TRANSITION OF ENDOCRINE CARE FROM PEDIATRIC TO ADULTHOOD

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DISCLOSURE

- No potential conflict of interest

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OBJECTIVES

- Review timing considerations for transition from pediatric to adult-centered care
- Identify challenges faced by the emerging adult with endocrine disorders
- Describe ways to create a successful transition from pediatric to adult-centered care
- Discuss key factors that should be considered when developing a transition in care program
- Provide information on helpful resources for transitioning care

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DEFINING TRANSITION OF CARE

- What is a transition of care?
  - "The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to an adult-oriented health care system."
    - Society for Adolescent Medicine
- What is it not?
  - Transition is not merely the transfer of care but a long-term process. It is not a one-time event, but begins long before the actual transfer of care occurs.
- Ideally, the timing of transfer to adult care should be determined by patient readiness and not defined by age.

Blum RW et al. *J Adolesc Health.* 1993; 14(7): 570-576.
Bowen ME et al. *Clin Diabetes.* 2010; 28(3): 99-106.

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CURRENT TRANSITION OF CARE

PEDIATRIC CARE

ADULT CARE

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CHALLENGES TO TRANSITIONING THE EMERGING ADULT

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CHALLENGES TO TRANSITIONING THE EMERGING ADULT

- LIFE
  - No routine and unpredictable schedules/ Late nights
  - Stress
  - Alcohol and drugs
  - No stable support system, new friends
  - Social pressures
  - Wanting to be normal
  - Limited food options
  - Desire for spontaneity
  - Financial concerns
  - Priorities evolve throughout college years
- CHRONIC CONDITION
  - Transition of care
  - Transition of independent management
  - Increased responsibility
  - Less parental involvement
  - Registration with “Disabilities services”
  - Responsibility for informing professors/bosses
  - No support resources or education typically available

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CHALLENGES TO TRANSITIONING THE EMERGING ADULT

- Due to prolonged supervision under parents or guardians, the patient "does not feel ready" to take full responsibility of her/his condition
- Chronicity of many endocrine disorders needs continuity of care
  - Diabetes
  - Growth Hormone Deficiency
  - Turner Syndrome
  - CAH
  - etc.

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CRITICAL FIRST STEPS

- In 2002, a consensus statement coauthored by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine was published, stating the importance of supporting and facilitating the transition of adolescents with special health care needs into adulthood. The consensus statement articulated 6 “critical first steps” to ensuring the successful transition to adult-oriented care.

1ST CRITICAL STEP

- Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning.

IDENTIFY ADULT ENDOCRINE PHYSICIAN

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2ND CRITICAL STEP

- Identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs; and to make them part of training and certification requirements for primary care residents and physicians in practice.

PROVIDE TRAINING TO RESIDENTS AND FELLOWS

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3RD CRITICAL STEP

- Prepare and maintain an up-to-date medical summary that is portable and accessible, providing a common knowledge base for collaboration among health care professionals.

CREATE AN ENDOCRINE MEDICAL SUMMARY TEMPLATE

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3RD CRITICAL STEP (ENDOCRINE MEDICAL SUMMARY TEMPLATE)

RESUMEN MÉDICO ENDOCRINOLÓGICO (RME)

Nombre del paciente: _____ Fecha de Nacimiento: _____
Condiciones Endocrinológicas: _____
Fecha de Diagnóstico de Condiciones: _____
Endocrinólogo Pediátrico: _____
Teléfono oficina: _____ Teléfono Emergencia: _____

TERAPIA ACTUAL (ENDOCRINOLOGÍA GENERAL)

Medicamento: _____ Dosis: _____ Vía: ___ Horario: _____
Medicamento: _____ Dosis: _____ Vía: ___ Horario: _____
Medicamento: _____ Dosis: _____ Vía: ___ Horario: _____
Medicamento: _____ Dosis: _____ Vía: ___ Horario: _____

TERAPIA ACTUAL (DIABETES TIPO 1)

Dispositivo de insulina: ☐ jeringuilla ☐ bolígrafo de insulina ☐ bomba de insulina
Marcas insulinas y/o bomba: _____

Tipo de terapia de insulina:

☐ Terapia de insulina basada en conteo de carbohidrato
☐ Terapia de insulina fija

Cuando inyecta insulina:

Desayuno

☐ No tiene cubierta
☐ Cubierta con dosis de corrección solamente **(ESCALA)**
☐ Cubierta de carbohidrato más dosis de corrección si la glucosa es mayor de _____ mg/dL
☐ _____ Unidades de insulina antes del desayuno más **(ESCALA)**
☐ _____ Unidades de insulina
☐ Otro: _____

Almuerzo

☐ No tiene cubierta
☐ Cubierta con dosis de corrección solamente **(ESCALA)**
☐ Cubierta de carbohidrato más dosis de corrección si la glucosa es mayor de _____ mg/dL
☐ _____ Unidades de insulina antes del almuerzo más **(ESCALA)**
☐ _____ Unidades de insulina
☐ Otro: _____

Meriendas

☐ No tiene cubierta
☐ Cubierta con dosis de corrección solamente **(ESCALA)**
☐ Cubierta de carbohidrato más dosis de corrección si la glucosa es mayor de _____ mg/dL
☐ _____ Unidades de insulina antes de la merienda más **(ESCALA)**
☐ _____ Unidades de insulina
☐ Otro: _____

ESCALA de dosis de corrección:

Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)
Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)
Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)
Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)
Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)
Nivel de Glucosa _____ a _____ mg/dL dar _____ unidades de insulina (_____)

Monitoreo de Glucosa

☐ Glucómetro
☐ Monitor Continuo de Glucosa (MCG)
☐ Ambos

Fecha	Peso	Estatura	BMI	Presión

HOSPITALIZACIONES RELACIONADAS A LA CONDICIÓN

☐ Ninguna
☐ Una
☐ Múltiples

ÚLTIMOS LABORATORIOS

☐ Ver adjunto
☐ Fecha: _____

_____
_____

SEGUIMIENTO PENDIENTE CON OTROS PROVEEDORES

☐ Nutricionista
☐ Psicólogo clínico
☐ Otros: _____

COMPLICACIONES

☐ Ninguna
☐ _____

_____
Firma, Endocrinólogo Pediátrico Fecha

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4TH CRITICAL STEP

- Development of up-to-date and detailed written transition plans, in collaboration with young people and their families.

CREATE TRANSITION PLAN/TIMELINE FOR THE PATIENT

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5TH CRITICAL STEP

- Ensure that the same standards for primary and preventive health care are applied to adolescents.

MAINTAIN SIMILAR TREATMENT PLAN

6TH CRITICAL STEP

- Ensure that affordable, comprehensive, and continuous health insurance is available to young people with chronic health conditions throughout adolescence and into adulthood.

