# Health Care Transition

Transition Bootcamp

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# Some of the Differences Between Pediatric & Adult Health Care Systems

**Pediatric System**

- Presumption that child lives within a family & physician works with both child and family to provide care.
- Presumption that the child is gradually learning to self-manage health.

**Adult System**

- Presumption that physician primarily works with the adult as an individual
- Presumption that the adult has the skills to adequately self-manage health and to negotiate the health care system
- Presumption that new knowledge & skills only needed when new conditions emerge

# “Diseases of childhood are now considered diseases of childhood onset”

| | 1970’s | 2000’s |
|---|---|---|
| Childhood Cancer | 25% 5y survival | 80% 5y survival |
| Congenital Heart | 59% survival | 85% survival |
| Cystic Fibrosis | 7 years old | 35 years old |
| Down Syndrome | 20 years old | 55 years old |
| Sickle Cell Disease | 9 years old | 46 years old |
| Spina Bifida | <20 years old | 60+ years old |

Rosen D. J of Adol Med. 1995

# Definition of Adolescent Health Care Transition

- Transition is defined as:
  - "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems."
- Healthcare Transition ≠ Transfer of Care
- Transition is a Process, not an Event
- Transition begins long before the actual transfer of care

(Society of Adolescent Medicine. *J Adol Health*. 1993;14:570-6.)

# Where is the Medical Home?

Non-developmental diagnoses

- CHD – Cardiology
- HIV – Infectious Diseases
- Sickle Cell Disease – Hematology
- Type 1 Diabetes – Endocrinology
- Cystic Fibrosis – Pulmonology
- Juvenile Arthritis – Rheumatology
- Epilepsy - Neurology

Developmental Diagnoses

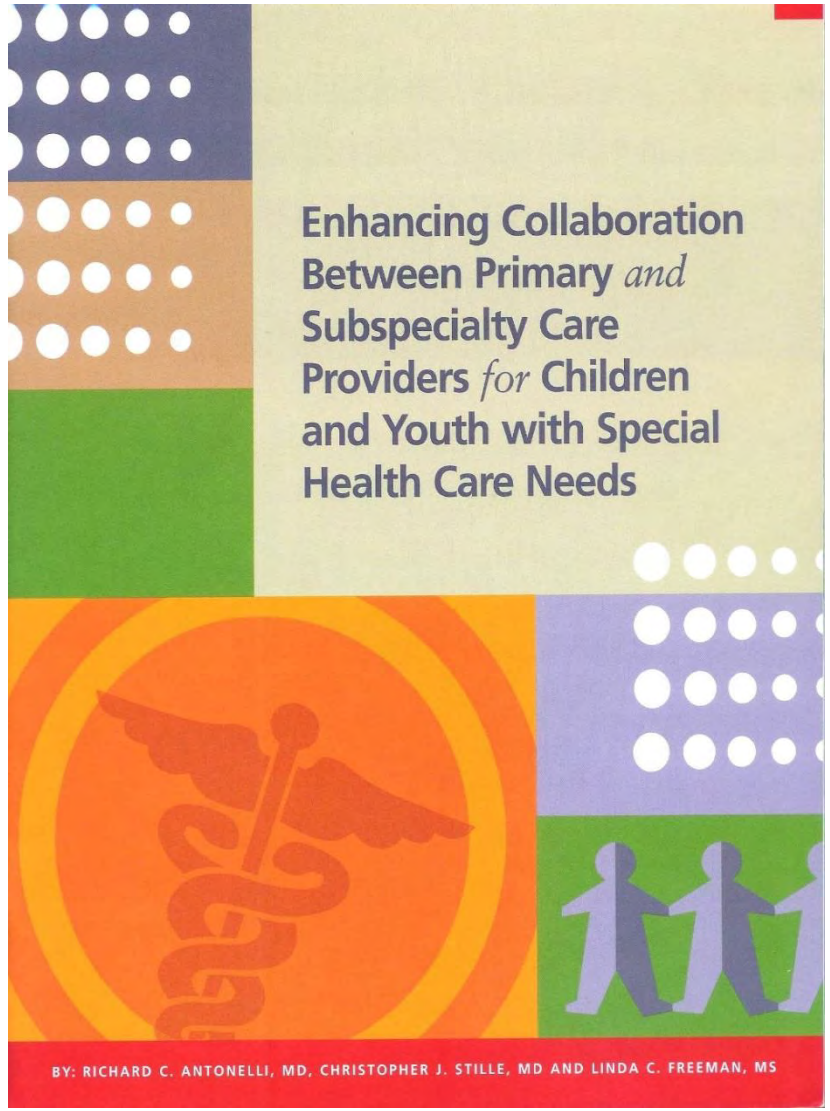
- ADHD
- Autism
- Cerebral Palsy
- Down syndrome
- Fetal Alcohol
- Intellectual disabilities
- Spina Bifida

