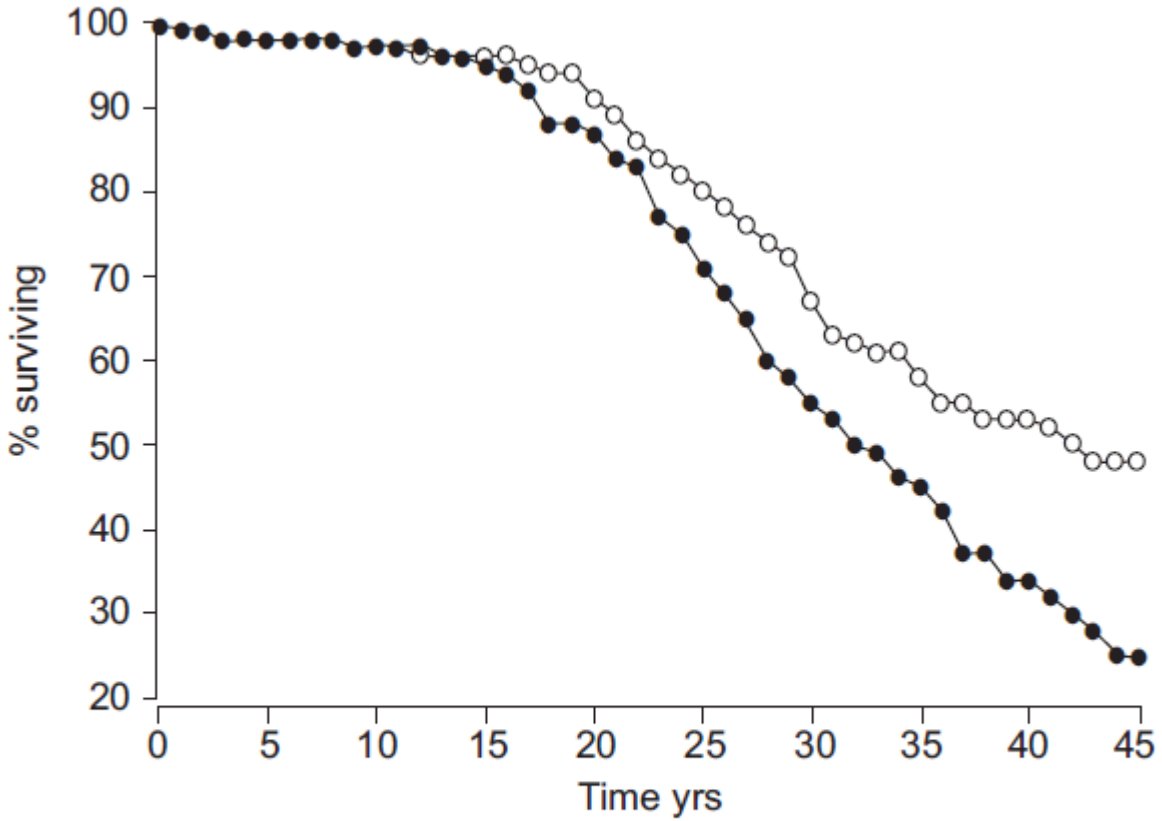


**FIGURE 3.** Current survival UK cystic fibrosis population by sex, 2003. ○: males; ●: females.

**Healthcare provision for adults with congenital heart disease in Europe: a review**

Philip Moons[a,b] and Folkert J. Meijboom[c]

**Current Opinion in Pediatrics** 2010, 22:573–578

Conclusions: This study demonstrated that the prospects to survive into adulthood in today's youngsters with CHD has increased to about 90%. These findings can be used for workforce planning for adult congenital heart disease programs.

# Current Issues in Transitioning from Pediatric to Adult-Based Care for Youth with Chronic Health Care Needs

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THE JOURNAL OF PEDIATRICS

Vol. 167, No. 6 2015

**(III)**

An estimated additional 600 000 16- to 17-year-olds in the US have serious mental illness.[2]

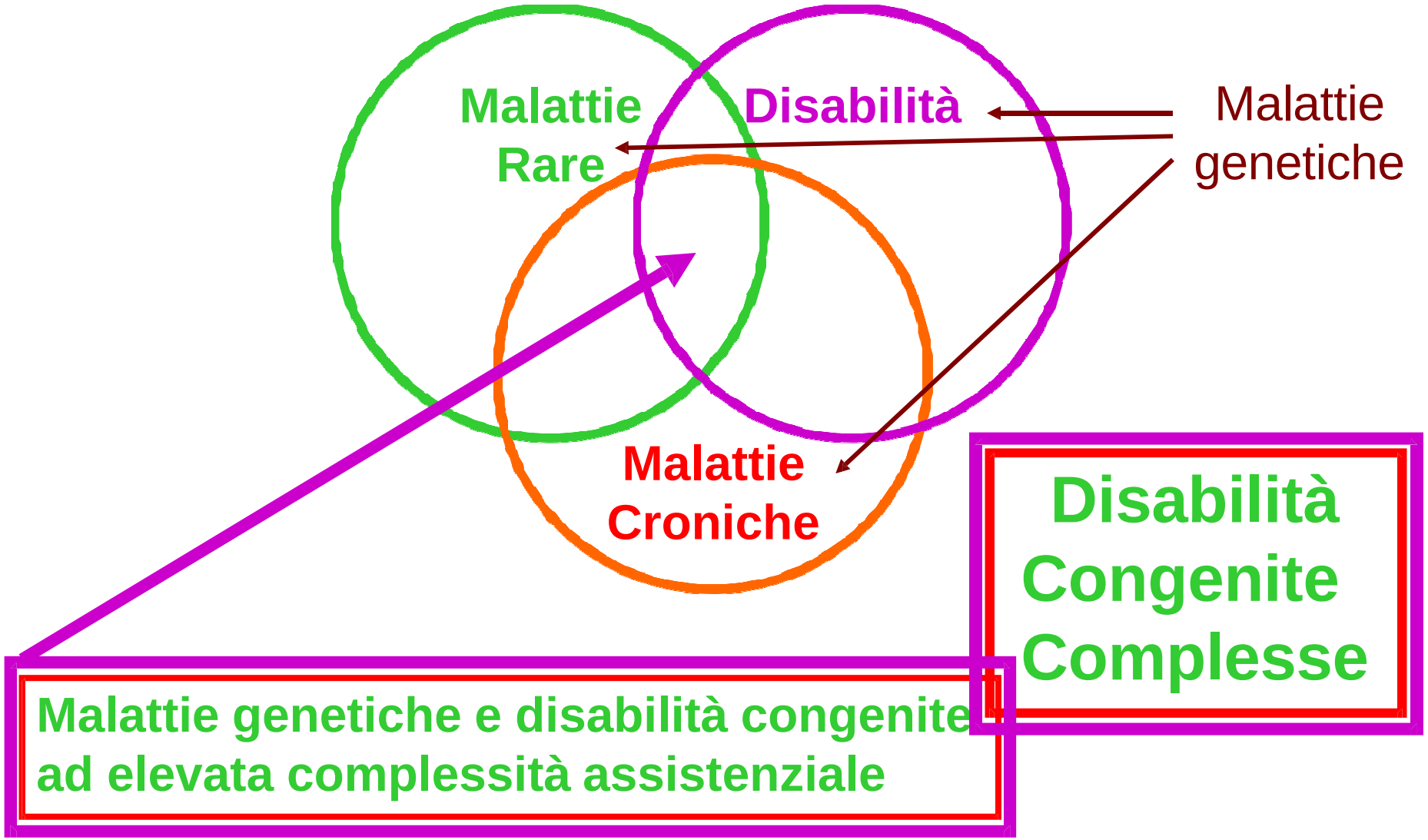
Annual Research Review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents

Guilherme V. Polanczyk,[1,2,3] Giovanni A. Salum,[3,4] Luisa S. Sugaya,[1,2] Arthur Caye,[4] and Luis A. Rohde[3,4]

*Journal of Child Psychology and Psychiatry* 56:3 (2015), pp 345–365

and median rates of 8% for preschoolers, 12% for preadolescents, and 15% for adolescents

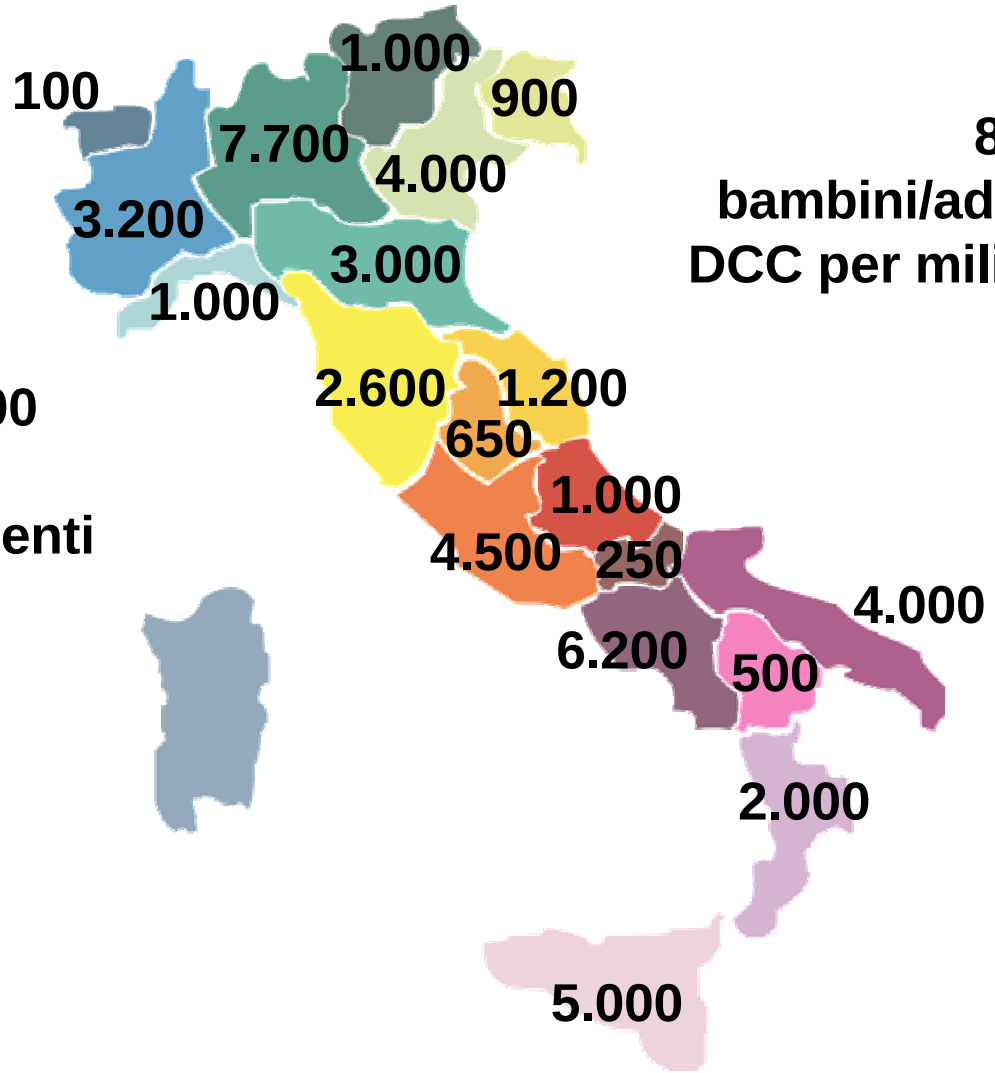
# Le malattie genetiche e le disabilità ad elevata complessità assistenziale



# Prevalenza in Italia

Su 10 milioni di bambini/adolescenti = 50.000

**DCC = 5 x 1.000**
**1 su 200**
**bambini/adolescenti**




**850**
**bambini/adolescenti con DCC per milione di abitanti**

# SINTESI

1) Definizione
2) **Perché discuterne ?**
   - aumento e aumentata sopravvivenza malattie croniche
   - **necessità di conoscere outcome a lungo termine**

# Carotid Intima-Media Thickness Is Associated with Increased Androgens in Adolescents and Young Adults with Classical Congenital Adrenal Hyperplasia

Horm Res Paediatr 2016;85:242–249

Mimi S. Kim[a, d, e] Anh Dao-Tran[a] Elana Davidowitz[a] Teresa Tseng[a]
Vicente Gilsanz[b, d, e] Anna Ryabets-Lienhard[a, d] Eugene Nguyen[c]
Mitchell E. Geffner[a, d, e]