CONTINUED INSURANCE COVERAGE

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6TH CRITICAL STEP

- Proyecto de la Cámara 1755

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TRANSITION OF CARE

DIABETES

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SUMMARY OF ISSUES GIVEN BY ADULT PATIENTS WITH TYPE 1 DIABETES IN PR (CEBNAD 8/13/2017)

- Getting appointments
- Knowledge of latest type 1 diabetes technology in adult endocrinologists
- Create a transition protocol
- Insurance coverage

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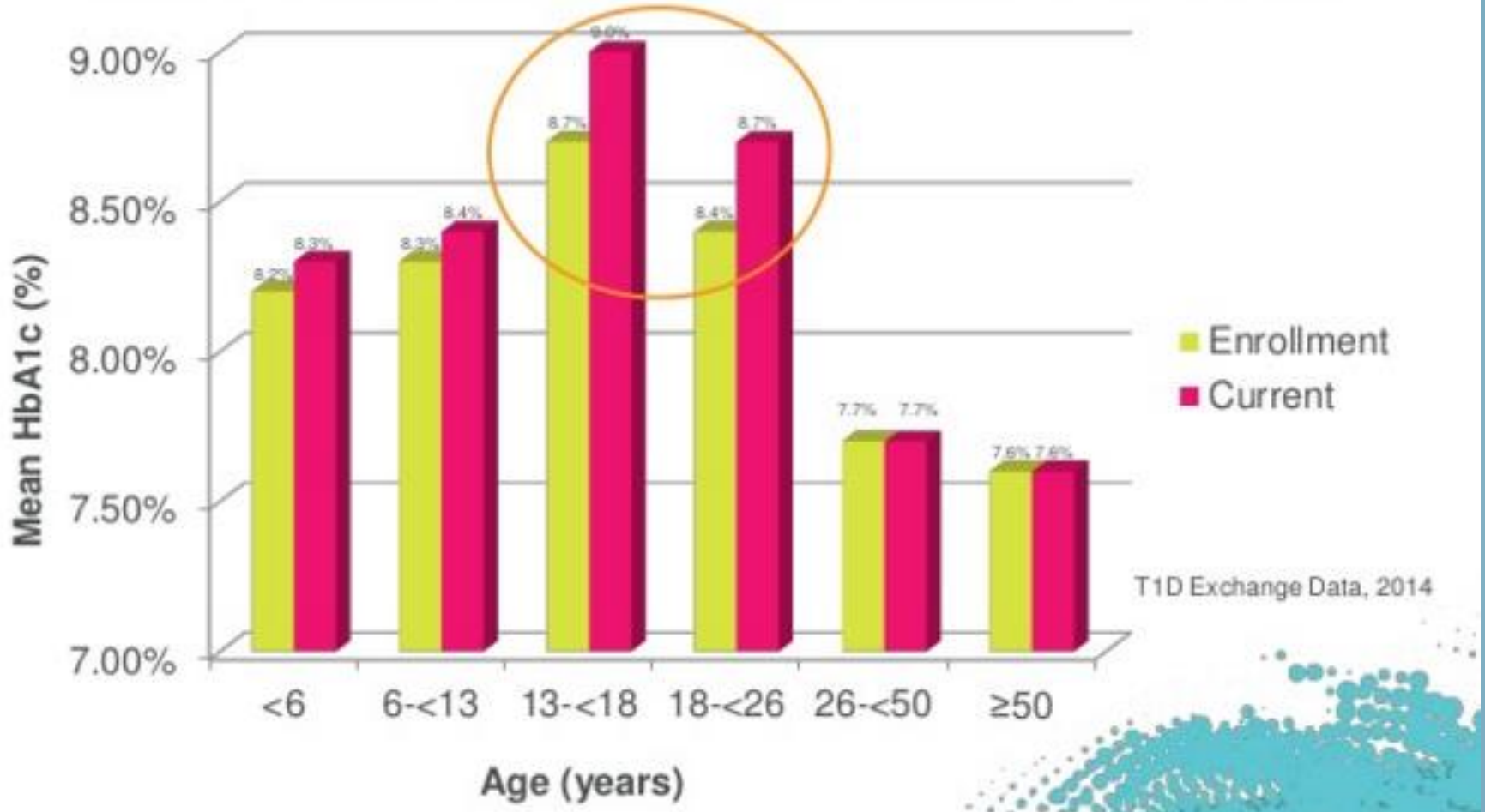
EMERGING ADULTS WITH TYPE 1 DIABETES FACE ADDITIONAL DEMANDS

- Normative Choices
  - Relationships
  - Occupations
  - Living arrangements
  - Financial management
- Diabetes Care
  - Finding appropriate care providers with experience treating type 1 diabetes
  - Access to diabetes supplies
  - Access to insurance coverage

Weissberg-Benchell J et al. Diabetes Care. 2007; 30(10): 2441-2446.

Young Adults with Diabetes

Average HbA1c significantly higher than ADA guidelines & increasing



https://t1dexchange.org

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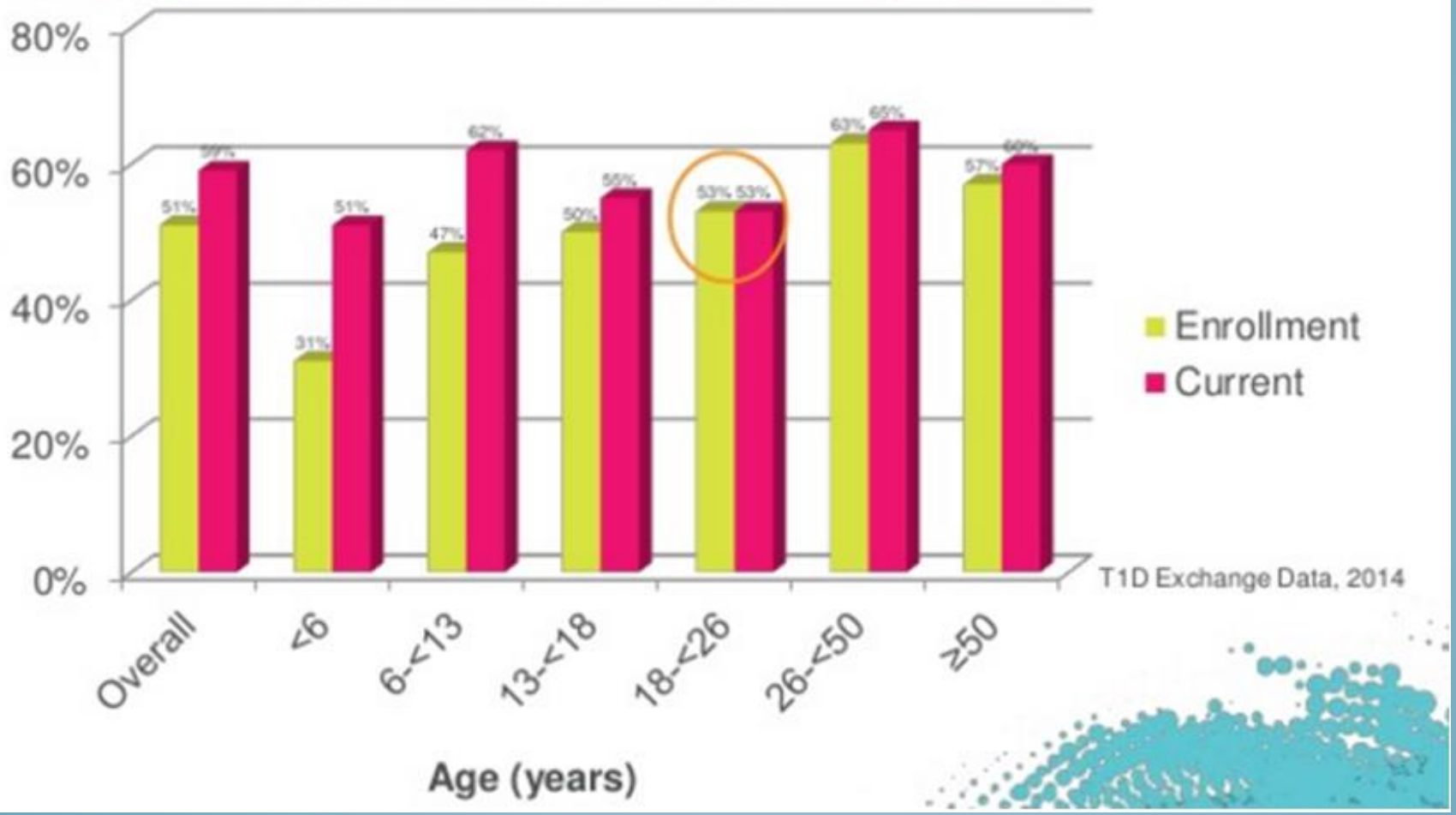
Young Adults with Diabetes