# Models of Medical Homes

1. ***Generalist serves as primary manager*** with occasional specialty consultation
   - Asthma
   - ADHD
   - Down syndrome
2. ***Co-management relationship*** with close involvement of each provider
   - CHD
   - Type I Diabetes
   - HIV
   - Autism
3. ***Sub-specialist serves as principal*** care provider for complex conditions
   - Cerebral Palsy
   - Spina Bifida
   - Sickle Cell
   - Intractable Epilepsy

# Primary and Specialty Care Collaboration

- Funded by HRSA
- Based on Wagner Chronic Care Model and AAP Medical Home
- Discusses improved co-management of chronic disease by PCP and specialist
- “Shared Care”

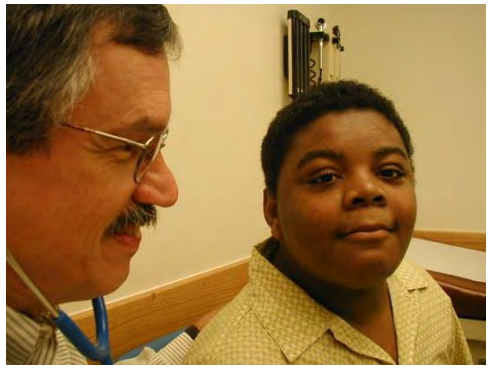



http://gucchd.georgetown.edu/products/PrimarySpecialityCollaboration.pdf

Antonelli RC, Stille CJ, Freeman, LC

# Simultaneous Transitions

- From pediatric child-centered care to adult oriented health services
- From living at home with family to living in the community
- From school to work
- Towards adult relationships



White. In: Batshaw, ed. Children with Disabilities, 2002

# Healthcare Transition

## Adolescent

- Developmental level
- Learning style
- Motor skills
- Mental Health

## Health Providers

- Knowledge
- Medical home
- Institutional support
- Financial/Insurance support

## Family

- Health literacy
- Family health
- Finances

## School

- Voc/Ed
- Living skills
- Behavior support

## Community

- Supported living
- Case facilitation
- Voc rehabilitation

# Principles of Health Care Transition (When)

1. A planned coordinated approach is essential.
2. Transfer should occur at a time of disease stability.
3. When possible, the transferring and receiving teams should meet together with the patient and family.
4. The adolescent/young adult should be continuously encouraged to increase their self-reliance and self-care well prior to the anticipated transfer time.
5. Family should actively transition their roles from direct caregivers to advocates and supporters.
6. Professional sensitivity to psychosocial issues of disability.
7. Health education for the adolescent.
8. Family support.
9. Professional and environmental or institutional support for the concept of transition.

Society for Adolescent Medicine 1993, Sawyer. *J Paediatric Child Health.* 1997.

# Pediatric Perspective

| Age at Which Pediatricians Think Transition Should Begin | | |
|---|---|---|
| Ages | Adolescents with Special Needs | Adolescents without Special Needs |
| <12 years | 3% | 2% |
| 12-14 years | 6 | 6 |
| 15-17 years | 25 | 26 |
| 18-20 years | 62 | 65 |
| Don't Know | 4 | 2 |

McManus et al. 2008

# Pediatric Perspective

| Barriers Affecting the Provision of Transition Services | | |
|---|---|---|
| Barrier | Major % | Rank |
| Lack of available adult PCPs (Family Med or Internal Med) | 41 | 1 |
| Lack of available adult specialists | 40 | 1 |
| Lack of knowledge about or linkages to community supports | 39 | 2 |
| Lack of insurance reimbursement for transition services | 38 | 2 |
| Fragmentation of primary and specialty adult health care | 39 | 2 |
| Lack of sufficient staff time to provide transition services | 36 | 2/3 |
| Lack of pediatric staff skills in transition planning | 33 | 3 |
| Difficulty in breaking bond between pediatrician and pts | 32 | 3 |
| Lack of adolescent knowledge of condition or self-care skills | 19 | 4 |

McManus et al. 2008

# Adult Medicine Perspective

| Barriers Affecting the Transfer to Adult Providers | | |
|---|---|---|
| Barrier | | Rank |
| Personal competence/Need for super-specialists | | 1 |
| Not enough family involvement (especially for cerebral palsy, MR) | | 1 |
| Families expect significant time/attention for care | | 1 |
| End of life issues | | 1 |
| Adolescent/young adults self-care skills and knowledge | | 2 |
| Insurance concerns | | 2 |
| Lack of staff skills in care for these patients | | 2 |
| Lack of knowledge about or linkages to community supports | | 2 |
| Inadequate transfer of medical information/records | | 2 |