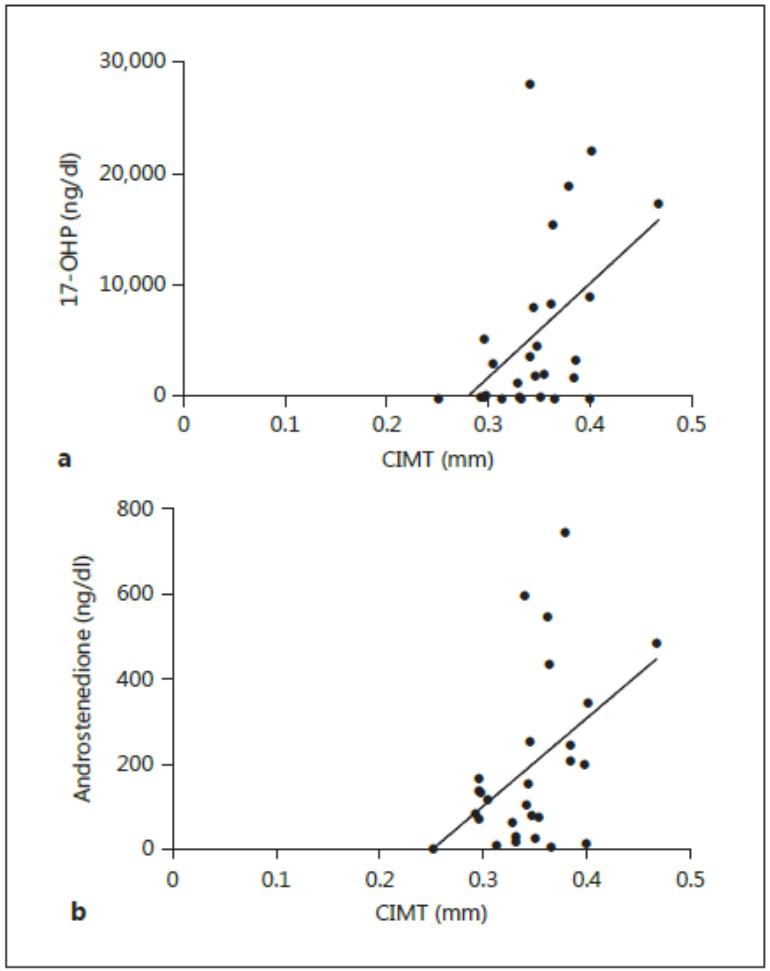



**Fig. 1.** CIMT in adolescents and young adults with classical CAH due to 21-hydroxylase deficiency. **a** CIMT correlated positively with 17-OHP ($R = 0.48$; $p < 0.05$). **b** CIMT correlated positively with androstenedione ($R = 0.46$; $p < 0.05$).

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

## Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?

Pierre D.E. Mouriquand [a,b], Daniela Brindusa Gorduza [a,b], Claire-Lise Gay [a,b], Heino F.L. Meyer-Bahlburg [c,d], Linda Baker [e], Laurence S. Baskin [f], Claire Bouvattier [g,h], Luis Braga [i], Anthony C. Caldamone [j,k], Lise Duranteau [h,l], Alaa El Ghoneimi [m], Terry W. Hensle [d], Piet Hoebeke [n], Martin Kaefer [o], Nicolas Kalfa [p], Thomas F. Kolon [q,r], Gianantonio Manzoni [s], Pierre-Yves Mure [a,b], Agneta Nordenskjöld [t], J.L. Pippi Salle [u], Dix Phillip Poppas [v], Philip G. Ransley [w], Richard C. Rink [p], Romao Rodrigo [x,y], Léon Sann [z], Justine Schober [aa], Hisham Sibai [ab], Amy Wisniewski [ac], Katja P. Wolffenbuttel [ad], Peter Lee [ae]

Journal of Pediatric Urology (2016) :

There is a general acknowledgement among experts that timing, the choice of the individual, and irreversibility of surgical procedures are sources of concerns. There is, however, little evidence provided regarding the impact of non-treated DSD during childhood for the individual development, the parents, the society, and the risk of stigmatization.

The low level of evidence in most DSD situations should lead multidisciplinary expert teams to design collaborative prospective studies involving all parties and using consensual protocols of evaluation.

# SINTESI

1) Definizione
2) **Perché discuterne ?**
   - aumento e aumentata sopravvivenza malattie croniche
   - necessità di conoscere outcome a lungo termine
   - **problema non risolto**

# Perché discuterne ?

**A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs**
American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine
*Pediatrics* 2002;110;1304

The goals of this policy statement are to ensure that by the year 2010 all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated.

# Perché discuterne ?

## Lost in transition? Between paediatric and adult services

*It's time to improve the transition of adolescents from paediatric to adult services*

BMJ VOLUME 332 25 FEBRUARY 2006

Janet E McDonagh
Russell M Viner

Preventing adolescents becoming lost in the transfer between paediatric and adult health services is a major challenge for healthcare providers, paediatric and adult alike. Until recently British health services have largely ignored adolescents.[1] But as increasing numbers of young people are surviving into adulthood with illnesses they developed in childhood, the need for transitional care appropriate to their age and development is becoming more obvious and acute.[2] Adolescence is also a time when adult behaviours become established and therefore represents a window of opportunity to promote healthy behaviour and influence the public health burden of tomorrow's adults.[1]

# Perché discuterne ?

**Current Status of Transition Preparation Among Youth With Special Needs in the United States**

Margaret A. McManus, Lauren R. Pollack, W. Carl Cooley, Jeanne W. McAllister, Debra Lotstein, Bonnie Strickland and Marie Y. Mann

*Pediatrics* 2013;131;1090; originally published online May 13, 2013;
DOI: 10.1542/peds.2012-3050

**WHAT THIS STUDY ADDS:** This study reports on transition findings from the 2009–2010 National Survey of Children with Special Health Care Needs and finds no discernible improvements since 2005–2006. New clinical recommendations and care processes should help to accelerate transition improvements in the future.