Only population with no increase in insulin pump use



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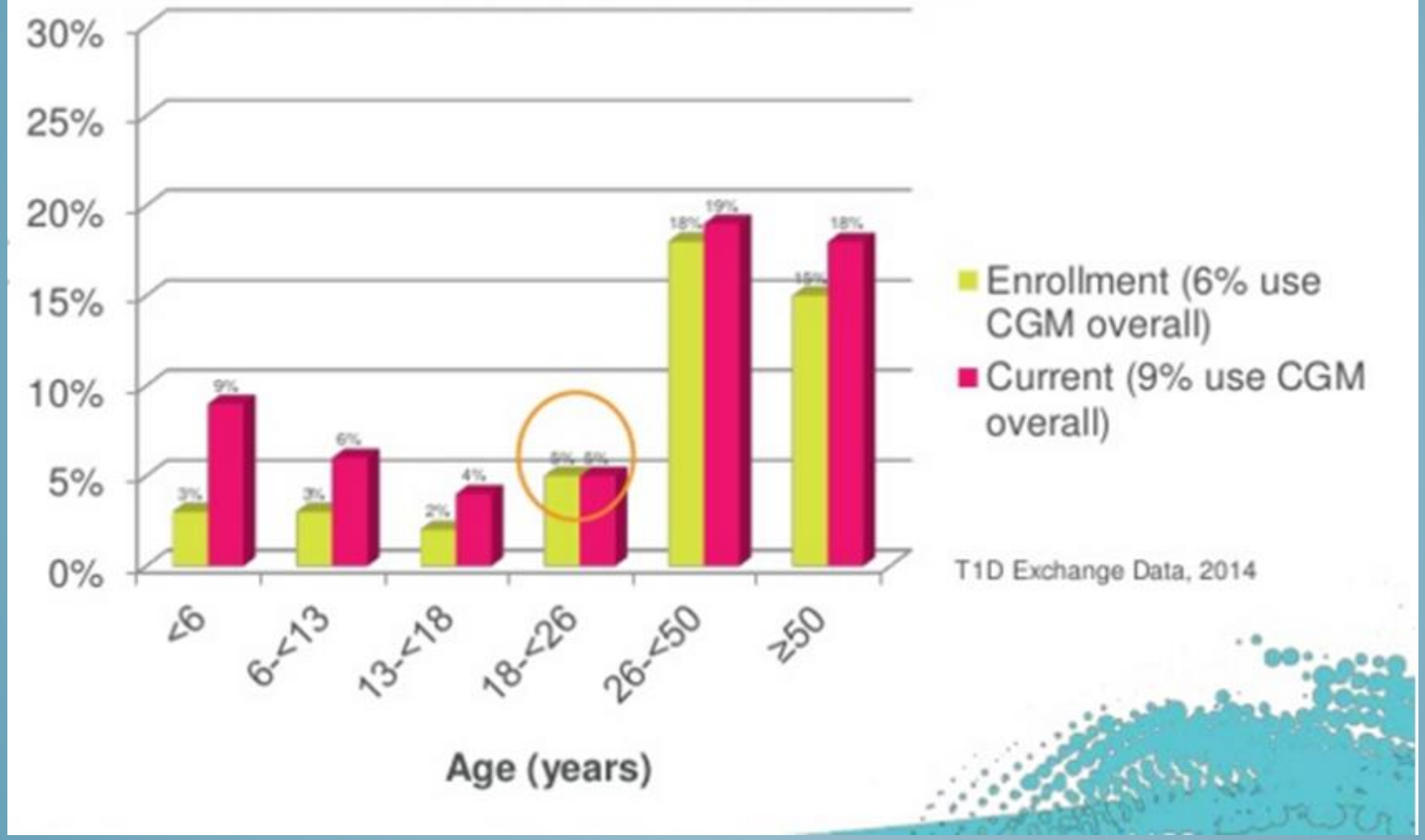
Young Adults with Diabetes

Only population with no increase in CGM use



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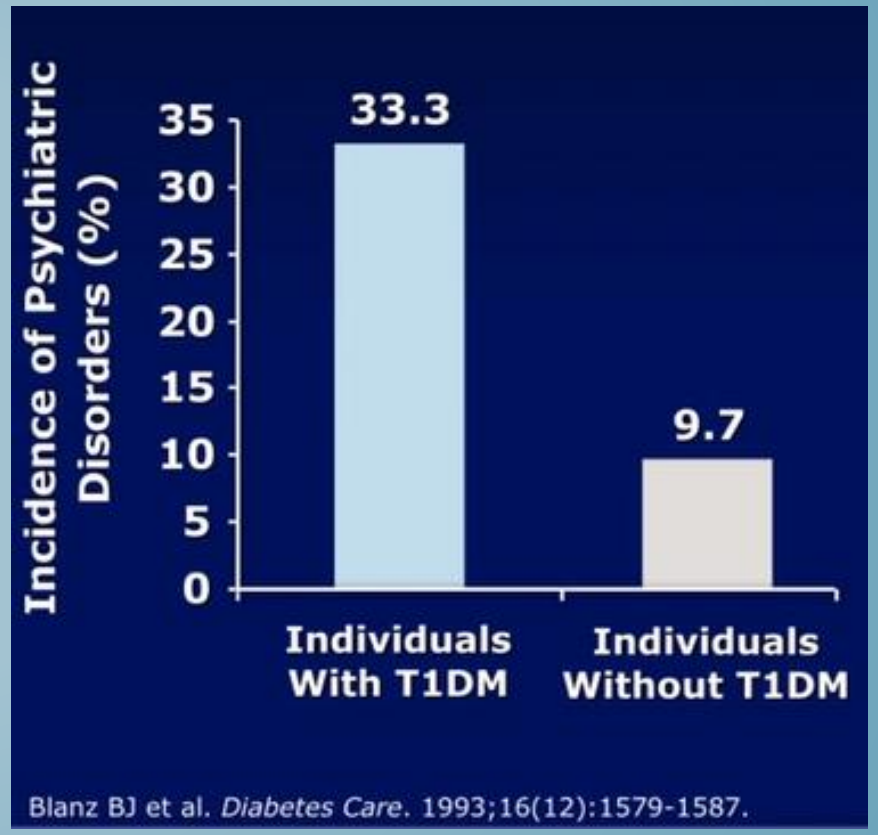
PSYCHIATRIC ISSUES MORE COMMON IN EMERGING ADULTS WITH TYPE 1 DIABETES

- High risk group for psychiatric disorders, similar to children that have other chronic diseases



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TYPE 1 DIABETES AND COLLEGE

- There are an estimated 53,000 college students with type 1 diabetes in the United States
- The majority of college students with diabetes do not leave home when it is time to go to college
- 71% of college students report having difficulty managing their diabetes while at school

Source: American Association of Diabetes Educator (AADE) Annual Meeting 2014.