Peter NG et al. 2009

# Adult Medicine Perspective

| Barriers Affecting the Transfer to Adult Providers | | |
|---|---|---|
| Barrier | | Rank |
| Internal medicine not paternalistic/ Worry patients lost to follow-up | | 2 |
| Time consuming to care for chronically ill young patients | | 2 |
| Literature on childhood illnesses mostly in pediatric journals | | 2 |
| Colleagues unwilling to care for teenage patients | | 3 |
| Confidentiality issues between young adults and parents | | 3 |
| Pediatricians keep compliant patients and transfer non-compliant ones | | 3 |
| Need to change treatment plan due to prior inadequate care | | 4 |
| Young patients distrust staff | | 4 |
| Pediatricians reluctant to let go | | 4 |

Peter NG et al. 2009

# Parent Perspective

- 50% of surveyed parents who had a child with a chronic condition reported discussing transition with their pediatrician
- 21-30% had discussed changing to an adult-oriented health provider
- 30% had a plan in place for transition

(2001 National Survey of Children with Special Health Care Needs)

[Lotstein et al. Pediatrics. 2005. (n=5533)  Scal P, Ireland M. Pediatrics. 2005. (n=4332)]

# Adolescent Perspective

- Competing demands and interests
  - “I have to think about graduation right now”
  - Also mentioned work issues and inconvenience of multiple medical visits
- Struggle for autonomy
  - “I wish my parents would allow me to try…”
  - “I wish my doctor would let me choose…”
- Peer mentorship
  - “I wish there was an adult with my condition who I could talk to about…” (usually an adult subject)
- Chronic (illness) fatigue syndrome
  - “Just don’t want to think about it anymore”
  - Don’t want to “start all over again” and educate a new doctor
  - “The (adult-oriented) doctor gets mad if I tell him this is what works best for me”

(Reiss et al. Pediatrics. 2005; Patterson et al. Fam Community Health. 1999.)

# Stages of Transition

- Envisioning a Future (diagnosis)
  - At the time of diagnosis
  - Maintaining a future orientation
- Age of Responsibility (pre-teen)
  - Self-care skills development
  - Decision-making rights and responsibilities
- Age of Transition (adolescence)
  - Practicing Interdependence
  - Formal “graduation” and transfer of care

**Health Care Transition: Youth, Family, and Provider Perspectives**
John G. Reiss, Robert W. Gibson and Leslie R. Walker
*Pediatrics* 2005;115;112-120

# Finding Adult Providers

- Those with experience with adults and children have more comfort level with developmental conditions (Family Medicine & Med-Peds)
- Those who have at least one patient with the same diagnosis in their practice have more comfort level
- Those within health care systems that provide clinical decision support for generalists
- Those with personal experience as parents of children with special health care needs

# Who Should Be The Adult Provider? Who Is The Most Comfortable?

- Survey of Providers in SW Ohio
- Representative diagnoses were selected based on relatively common frequencies.
  - 9 conditions with developmental disabilities
  - 9 conditions without developmental disabilities
  - 2 control conditions
    - Asthma, essential hypertension
- Hypothetical patient was either 15, 21, or 27 years old
- Participants were asked to rate comfort level on a 5-point Likert scale based on providing "usual care."
  - 1 = Very uncomfortable to 5 = Very comfortable
- Participants were also asked to rank how many patients with the given diagnosis they had seen in their practice in the last year
  - 0, 1-5, or >5
- 2150 providers identified from SW Ohio AMA Masterfile.

## BACK SIDE

| A 21-year-old established patient comes back to your office for a return visit with one of the childhood onset diseases in the list below. For each disease, please indicate how comfortable you would feel providing your usual care to this patient in conjunction with the patient's other specialists. | | | | | | | How many patients with this diagnosis have you seen in the last year? | | |
|---|---|---|---|---|---|---|---|---|---|
| **The patient is 21 years old with:** | Very uncomfortable | Fairly uncomfortable | Neither Comfortable or Uncomfortable | Fairly comfortable | Very comfortable | | None | 1-5 | >5 |
| ADHD | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Asthma | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Autism | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Congenital Heart Disease | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Crohn's Disease | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Cystic Fibrosis | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Down Syndrome | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Epilepsy | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Essential Hypertension | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Fragile X syndrome | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Idiopathic Mental Retardation | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Juvenile Rheumatoid Arthritis | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Klinefelter's (47,XXY) Syndrome | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Marfan's Syndrome | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Paraplegia from a Spinal Cord Injury | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Sickle Cell Disease | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Spastic Quadriplegic Cerebral Palsy | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Spina Bifida | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Turner (45,XO) Syndrome | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |
| Type I Diabetes Mellitus | 1 | 2 | 3 | 4 | 5 | | 0 | 1-5 | >5 |