# Perché discuterne ?

## Transition of care for adolescents from paediatric services to adult health services

Fiona Campbell[1], Katie Biggs[1], Susie K Aldiss[2], Philip M O'Neill[3], Mark Clowes[1], Janet McDonagh[4], Alison While[5], Faith Gibson[2]

2016 The Cochrane Collaboration.

Nine relevant reviews have been published. These include a review of transition services for adolescents with specific conditions including: diabetes (Fleming 2002), palliative care (Doug 2011), mental health (Paul 2014), and spina bifida (Binks 2007). Three reviews included studies where patients might have a range of special healthcare needs or disabilities (Bloom 2012; Crowley 2011; Forbes 2002). Two reviews synthesised qualitative evidence of patients perspectives (Fegran 2014; Lugasi 2011). The reviews all concluded that there was a weak evidence base to inform practice and a need for additional studies with strong research design.

# Perché discuterne ?

- The Pediatric to Adult Care Transitions Initiative, which provides free online specialty-specific tools, was developed by the American College of Physicians (ACP), Council of Subspecialty Societies, in collaboration with numerous specialty and subspecialty organizations.

got transition

# Side-by-Side Version

## Six Core Elements of Health Care Transition 2.0

The ***Six Core Elements of Health Care Transition 2.0*** are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition.[1] Sample clinical tools and measurement resources are available for quality improvement purposes at **www.GotTransition.org** ■

| Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers) | Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers) | Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers) |
|---|---|---|
| **1. Transition Policy**<br>• Develop a transition policy/statement with input from youth and families that describes the practice's approach to transition, including privacy and consent information.<br>• Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.<br>• Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care. | **1. Transition Policy**<br>• Develop a transition policy/statement with input from youth/young adults and families that describes the practice's approach to transitioning to an adult approach to care at 18, including privacy and consent information.<br>• Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences.<br>• Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care. | **1. Young Adult Transition and Care Policy**<br>• Develop a transition policy/statement with input from young adults that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information.<br>• Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements* and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.<br>• Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care. |
| **2. Transition Tracking and Monitoring**<br>• Establish criteria and process for identifying transitioning youth and enter their data into a registry.<br>• Utilize individual flow sheet or registry to track youth's transition progress with the *Six Core Elements*.<br>• Incorporate the *Six Core Elements* into clinical care process, using EHR if possible. | **2. Transition Tracking and Monitoring**<br>• Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry.<br>• Utilize individual flow sheet or registry to track youth/young adults' transition progress with the *Six Core Elements*.<br>• Incorporate the *Six Core Elements* into clinical care process, using EHR if possible. | **2. Young Adult Tracking and Monitoring**<br>• Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.<br>• Utilize individual flow sheet or registry to track young adults' completion of the *Six Core Elements*.<br>• Incorporate the *Six Core Elements* into clinical care process, using EHR if possible. |
| **3. Transition Readiness**<br>• Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.<br>• Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care. | **3. Transition Readiness**<br>• Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.<br>• Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care. | **3. Transition Readiness/Orientation to Adult Practice**<br>• Identify and list adult providers within your practice interested in caring for young adults.<br>• Establish a process to welcome and orient new young adults into practice, including a description of available services.<br>• Provide youth-friendly online or written information about the practice and offer a "get-acquainted" appointment, if feasible. |

got transition

# Side-by-Side Version (continued)

## Six Core Elements of Health Care Transition 2.0

| Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers) | Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers) | Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers) |
|---|---|---|
| **4. Transition Planning**<br>• Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.<br>• Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.<br>• Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.<br>• Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.<br>• Obtain consent from youth/guardian for release of medical information.<br>• Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.<br>• Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. | **4. Transition Planning/Integration into Adult Approach to Care**<br>• Develop and regularly update a plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents.<br>• Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.<br>• Determine of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.<br>• Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care<br>• Obtain consent from youth/guardian for release of medical information.<br>• Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. | **4. Transition Planning/Integration into Adult Practice**<br>• Communicate with young adult's pediatric provider(s) and arrange for consultation assistance, if needed.<br>• Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.)<br>• Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.<br>• Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. |
| **5. Transfer of Care**<br>• Confirm date of first adult provider appointment.<br>• Transfer young adult when his/her condition is stable.<br>• Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.<br>• Prepare letter with transfer package, send to adult practice, and confirm adult practice's receipt of transfer package.<br>• Confirm with adult provider the pediatric provider's responsibility for care until young adult is seen in adult setting. | **5. Transfer to Adult Approach to Care**<br>• Address any concerns that young adult has about transferring to adult approach to care. Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.<br>• Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss needed self-care skills.<br>• Review young adult's health priorities as part of ongoing plan of care.<br>• Continue to update and share portable medical summary and emergency care plan. | **5. Transfer of Care/Initial Visit**<br>• Prepare for initial visit by reviewing transfer package with appropriate team members.<br>• Address any concerns that young adult has about transferring to adult approach to care. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.<br>• Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult's needs and goals in self-care.<br>• Review young adult's health priorities as part of their plan of care.<br>• Update and share portable medical summary and emergency care plan. |
| **6. Transfer Completion**<br>• Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process.<br>• Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.<br>• Build ongoing and collaborative partnerships with adult primary and specialty care providers. | **6. Transfer Completion/Ongoing Care**<br>• Assist young adult to connect with adult specialists and other support services, as needed.<br>• Continue with ongoing care management tailored to each young adult.<br>• Elicit feedback from young adult to assess experience with adult health care.<br>• Build ongoing and collaborative partnerships with specialty care providers. | **6. Transfer Completion/Ongoing Care**<br>• Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.<br>• Assist young adult to connect with adult specialists and other support services, as needed.<br>• Continue with ongoing care management tailored to each young adult.<br>• Elicit feedback from young adult to assess experience with adult health care.<br>• Build ongoing and collaborative partnerships with pediatric primary and specialty care providers. |

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

ACP | High Value Care

Endocrinology

## Turner Syndrome

**Developed by:**

*Endocrine Society*

*Hormone Health Network*

*Turner Syndrome Foundation*

**How Developed:** Chronic endocrine conditions like Turner Syndrome can be complex and challenging for patients to successfully manage—and especially when transitioning to a new health care team. Recognizing the need to improve this transition process and to enhance care coordination between practices, the Endocrine Society spearheaded an initiative to develop pediatric-to-adult transitions of care tools for a variety of endocrine conditions. Partnering with a broad coalition of stakeholder organizations, condition-specific working groups were established with experts in the field to evaluate gaps in care coordination and to begin addressing needs in these areas. The resulting toolkits provide a comprehensive approach to successfully managing transitions for patients with various endocrine conditions.