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TYPE 1 DIABETES AND COLLEGE

- Questionnaire given to students participating in the College Diabetes Network (CDN) reported the following recommendations for clinicians:
  - Ask me about my life outside of diabetes
  - Be positive! Avoid criticism, judgment, and negativity
  - Don't be afraid to bring up "taboo topics" such as alcohol, sex, and drugs
  - Peers are an important piece of the diabetes care team
  - Acknowledge the spontaneity and lack of routine of college and help make a plan of attack

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TEAM-BASED CARE OF ADOLESCENTS AND YOUNG ADULTS WITH TYPE 1 DIABETES

- Developed at Barbara Davis Center for Childhood Diabetes in Denver, Colorado
- Change clinical care structure
  - Shared medical appointments
    - Improved patient outcomes
    - Increased satisfaction
    - Improved efficiency
      - Including billing
    - More comprehensive visits
  - Multidisciplinary team

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TEAM-BASED CARE OF ADOLESCENTS AND YOUNG ADULTS WITH TYPE 1 DIABETES

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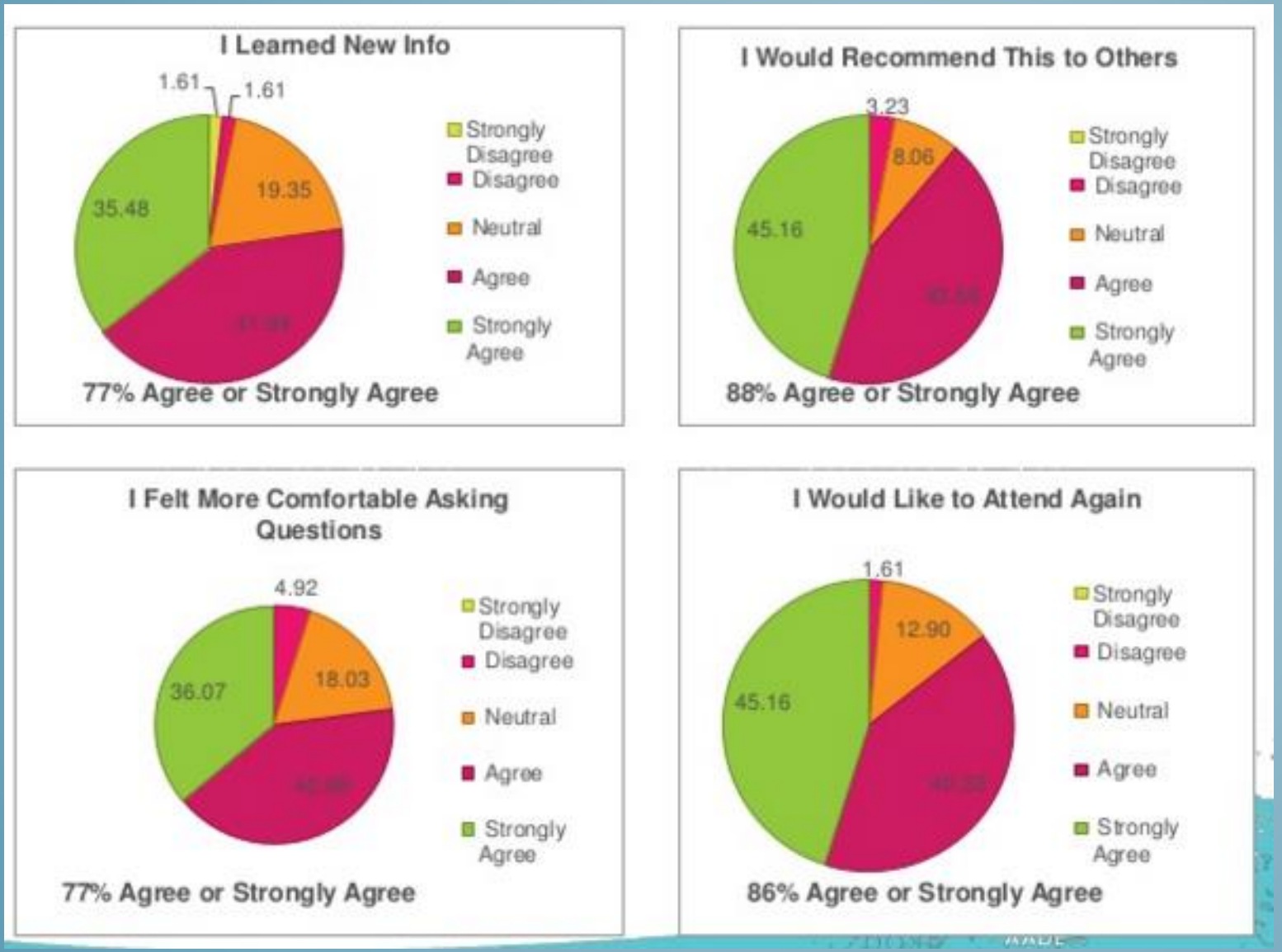
TEAM-BASED CARE (ADOLESCENTS' RESPONSE)



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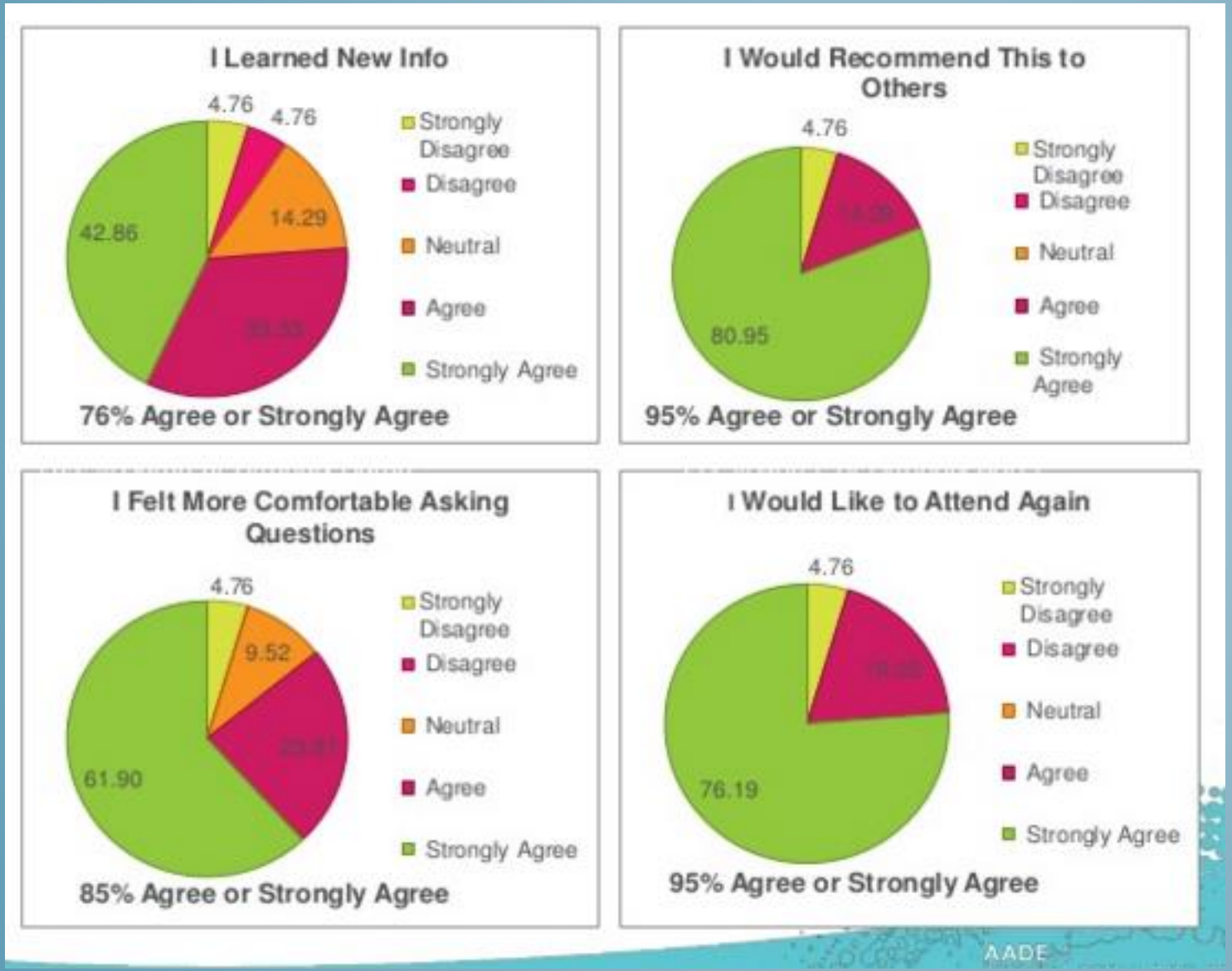
TEAM-BASED CARE (PARENT'S RESPONSE)