# Comfort Level by Provider Type

| | Pediatrics | Internal Med | Family Med | Med-Peds |
|---|---|---|---|---|
| **Developmental** | % | % | % | % |
| **ADHD** | 79.2 | 51.0* | 85.9^ | 90.3^ |
| **Autism** | 66.2 | 17.1* | 32.5*^ | 35.5*^ |
| **Cerebral Palsy** | 62.8 | 32.1* | 42.0* | 71.0^ |
| **Down Syndrome** | 81.4 | 53.8* | 68.7*^ | 83.9^ |
| **Fragile X** | 56.6 | 7.8* | 19.1*^ | 64.5^ |
| **Klinefelter's** | 52.4 | 23.6* | 32.1* | 54.8^ |
| **Intellectual Disabilities** | 69.9 | 51.9* | 66.0^ | 86.7^ |
| **Spina Bifida** | 63.2 | 21.9* | 45.7*^ | 67.7^ |
| **Turner Syndrome** | 68.1 | 27.6* | 40.4*^ | 64.5^ |

*p < 0.05 internal med, family med, or med-peds compared to pediatrics;
^p <0.05 family med or med-peds compared to internal med

# Comfort Level by Provider Type

| | Pediatrics | Internal Med | Family Med | Med-Peds |
|---|---|---|---|---|
| **Medical** | **%** | **%** | **%** | **%** |
| **CHD** | **63.2** | **44.3*** | **48.5*** | **80.6^** |
| **Crohn's** | **57.6** | **70.8*** | **64.0** | **83.9*** |
| **Cystic Fibrosis** | **54.9** | **23.8*** | **27.2*** | **80.6*^** |
| **Epilepsy** | **86.6** | **84.0** | **84.6** | **93.6** |
| **JRA** | **50.0** | **35.8*** | **46.6** | **71.0*^** |
| **Marfan's** | **54.2** | **43.8** | **43.5** | **73.3^** |
| **Paraplegia** | **45.8** | **55.2** | **51.2** | **77.4^** |
| **Sickle Cell** | **53.5** | **50.9** | **43.8** | **77.4*^** |
| **Type I Diabetes** | **63.4** | **90.6*** | **78.5*^** | **100.0*** |

***p < 0.05 internal med, family med, or med-peds compared to pediatrics;**
**^p <0.05 family med or med-peds compared to internal med**

# Comfort Level by Experience

| | No patients | 1-5 patients | > 5 patients | Test of Trend |
|---|---|---|---|---|
| | % | % | % | p-value |
| ADHD | 20.0 | 54.6 | 88.1 | <0.0001 |
| Autism | 11.5 | 39.7 | 88.2 | <0.0001 |
| Cerebral Palsy | 20.0 | 67.0 | 93.3 | <0.0001 |
| Down Syndrome | 32.9 | 75.9 | 97.6 | <0.0001 |
| Fragile X | 13.2 | 52.5 | 100.0 | <0.0001 |
| Klinefelter's | 25.6 | 71.4 | 100.0 | <0.0001 |
| Mental Retardation | 27.4 | 67.5 | 88.1 | <0.0001 |
| Spina Bifida | 26.2 | 61.1 | 85.7 | <0.0001 |
| Turner Syndrome | 30.6 | 68.5 | 100.0 | <0.0001 |

# Helping Families Find New Providers

- Ask family advocacy groups, county board agency, local group home provider
- Transfer while still on family private insurance
- Insure information is transferred at/before first visit
- Adjust time of appointment according to person's needs (first vs. last appointment of day)
- Screen for physical access issues
- Provide resources to new provider (info on diagnosis)

# Adolescent Self-Management Skills

- Self-care skills were identified by pediatrics, adult medicine, parents, and adolescents as critical to successful transition.
- In a Cincinnati survey, 80% of the adult providers felt the transferred adolescents lacked adequate self-care skills
- Functional knowledge is believed more important than book knowledge
- “Teach-back” assesses understanding

Charvat and Nebrig, 1998; Johnson CP, 2001.