| Tool Name | Description of Tool | How to Use Tool |
|---|---|---|
| *Provider Assessment of Patient Skill Set* | An assessment tool intended to be utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth's needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice. | This form is suggested to help assess the teen/emerging young adult's knowledge and skills regarding Turner Syndrome and its management. The tool is intended as an aide to help assess the readiness of older teens/emerging young adults in the transition and to be transferred from pediatric to adult care providers. |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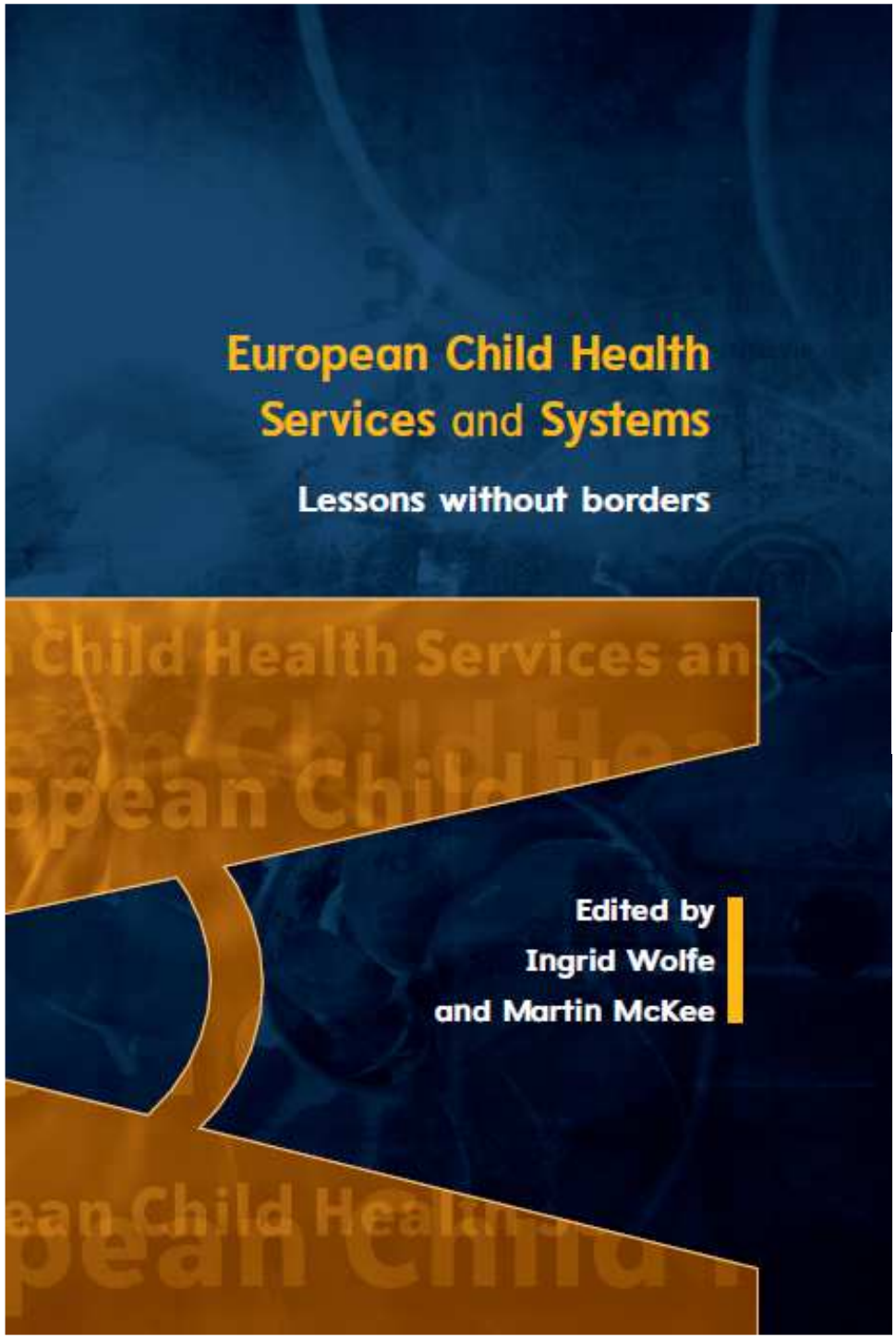


*Transition from children's to adults' services*
*Rose Crowley, Ingrid Wolfe*

# SINTESI

1) Definizione

2) **Perché discuterne ?**

- aumento e aumentata sopravvivenza malattie croniche
- necessità di conoscere outcome a lungo termine
- problema non risolto
- **scarso dibattito in Italia**

Management of adults with paediatric-onset chronic liver disease: Strategic issues for transition care☆

Digestive and Liver Disease 46 (2014) 295–301

Pietro Vajro[a,*], Lorenza Ferrante[c], Selvaggia Lenta[d], Claudia Mandato[d], Marcello Persico[b]