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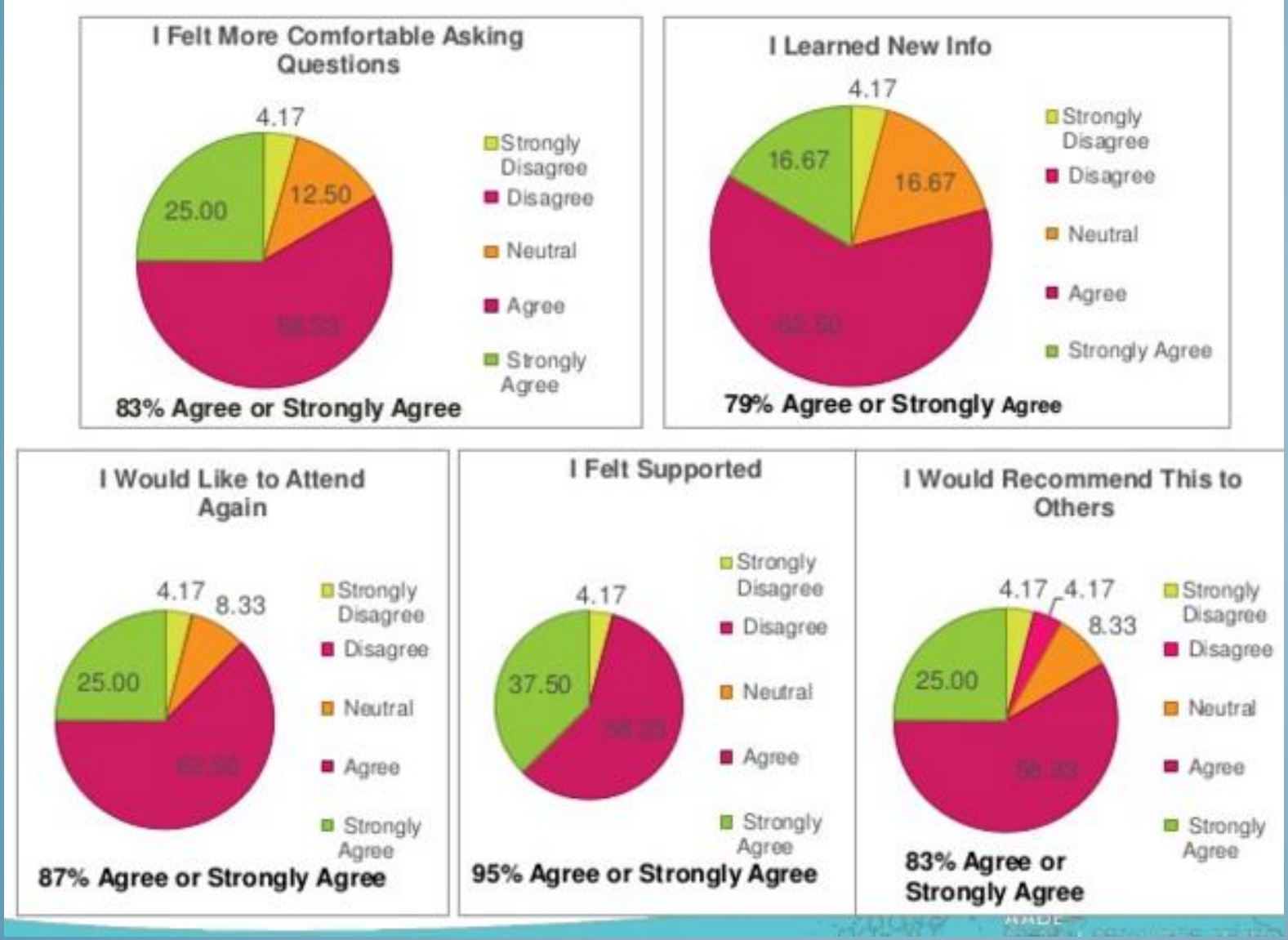
TEAM-BASED CARE (YOUNG ADULTS' RESPONSE)



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Online Tool from the National Diabetes Education Program Helps Youth

Transition from Pediatric to Adult Care

Transitions from Pediatric to Adult Care from the National Diabetes Education Program (NDEP) helps teens with diabetes make a smooth transition to adult health care. Families and health care professionals will also find these materials very helpful.

NDEP
National Diabetes Education Program

A program of the National Institutes of Health and the Centers for Disease Control and Prevention

The online tool contains the following materials:

- **Transition Planning Checklist:** suggests a timeline, topics to review, and key action steps to support various aspects of the transition process
- **Patient Clinical Summary:** provides a summary of the teen's health status to be completed by the pediatric health care team and provided to the adult health care team
- **Resource List:** offers hyperlinks to additional resources such as videos, message boards, social networks, workbooks, checklists, guides, and books and can be viewed by category

www.YourDiabetesInfo.org/Transitions

HHS' National Diabetes Education Program (NDEP) is jointly sponsored by the NIH and CDC with the support of more than 200 partner organizations.

CDEP
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NDEP

National Diabetes Education Program

A program of the National Institutes of Health and the Centers for Disease Control and Prevention

www.YourDiabetesInfo.org

1-888-693-NDEP (1-888-693-6337)

TTY: 1-866-569-1162

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

NIH National Institutes of Health

CDC Centers for Disease Control and Prevention

Purpose of Transitions

Transitioning from pediatric to adult health care can be a challenge for teens and young adults with diabetes, their parents, and pediatric and adult health care providers. The NDEP has developed the Transitions from Pediatric to Adults Care online tool to help with the following:

- Encourage teens and young adults to assume more responsibility for diabetes self-management and make more independent judgments for their health care needs
- Help teens with diabetes make a smooth transition to adult care
- Provide families and health care professionals with guidance in helping teens with diabetes transition to adult care