# Adolescent Self-Management Skills

- Cognitive level, learning disability, and health literacy can impact self-care abilities
- Many “typical appearing” adolescents with special health care needs have “hidden” learning disabilities
- Neuropsychological testing ideal but difficult to obtain
- Language testing, particularly higher level testing of pragmatic/social skills, can be enlightening

# Self-Management vs “Shared Management”

- Not everyone can achieve full independence or “**self-management**”
- Maximizing autonomy, the ability to make decisions about one’s life (**Self-determination**)
- View the highest level of achievement is not independence but **effective interdependence**

(Kieckhefer 2000)

# Adolescent Autonomy Checklist

| Health Care Skills | Can Do Already | Needs Practice | Plan to Start | Accomplished |
|---|---|---|---|---|
| Understand health condition | | | | |
| Perform self-care skills, i.e. bowel and bladder care | | | | |
| Prepare questions for doctors, nurses, therapists | | | | |
| Respond to questions from doctors, nurses, therapists | | | | |
| Know medications and what they're for | | | | |
| Get a prescription refilled | | | | |
| Keep a calendar of doctor, dentist appointments | | | | |
| Know height, weight, birthdate | | | | |
| Learn how to read a thermometer | | | | |
| Know health emergency telephone numbers | | | | |
| Know medical coverage numbers | | | | |
| Obtain sex education materials/birth control if indicated | | | | |
| Discuss role in health maintenance | | | | |
| Have genetic counseling if appropriate | | | | |
| Discuss drugs and alcohol with family | | | | |
| Make contact with appropriate community advocacy organization | | | | |
| Take care of own menstrual needs and keep a record of monthly periods | | | | |

# Medications

| Name | Dose | Frequency | Reason |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

- Know your Medications, dosages, and frequency and carry a card in your wallet
- Adderall XR – take 1 capsule after breakfast

# Sometimes it’s hard to remember to take your medicine

# Transition Support Services

Survey of 126 clinics identified as offering transition services to adolescents with special health care needs.

| Services Offered | % |
|---|---|
| Clinical/medical | 78 |
| Mental health | 57 |
| MH referral | 37 |
| Case management | 72 |
| • Nurse or social worker | |

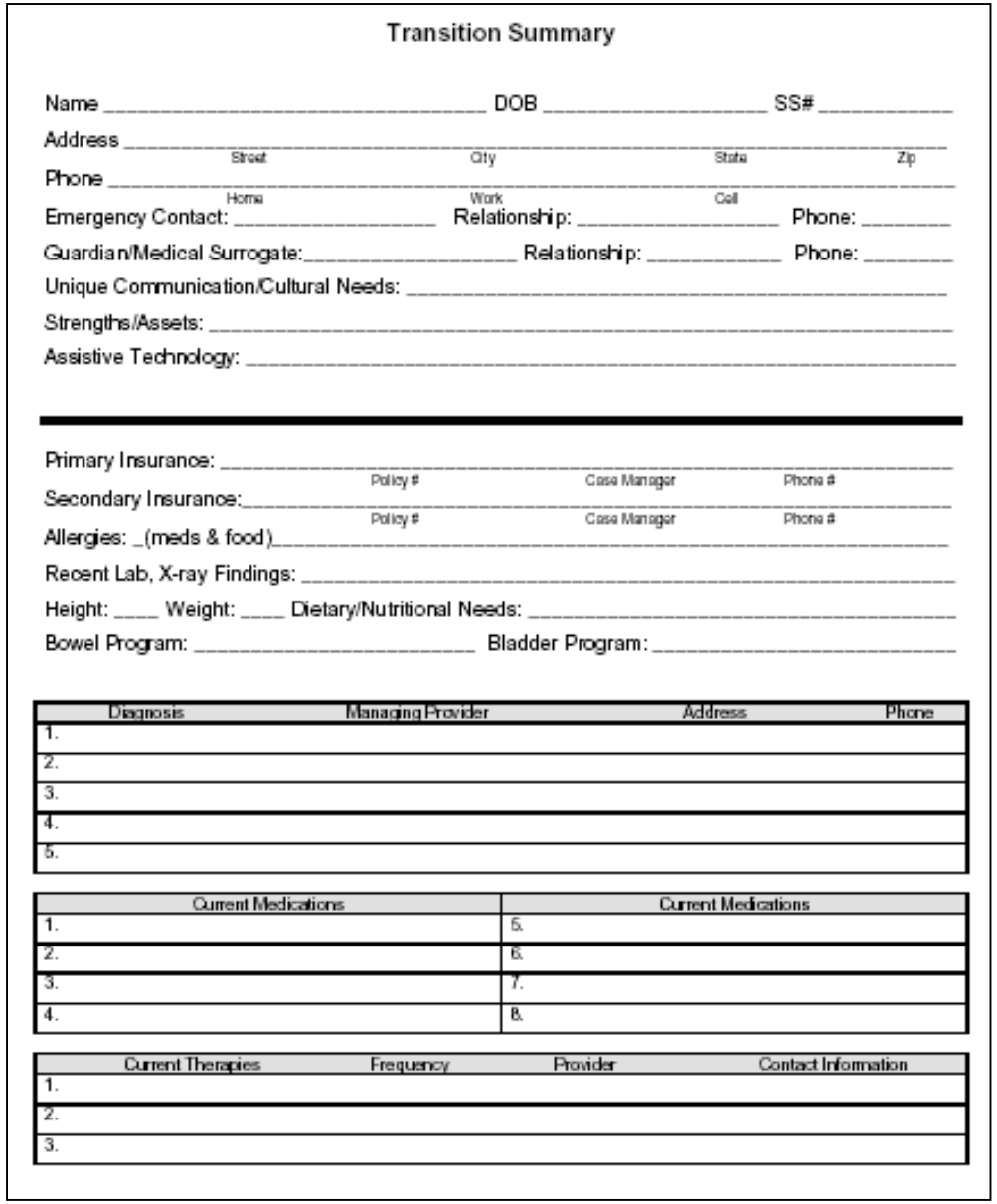
| Service Priorities | % |
|---|---|
| Psychosocial well-being | 95 |
| Chronic condition care | 90 |
| Primary care needs | 85 |
| Family well-being | 84 |
| Vocational needs | 56 |
| Teaching self-advocacy | 25 |