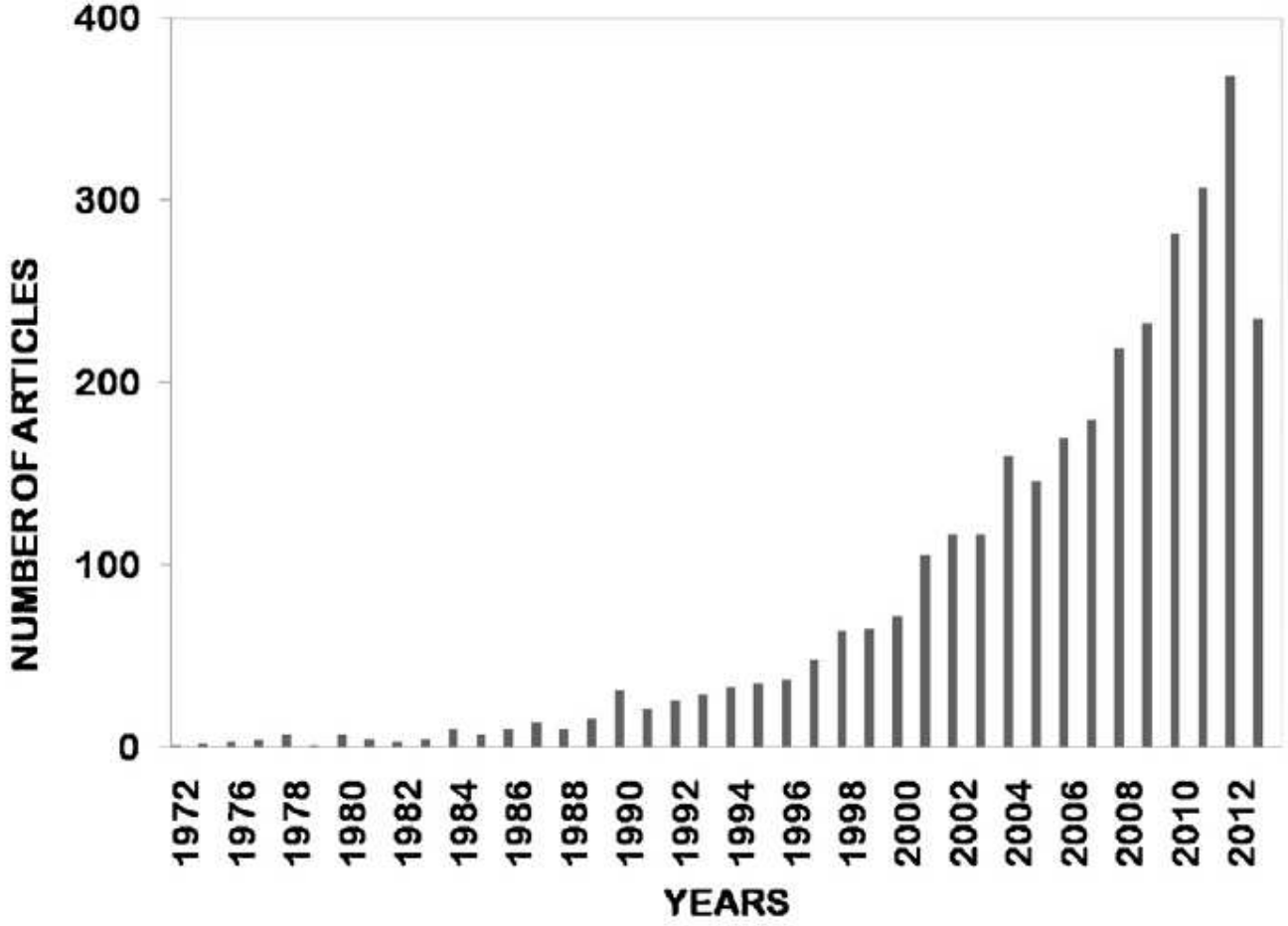


**Fig. 1.** Increasing number of publications on the topic of '*transition to adult care*' in recent decades.

*Source*: pubmed.gov (15 September 2013).

Transition from pediatric to adult care of children with chronic endocrine diseases: A survey on the current modalities in Italy

C. Volta, T. Luppino, M.E. Street and S. Bernasconi

J. Endocrinol. Invest. *26*: 157-162, 2003

## Soddisfazione per le modalita' di trasferimento

| | SI | NO |
|---|---|---|
| **Pediatri** | **42%** | **58%** |
| **Endocrinologi** | **46%** | **54%** |

# Management of adults with paediatric-onset chronic liver disease: Strategic issues for transition care☆

Digestive and Liver Disease 46 (2014) 295–301

Pietro Vajro[a,*], Lorenza Ferrante[c], Selvaggia Lenta[d], Claudia Mandato[d], Marcello Persico[b]

**Table 1**
Main paediatric-onset liver disorders that may require specific management at and after Transition.

| Group | Disease | Specific issues |
|---|---|---|
| Surgical cholestasis | Biliary atresia, choledocal cyst | Pregnancy complications |
| Genetic-metabolic | Alagille syndrome | Cardiovascular accidents |
| | Progressive familial intrahepatic cholestasis; bile acid synthesis defects | Cholestatic flares during pregnancy and/or stress |
| | $Alpha_1$-antitrypsin deficiency | Pulmonary disease |
| | Wilson disease | Neurological disease; compliance to treatment |
| | Amino acid, carbohydrates, lipid metabolic disorders | Diet |
| | Other storage diseases (e.g., glycogenosis) | Hepatic adenomas |
| | Other (e.g., mitochondrial disease) | Systemic localizations |
| Caroli disease and/or congenital hepatic fibrosis | | Cholangiocarcinoma |
| Autoimmune disorders | Autoimmune hepatitis | Compliance to treatment. Celiac disease and extra GI autoimmune diseases |
| | | Inflammatory flares after pregnancy |
| | Sclerosing cholangitis | IBD |
| Nonalcholic fatty liver disease | | Metabolic syndrome, polycystic ovary syndrome. |
| Viral infections | Hepatitis B and C viruses | Pregnancy (mother: HBV antiviral therapy during 3rd trimester to reduce viral load; newborn: HBV specific Ig and vaccination at birth) |
| Orthotopic liver transplantation | | Compliance to treatment, PTLD, de novo AIH, de novo allergies |

*Abbreviations*: AIH, autoimmune hepatitis; GI, gastrointestinal; HBV, hepatitis B virus; IBD, inflammatory bowel disease; Ig, immunoglobulins; PTLD, post transplantation lymphoproliferative disease.

# Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology

Italian Society of Paediatric Gastroenterology, Hepatology and Nutrition (SIGENP), Italian Association of Hospital Gastroenterologists and Endoscopists (AIGO), Italian Society of Endoscopy (SIED), Italian Society of Gastroenterology (SIGE)

Digestive and Liver Disease 47 (2015) 734–740

### *3.1. The panel's recommendations*

- **Adolescent patients are generally characterized by low levels of compliance to therapy and should be strictly monitored before starting the transition (2c-B).**
- **Although difficult to establish, the ideal age for transition is between 16 and 20 years, depending on physical and emotional maturity, disease activity, compliance to treatment, autonomy in disease management (2c-B).**
- **Paediatricians should decide when their young patients are ready to start the transition program, by taking into account the above reported factors and with the help of psychologists when needed (3b-C).**
- **Paediatricians should start the transition program by informing patients and families or caregivers about the purpose of transfer to an adult setting; they should be informed on the disease characteristics, treatments (including side effects) and how to recognize alarm symptoms. They should also be informed on the location of available adult centres, taking into consideration the patient's wishes and needs (5-D).**
- **The transition process should include a period of overlap between paediatric and adult care providers; the length of this period depends on disease severity (5-D).**
- **Regular meetings or suitable Web-based interaction between paediatric and adult Gastroenterologists should be scheduled to improve the effectiveness of the transition program (5-D).**

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

# Transizione dei giovani con diabete mellito verso l'età adulta: passaggio dal pediatra al medico dell'adulto.

*Gruppo di Studio SIEDP-AMD-SID*
*Vol 23 n. 1 Marzo 2011*

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

'Transitional care' is the term used to describe services that seek to bridge this 'care gap'. It has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems" (Blum 1993). Until recently, the literature on transition had a fairly limited focus on conditions such as diabetes and arthritis, but transition is now emerging as a priority across all long-term conditions. This shift is partly due to advances in health care, resulting in more young people with conditions, such as cystic fibrosis, now surviving into adulthood, but also to the growing realisation that services are failing to meet the needs of young people.