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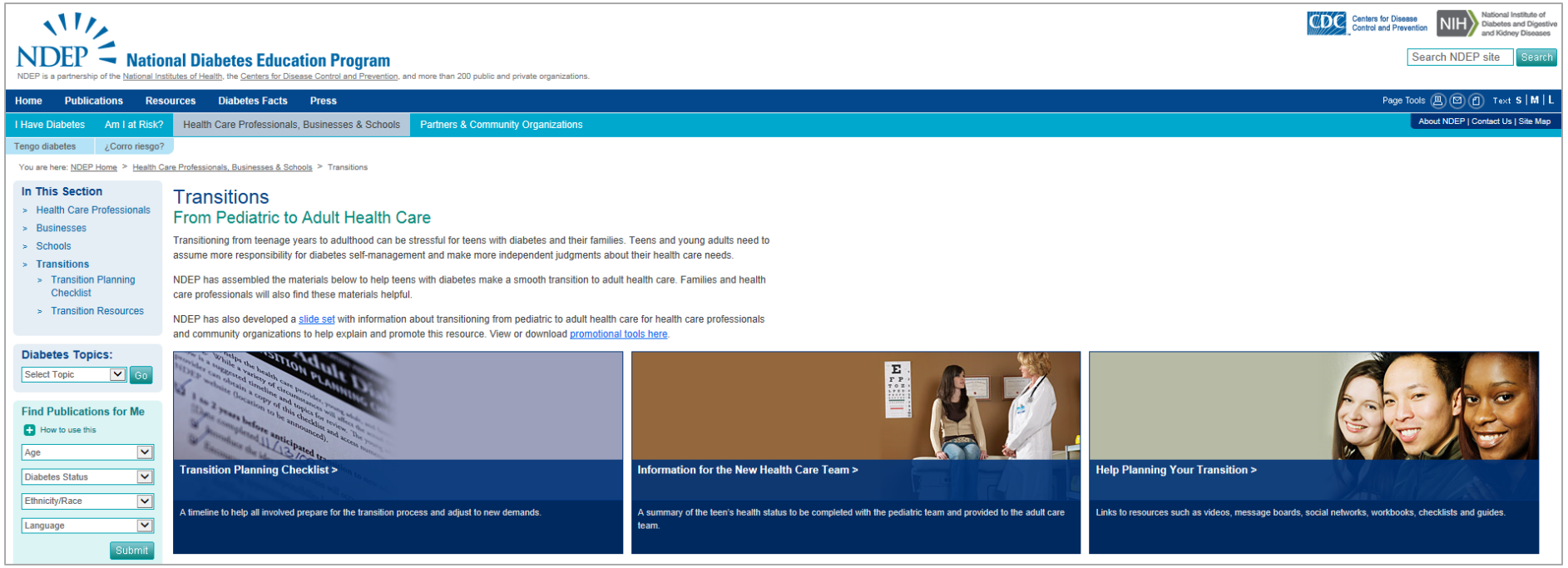
YourDiabetesInfo.org/Transitions



Transitions: Checklist

NDEP National Diabetes Education Program
NDEP is a partnership of the National Institutes of Health, the Centers for Disease Control and Prevention, and more than 200 public and private organizations.

In This Section
- Health Care Professionals
- Businesses
- Schools
- Transitions
  - Transition Planning Checklist
  - Transition Resources

Diabetes Topics:
Select Topic | Go

Find Publications for Me
How to use this
Age
Diabetes Status
Ethnicity/Race
Language
Submit
Privacy Statement

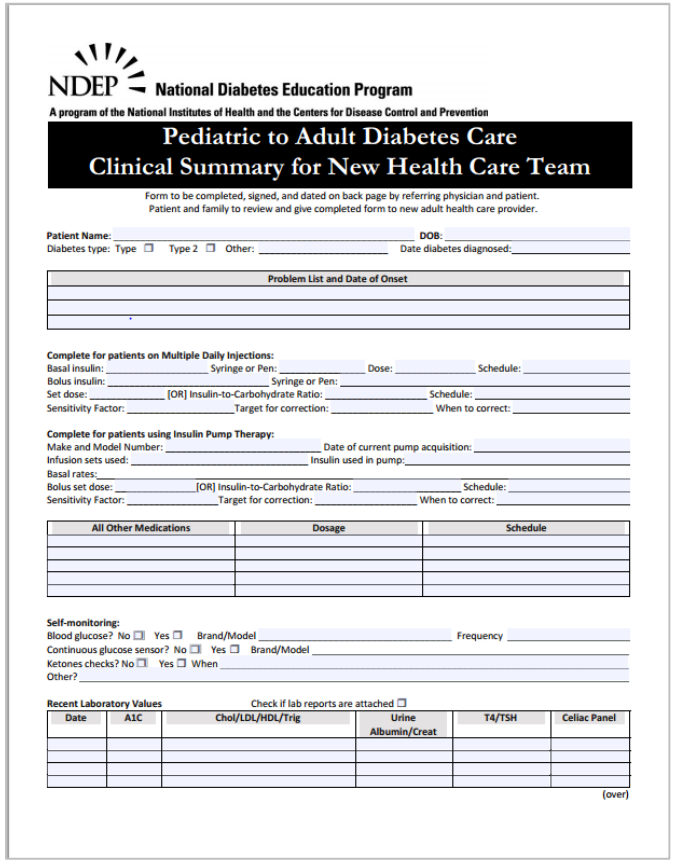
Also visit these NDEP sites:
diabetesatwork.org

Pediatric to Adult Diabetes Care: Transition Planning Checklist

This checklist helps the health care provider, young adult, and family discuss and plan the change from pediatric to adult health care. While a variety of events may affect the actual timing when this change occurs, below is a suggested timeline and topics for review. The young adult, family, and health care provider can obtain a copy of this checklist and access many online transition resources at the NDEP website (www.YourDiabetesInfo.org/transitions).

- **1 to 2 years before anticipated transition to new adult care providers**
  - Introduce the idea that transition will occur in about 1 year
  - Encourage shared responsibility between the young adult and family for:
    - Making appointments
    - Refilling prescriptions
    - Calling health care providers with questions or problems
    - Making insurance claims
    - Carrying insurance card
    - Reviewing blood sugar results with provider between visits
  - Discuss with teen alone: *
    - Sexual activity and safety
    - How smoking, drugs, and alcohol affect diabetes
    - How depression and anxiety affect diabetes and diabetes care
- **6 to 12 months before anticipated transition**
  - Discuss health insurance coverage and encourage family to review options
    - Assess current health insurance plan and new options, e.g. family plan, college plan, employer plan, and healthcare.gov
    - Consider making an appointment with a case manager or social worker
    - Discussion of career choices in relationship to insurance issues
  - Encourage family to gather health information to provide to the adult care team *(See Clinical Summary for New Health Care Team at* www.YourDiabetesInfo.org/transitions)
  - Review health status: diabetes control, retina (eye), kidney and nerve function, oral health, blood pressure, and lipids (cholesterol)
  - Discuss with teen alone: *
    - Sexual activity and safety
    - Smoking status, alcohol, and other drug use
    - Issues of independence, emotional ups and downs, depression, and how to seek help

Transitions: Clinical Summary Page



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Pediatric to Adult Diabetes Care
Clinical Summary for New Health Care Team

Form to be completed, signed, and dated on back page by referring physician and patient.
Patient and family to review and give completed form to new adult health care provider.