Scal. *J Adol Health* 1999. 24:259-64.

# Vocational/Educational Transitions

- Individuals with Disabilities Education Act 1990, Amendments 1997, Improvement Act 2004
- Individualized Education Programs (IEP) should include:
  - Transition planning starting by 16 years old
  - Student participation by 14-16 years old
  - Transition team (including community providers, vocational rehabilitation, health care providers) by 16 years old
  - Strategies to develop daily living and functional vocational skills which will support independent living and community participation.

Individuals with Disabilities Education Act (www.cec.sped.org/law_res/doc/law/law/index.php)



## Transition Summary

Name _____ DOB _____ SS# _____

Address _____
Street City State Zip

Phone _____
Home Work Cell

Emergency Contact: _____ Relationship: _____ Phone: _____

Guardian/Medical Surrogate: _____ Relationship: _____ Phone: _____

Unique Communication/Cultural Needs: _____

Strengths/Assets: _____

Assistive Technology: _____

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Primary Insurance: _____
Policy # Case Manager Phone #

Secondary Insurance: _____
Policy # Case Manager Phone #

Allergies: _(meds & food)_____

Recent Lab, X-ray Findings: _____

Height: ____ Weight: ____ Dietary/Nutritional Needs: _____

Bowel Program: _____ Bladder Program: _____

| Diagnosis | Managing Provider | Address | Phone |
|---|---|---|---|
| 1. | | | |
| 2. | | | |
| 3. | | | |
| 4. | | | |
| 5. | | | |

| Current Medications | Current Medications |
|---|---|
| 1. | 5. |
| 2. | 6. |
| 3. | 7. |
| 4. | 8. |

| Current Therapies | Frequency | Provider | Contact Information |
|---|---|---|---|
| 1. | | | |
| 2. | | | |
| 3. | | | |

http://depts.washington.edu/healthtr/medsum/shriners.pdf

# Information at Transfer of Care

- Portable medical record
  - Diagnoses
  - Medications
  - Allergies
  - Procedures
  - Important and/or most recent labs and rads
  - Equipment
  - Care providers
  - Community agencies

**Family creates**

- Clinical summary
  - Medical
    - Equipment
    - Procedures
    - Labs and Rads
  - Info on condition
  - Developmental
  - Psychosocial/Family
  - Vocational-educational
  - Community/financial resources