# ESPERIENZA PERSONALE

IL BAMBINO CON MALATTIA CRONICA NELLA FASE DI TRANSIZIONE TRA PLS E MMG

# INDAGINE PERSONALE (PLS)

| | | | |
|---|---|---|---|
| **Periodo di lavoro specialistico** | **> 20 anni** | **≤ 20 anni** | **≤10 anni** |
| **Insegnamento durante la specializzazione** | **99% no** | **97% no** | **100% no** |
| **Aggiornamenti** | **80% no** | **99% no** | **100% no** |
| **Interesse** | **100% si** | **100% si** | **100% si** |

# SINTESI

1) Definizione
2) Perché discuterne ?
3) **Gli ostacoli**
4) Che fare ?

Alan R. Watson

# Problems and pitfalls of transition from paediatric to adult renal care

Pediatr Nephrol (2005) 20:113–117
DOI 10.1007/s00467-004-1763-y

**Table 1** Differences between paediatric and adult units

| Paediatrics |
| --- |
| Family consultation |
| Multidisciplinary team and psychosocial support |
| Fewer patients |
| Specialist knowledge about rare genetic conditions, e.g. cystinosis |
| Shorter waiting lists |
| Peer support |
| Medications usually free |

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Alan R. Watson

# Problems and pitfalls of transition from paediatric to adult renal care

Pediatr Nephrol (2005) 20:113–117
DOI 10.1007/s00467-004-1763-y

**Table 1** Differences between paediatric and adult units

| Adult |
| --- |
| Individual consultation |
| Limited team support (especially psychosocial) |
| Large patient numbers |
| Lack of experience with rare 'paediatric' conditions |
| Longer waiting lists and pressure on dialysis 'spaces' |
| No 'young adult' clinic |
| Payment for medications |

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# Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers

2011 Blackwell Publishing Ltd, *Child: care, health and development*, **37**, 6, 821–832

A. L. van Staa,*† S. Jedeloo,* J. van Meeteren‡ and J. M. Latour§

**Table 5.** Cultures of care: typical differences between paediatrics and adult specialist medicine, according to interviewed healthcare professionals

| Paediatrics | Adult care |
|---|---|
| Typical patient is healthy, only a minority is chronically or terminally ill | Typical patient has complex, chronic and often progressive condition |
| Patient seen as fragile, vulnerable, dependent | Patient seen as co-responsible, self-reliant |
| Family-centred care: parents always involved | Individual-based care |
| Shared decision making and education focuses on parents rather than on patients | Empowerment of patient by means of being with information and expectations of self-reliance |
| Informal, relaxed communication style; empathic but also more paternalistic | Formal and direct communication style; more distant and 'business-like' |
| Holistic care: attention to developmental and learning issues, social functioning | Disease-oriented care: strong focus on treatment complications and adherence |
| Interdisciplinary team approach | Specialist orientation, less team work and care co-ordination |

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# Gli ostacoli : pazienti

- I pazienti possono essere riluttanti a spostarsi verso un'organizzazione sanitaria per adulti perché devono abbandonare un'atmosfera a loro familiare e servizi specifici che fanno parte della organizzazione sanitaria a loro nota.
- Vi è però da sottolineare che il rimanere in una organizzazione pediatrica può ritardare lo sviluppo di uno spirito di indipendenza e può privare pazienti con specifiche malattie delle cure appropriate alla loro età.

# Gli ostacoli : famiglia

**I genitori sono spesso riluttanti a lasciare la struttura pediatrica a cui sono stati legati per anni. Inoltre spesso lo staff del singolo centro costituisce la parte più importante del sistema di supporto alla famiglia.**

**Ne deriva che per organizzare con successo la transizione è necessario pianificarla con la famiglia.**

# Gli ostacoli : pediatri

I pediatri hanno profondi legami affettivi con i loro pazienti e le rispettive famiglie e possono desiderare mantenerli.

Possono inoltre avere la sensazione che nessuna organizzazione per adulti abbia la sufficiente competenza per confrontarsi con i propri pazienti e soprattutto che gli internisti non siano preparati a rispondere alle necessità psicosociali che si creano nel corso di una malattia cronica.

# Gli ostacoli : medico dell'adulto

- Il medico dell'adulto può pensare che i pazienti con malattie croniche iniziate in età pediatrica siano immaturi e che le loro famiglie siano troppo coinvolte e pressanti.
- Qualcuno può ritenere che il tempo utilizzato per spiegare i vari aspetti della terapia sia eccessivo e ridondante.
- L'organizzazione sotto forma di team non è il modello più frequente sia per i costi sia perché l'internista è abituato ad assumersi la responsabilità anche dei vari aspetti del piano terapeutico.