Patient Name: _____ **DOB:** _____
Diabetes type: Type ❒ Type 2 ❒ Other: _____ Date diabetes diagnosed: _____

Problem List and Date of Onset

Complete for patients on Multiple Daily Injections:
Basal insulin: _____ Syringe or Pen: _____ Dose: _____ Schedule: _____
Bolus insulin: _____ Syringe or Pen: _____
Set dose: _____ [OR] Insulin-to-Carbohydrate Ratio: _____ Schedule: _____
Sensitivity Factor: _____ Target for correction: _____ When to correct: _____

Complete for patients using Insulin Pump Therapy:
Make and Model Number: _____ Date of current pump acquisition: _____
Infusion sets used: _____ Insulin used in pump: _____
Basal rates: _____
Bolus set dose: _____ [OR] Insulin-to-Carbohydrate Ratio: _____ Schedule: _____
Sensitivity Factor: _____ Target for correction: _____ When to correct: _____

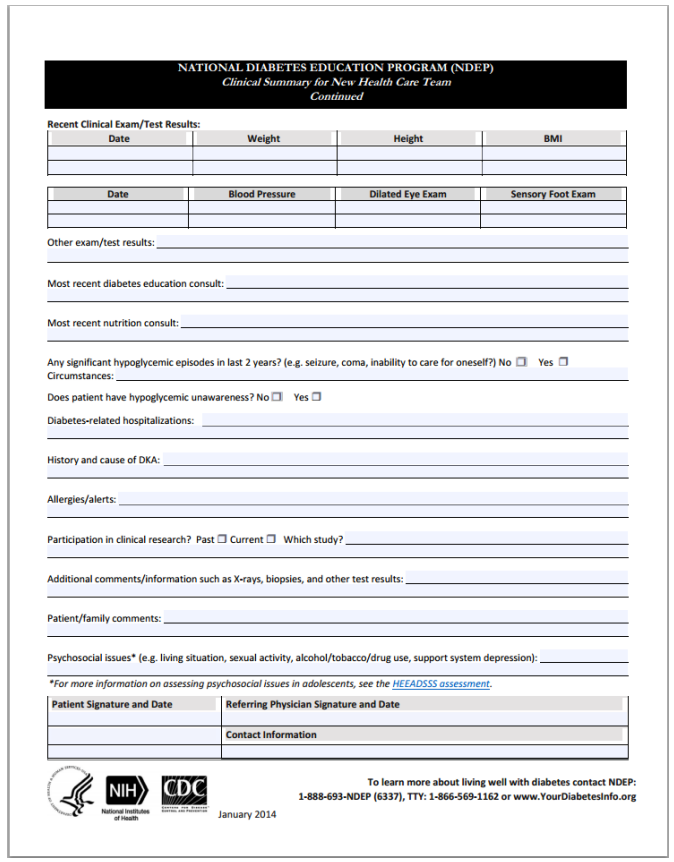
All Other Medications	Dosage	Schedule

Self-monitoring:
Blood glucose? No ❒ Yes ❒ Brand/Model _____ Frequency _____
Continuous glucose sensor? No ❒ Yes ❒ Brand/Model _____
Ketones checks? No ❒ Yes ❒ When _____
Other? _____

Recent Laboratory Values Check if lab reports are attached ❒

Date	A1C	Chol/LDL/HDL/Trig	Urine Albumin/Creat	T4/TSH	Celiac Panel

(over)



NATIONAL DIABETES EDUCATION PROGRAM (NDEP)
Clinical Summary for New Health Care Team
Continued

Recent Clinical Exam/Test Results:

Date	Weight	Height	BMI

Date	Blood Pressure	Dilated Eye Exam	Sensory Foot Exam

Other exam/test results: _____

Most recent diabetes education consult: _____

Most recent nutrition consult: _____

Any significant hypoglycemic episodes in last 2 years? (e.g. seizure, coma, inability to care for oneself?) No ❒ Yes ❒
Circumstances: _____

Does patient have hypoglycemic unawareness? No ❒ Yes ❒

Diabetes-related hospitalizations: _____

History and cause of DKA: _____

Allergies/alerts: _____

Participation in clinical research? Past ❒ Current ❒ Which study? _____

Additional comments/information such as X-rays, biopsies, and other test results: _____

Patient/family comments: _____

Psychosocial issues* (e.g. living situation, sexual activity, alcohol/tobacco/drug use, support system depression): _____

*For more information on assessing psychosocial issues in adolescents, see the HEEADSSS assessment.

Patient Signature and Date	Referring Physician Signature and Date
	Contact Information

NIH National Institutes of Health CDC

January 2014

To learn more about living well with diabetes contact NDEP:
1-888-693-NDEP (6337), TTY: 1-866-569-1162 or www.YourDiabetesInfo.org

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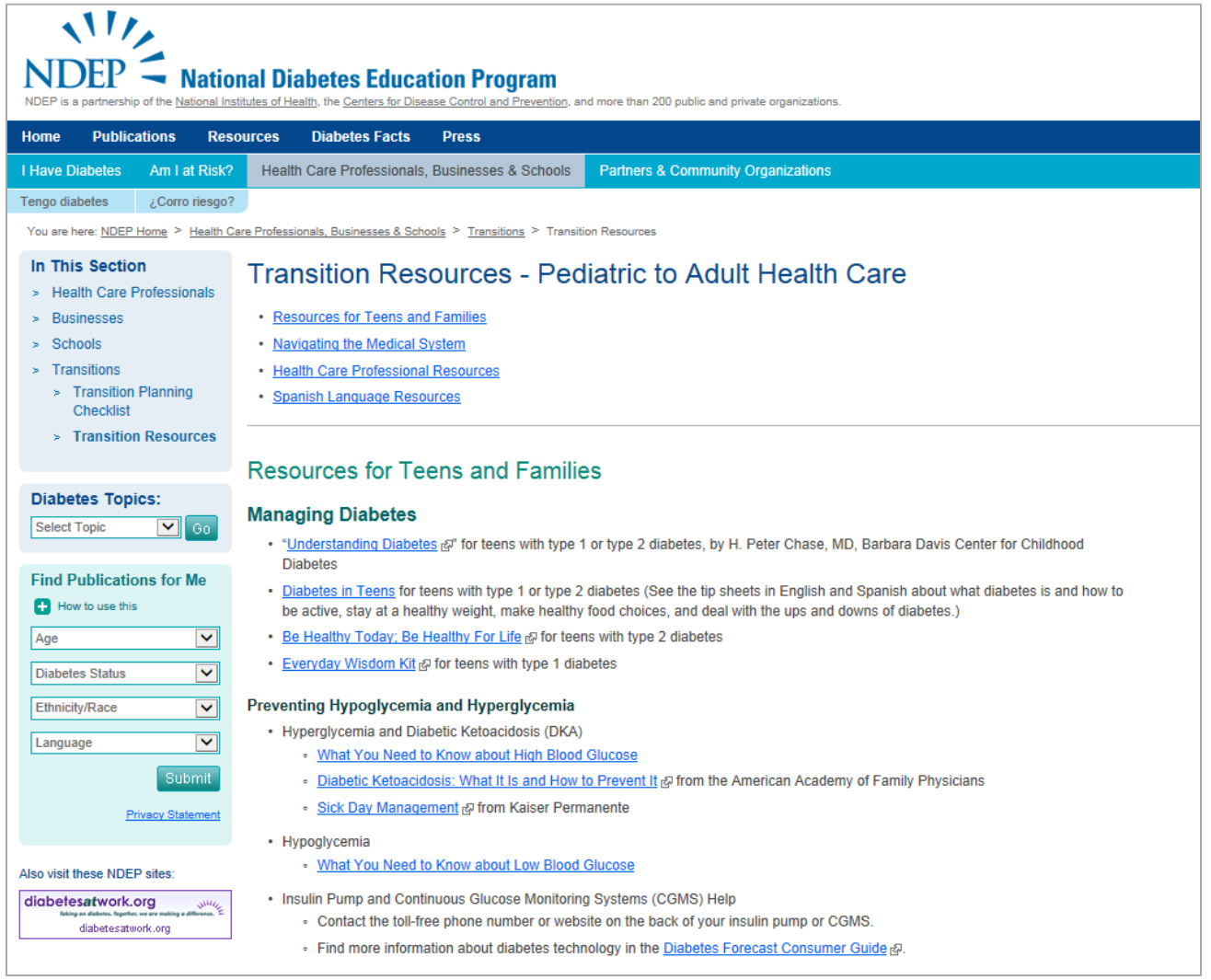
Transitions: Resource List



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Home | Publications | Resources | Diabetes Facts | Press

I Have Diabetes | Am I at Risk? | Health Care Professionals, Businesses & Schools | Partners & Community Organizations

Tengo diabetes | ¿Corro riesgo?