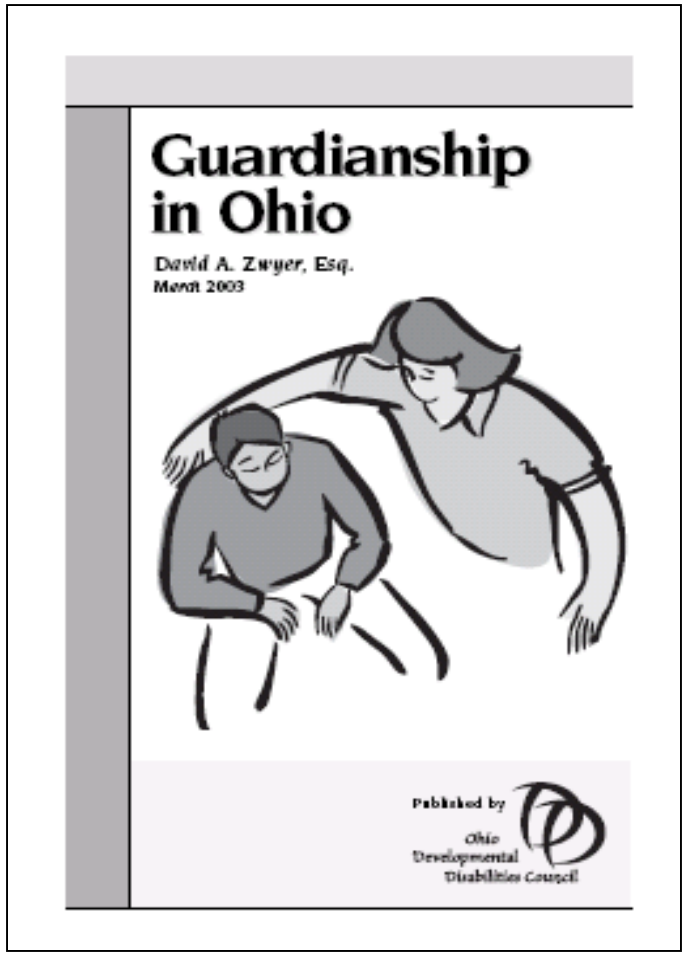
**Provider creates**

# Transferring Care – The Basics

- Transfer occurs at the time of disease stability
- Many adolescents and parents believe the process should occur usually around 18-21 (19 average)*
- The process should take about 1 year
  - Refer, have initial visit, see back, feedback, fix problems
- Help family identify adult provider at the same level of service (i.e. specialist to specialist)
  - Accepts insurance (transfer when still on parents' insurance)
  - Will follow medical condition
  - Is located reasonably close to patient
- Provide appropriate medical summary

(Yi M, et al. 2007)