# SINTESI

1) Definizione
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# SINTESI

***Patient-Centered Medical Home (PCMH) Transition, Flow of Information, and Care Coordination Document***

ACP
AMERICAN COLLEGE OF PHYSICIANS
INTERNAL MEDICINE | *Doctors for Adults*

1. Respecting the hub of coordination of care-

2. Accountability-

3. Clear and direct communication of treatment plans and follow-up expectation

4. Timely feed-forward and feedback of information-

5. The *involvement and awareness* of the patient and family member, unless inappropriate, in all steps

6. *Establishing national standards*-

7. *Measurement*-

**THE PATIENT-CENTERED MEDICAL HOME NEIGHBOR**

# SINTESI

1) Definizione
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4) **Che fare ?**

   **- linee guida condivise**

NICE National Institute for Health and Care Excellence

NICE guideline

# Transition from children's to adults' services for young people using health or social care services

NICE guideline

Published: 24 February 2016
nice.org.uk/guidance/ng43

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# Transition From Child to Adult Care – *'It's Not a One-Off Event'*: Development of Benchmarks to Improve the Experience

Susie Aldiss MSc[a,*], Judith Ellis PhD[b,1], Hilary Cass MB BS, BSc[c,d], Tanya Pettigrew[e], Laura Rose MSc[f], Faith Gibson PhD[a,g]

Journal of Pediatric Nursing (2015) **30**, 638–647

**Table 1** Benchmarks for Transition – Factors and Statements of Best Practice.

| Factor | Best practice |
|---|---|
| Factor 1: Moving to manage a health condition as an adult. | Young people are offered advice and information in a clear and concise manner about how to manage their health condition as an adult. |
| Factor 2: Support for gradual transition. | The young person as they progress through the transition process is gradually prepared and provided with personally understandable information and support. |
| Factor 3: Co-ordinated child and adult teams. | The young person is supported through a smooth transition by knowledgeable and coordinated child and adult teams. |

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# Transition From Child to Adult Care – *'It's Not a One-Off Event'*: Development of Benchmarks to Improve the Experience

Susie Aldiss MSc[a,*], Judith Ellis PhD[b,1], Hilary Cass MB BS, BSc[c,d], Tanya Pettigrew[e], Laura Rose MSc[f], Faith Gibson PhD[a,g]

Journal of Pediatric Nursing (2015) **30**, 638–647

**Table 1** Benchmarks for Transition – Factors and Statements of Best Practice.

| Factor | Best practice |
|---|---|
| Factor 4: Services 'young people friendly'. | Young people are provided with care and in an environment that recognises and respects that they are a 'young person', not a child or adult. |
| Factor 5: Written documentation. | Concise, consistent and clear written document containing all relevant information about the young person's transition is provided to the teams involved in the transition process. |
| Factor 6: Parents. | Parents are included in the transition process gradually transferring responsibility for health to the young person. |

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Susie Aldiss MSc[a,*], Judith Ellis PhD[b,1], Hilary Cass MB BS, BSc[c,d], Tanya Pettigrew[e], Laura Rose MSc[f], Faith Gibson PhD[a,g]

Journal of Pediatric Nursing (2015) 30, 638–647

**Table 1** Benchmarks for Transition – Factors and Statements of Best Practice.

| Factor | Best practice |
|---|---|
| Factor 7: Assessment of 'readiness'. | The young person's readiness for transition to adult care is assessed. |
| Factor 8: Involvement of the GP. | The young person's GP is informed of the plan for transition and is able to liaise with other relevant teams to facilitate services requested/needed by the young person. |

# Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology

Italian Society of Paediatric Gastroenterology, Hepatology and Nutrition (SIGENP), Italian Association of Hospital Gastroenterologists and Endoscopists (AIGO), Italian Society of Endoscopy (SIED), Italian Society of Gastroenterology (SIGE)

Digestive and Liver Disease 47 (2015) 734–740

### *3.1. The panel's recommendations*

- **Adolescent patients are generally characterized by low levels of compliance to therapy and should be strictly monitored before starting the transition (2c-B).**
- **Although difficult to establish, the ideal age for transition is between 16 and 20 years, depending on physical and emotional maturity, disease activity, compliance to treatment, autonomy in disease management (2c-B).**
- **Paediatricians should decide when their young patients are ready to start the transition program, by taking into account the above reported factors and with the help of psychologists when needed (3b-C).**
- **Paediatricians should start the transition program by informing patients and families or caregivers about the purpose of transfer to an adult setting; they should be informed on the disease characteristics, treatments (including side effects) and how to recognize alarm symptoms. They should also be informed on the location of available adult centres, taking into consideration the patient's wishes and needs (5-D).**
- **The transition process should include a period of overlap between paediatric and adult care providers; the length of this period depends on disease severity (5-D).**
- **Regular meetings or suitable Web-based interaction between paediatric and adult Gastroenterologists should be scheduled to improve the effectiveness of the transition program (5-D).**

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# SINTESI

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   - linee guida condivise
   - **spazi dedicati**

# Care of Adults in Children's Hospitals
## Acknowledging the Aging Elephant in the Room

**JAMA Pediatrics** December 2015

**Benjamin Kinnear, MD**

Patients older than 21 years account for 15 000 admissions to children's hospitals annually, and this number is trending upward.[1] Transitional patients (ages 18-21 years) had a greater than 150% increase in total inpatient charges at children's hospitals between 1999 and 2009, while adult patients (>21 years old) had a greater than 50% increase during that time.[2] For some conditions such as malignant neoplasm and cerebral palsy, admissions to pediatric institutions are growing at a faster rate in adult-aged patients than in children.[2] As these numbers increase, children's hospitals will need to develop additional infrastructure and new models of care to treat these adults in a safe, standardized, and evidence-based manner.

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# SINTESI

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   - linee guida condivise
   - spazi dedicati
   - **formazione medico e team**

# Adolescent and young adult medicine is a special and specific area of medical practice

Kate Steinbeck,[1,2] Susan Towns[2,3] and David Bennett[2,3]

Journal of Paediatrics and Child Health **50** (2014) 427–431

# Health for the World's Adolescents: A Second Chance in the Second Decade

Bruce Dick, M.B.[a,*], and B. Jane Ferguson, M.Sc.[b]

1054-139X/© 2015 Published by Elsevier Inc. on behalf of Society for Adolescent Health and Medicine.
http://dx.doi.org/10.1016/j.jadohealth.2014.10.260

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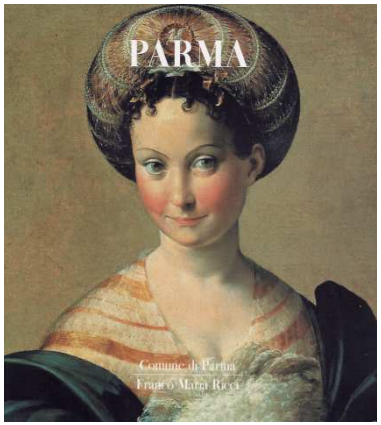
# GRAZIE PER L'ATTENZIONE