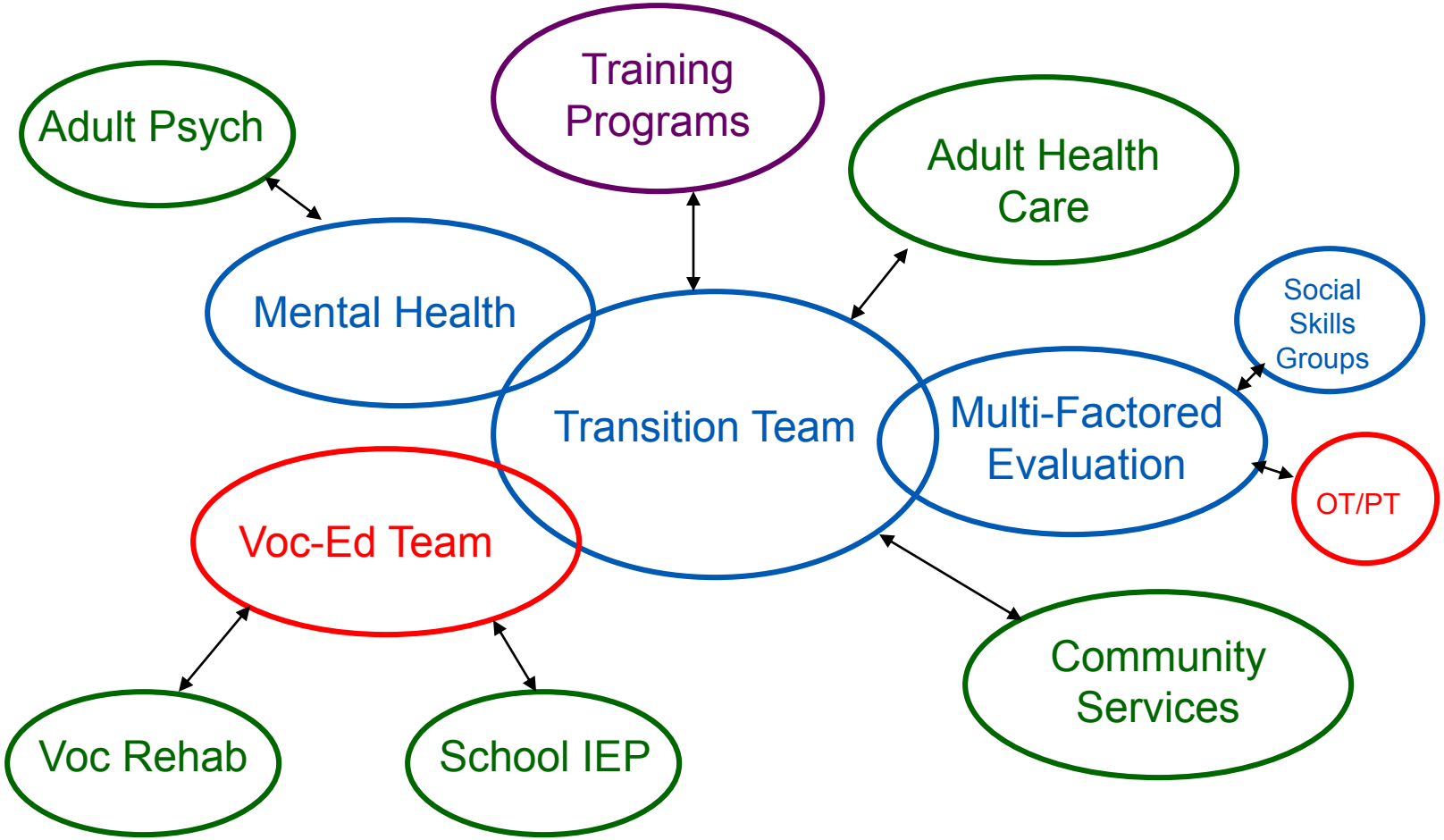
# Guardianship




- Individuals automatically become their own guardian at age 18, regardless of disability.
- HIPAA has had a significant impact on advice regarding guardianship and/or health care proxies.
- Families should discuss if legal guardianship or alternatives to guardianship is needed for their adolescent, either long-term or temporarily as they develop independent living skills.

# Health Care Insurance Considerations

- Private Insurance
  - Investigate insurance provisions for adult children with life-long economic dependency
  - Some would recommend maintaining private insurance as long as possible
- Medicaid- only coverage
  - May limit access to physicians and health care systems
- Dual eligibility for both Medicare and Medicaid




# Sample Transition Clinic Services Schema

# Conclusions

- Adolescents living to adulthood with childhood-onset chronic conditions will continue to increase in numbers
- Preparation is key to an optimal transition
  - Collaboration and communication between adult and pediatric care (and family) is needed
- Maximizing self-management skills of adolescents is paramount to success in the adult system
- Insurance and work/school issues play a significant (and often under-appreciated) role in transition and transfer of care
- Both primary and specialty care transfer must be considered
  - Time for an institutional-level evaluation and plan

got transition

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Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

## News & Announcements

**Got Transition Publishes Systematic Review on Transition**
Got Transition has published a systematic review of pediatric-to-adult transition studies in the Journal of Pediatrics more>

**SAHM's New Adolescent Medicine Resident Curriculum on Transition**
The Society for Adolescent Health and Medicine (SAHM) has released a new Adolescent Medicine Resident Curriculum, with one of its ten core content modules dedicated to Transition to Adult Care. more>

**New Tip Sheet Links 2017 Patient-Centered Medical Home Standards with Six Core Elements**
Got Transition released a new tip sheet that cross-walks the Six Core Elements with the 2017 Patient-Centered Medical Home Standards from the National Committee on Quality Assurance (NCQA). more>

**Standards for Systems of Care for CYSHCN Streamlined and Updated**
AMCHP, in partnership with NASHP and the Lucile Packard Foundation for Children's Health, has released an updated Standards for Systems of Care for Children and Youth with Special Health Care Needs. more>

**2017 Call for Abstracts: Health Care Transition Research Consortium**
The International and Interdisciplinary Health Care Transition Research Consortium (HCTRC) has announced its Call for Abstracts for researchers to be presented at the 9th Annual HCTRC Research Symposium and the 4th Annual Mental Health Dialogue on Transition in Houston, Texas between October 3-5, 2017. The deadline for submissions is July 31, 2017. more>

**The National Alliance to Lead Transition Payment Roundtable**
The Lucile Packard Foundation for Children's Health recently funded The National Alliance to lead an expert committee of public and private payers and health plan leaders to develop

## Health Care Providers

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

Customize the Six Core Elements of Health Care Transition to meet your patients' and practice's needs!

New Tip Sheet Linking 2017 Patient-Centered Medical Home Standards with Six Core Elements

See our Health Care Transition Resources page

## Youth & Families

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

Turning 18: What it Means for Your Health

The "Medical ID" Feature on Apple's Health app

The "Medical ID" app for Android phones

¡Nueva traducción al español de las preguntas más frecuentes sobre jóvenes y familias!

## Researchers & Policymakers

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.

2017 Report on Innovative State Title V Transition Efforts

State Title V Transition Information and Resources