You are here: NDEP Home > Health Care Professionals, Businesses & Schools > Transitions > Transition Resources

In This Section

- Health Care Professionals
- Businesses
- Schools
- Transitions
  - Transition Planning Checklist
  - Transition Resources

Diabetes Topics:

Select Topic | Go

Find Publications for Me

How to use this

Age | Diabetes Status | Ethnicity/Race | Language | Submit

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Also visit these NDEP sites:

diabetesatwork.org

diabetesatwork.org

Transition Resources - Pediatric to Adult Health Care

- Resources for Teens and Families
- Navigating the Medical System
- Health Care Professional Resources
- Spanish Language Resources

Resources for Teens and Families

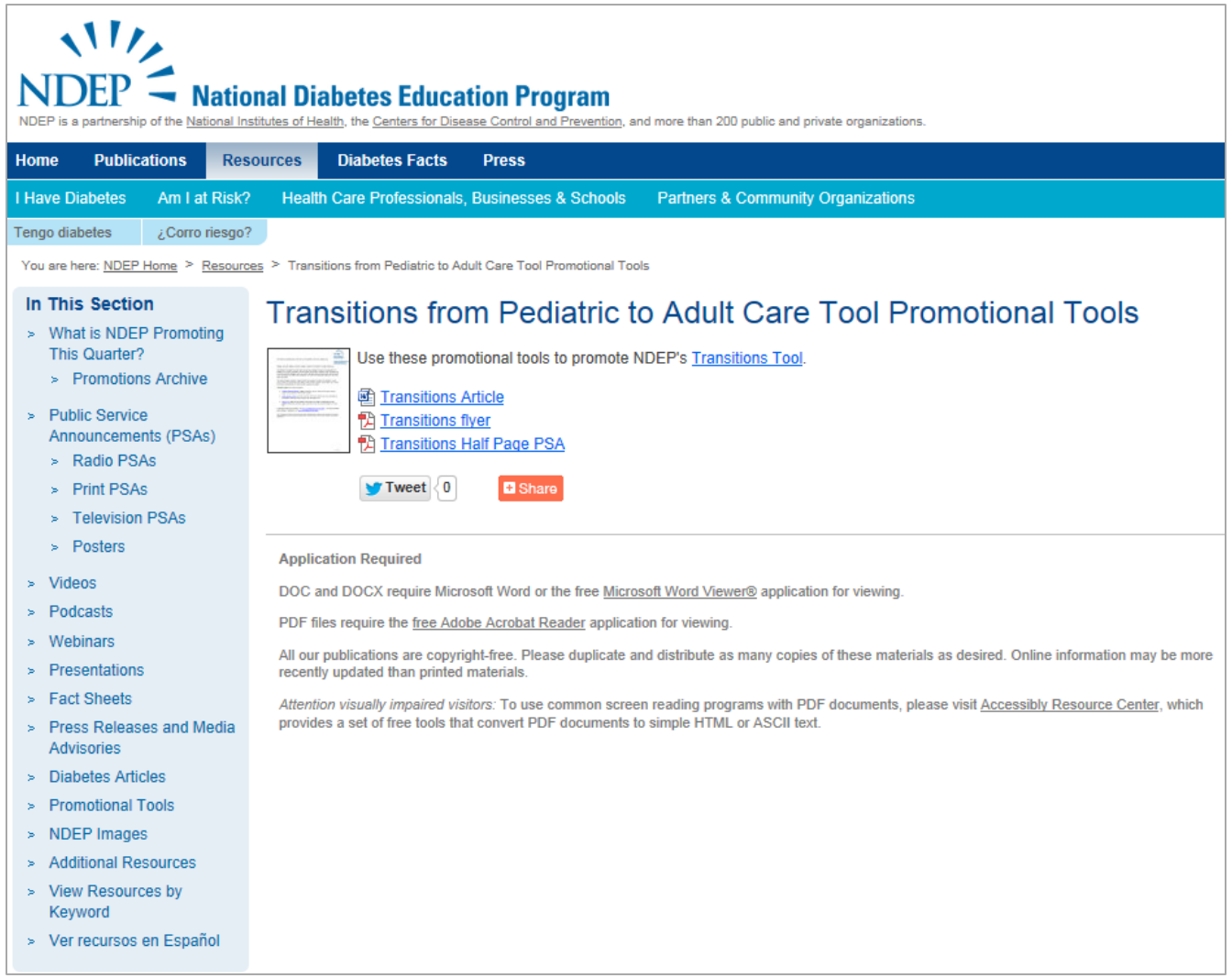
Managing Diabetes

- "Understanding Diabetes" for teens with type 1 or type 2 diabetes, by H. Peter Chase, MD, Barbara Davis Center for Childhood Diabetes
- Diabetes in Teens for teens with type 1 or type 2 diabetes (See the tip sheets in English and Spanish about what diabetes is and how to be active, stay at a healthy weight, make healthy food choices, and deal with the ups and downs of diabetes.)
- Be Healthy Today; Be Healthy For Life for teens with type 2 diabetes
- Everyday Wisdom Kit for teens with type 1 diabetes

Preventing Hypoglycemia and Hyperglycemia

- Hyperglycemia and Diabetic Ketoacidosis (DKA)
  - What You Need to Know about High Blood Glucose
  - Diabetic Ketoacidosis: What It Is and How to Prevent It from the American Academy of Family Physicians
  - Sick Day Management from Kaiser Permanente
- Hypoglycemia
  - What You Need to Know about Low Blood Glucose
- Insulin Pump and Continuous Glucose Monitoring Systems (CGMS) Help
  - Contact the toll-free phone number or website on the back of your insulin pump or CGMS.
  - Find more information about diabetes technology in the Diabetes Forecast Consumer Guide.

Transitions: Promotional Tools



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Home | Publications | Resources | Diabetes Facts | Press

I Have Diabetes | Am I at Risk? | Health Care Professionals, Businesses & Schools | Partners & Community Organizations

Tengo diabetes | ¿Corro riesgo?

You are here: NDEP Home > Resources > Transitions from Pediatric to Adult Care Tool Promotional Tools

In This Section

- What is NDEP Promoting This Quarter?
  - Promotions Archive
- Public Service Announcements (PSAs)
  - Radio PSAs
  - Print PSAs
  - Television PSAs
  - Posters
- Videos
- Podcasts
- Webinars
- Presentations
- Fact Sheets
- Press Releases and Media Advisories
- Diabetes Articles
- Promotional Tools
- NDEP Images
- Additional Resources
- View Resources by Keyword
- Ver recursos en Español

Transitions from Pediatric to Adult Care Tool Promotional Tools

Use these promotional tools to promote NDEP's Transitions Tool.

Transitions Article
Transitions flyer
Transitions Half Page PSA

Tweet 0 Share

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TRANSITION OF CARE

GROWTH HORMONE DEFICIENCY

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TRANSITION OF CARE

TURNER SYNDROME

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TURNER SYNDROME

- Many young women with Turner syndrome are lost to follow-up.
  - An Australian study of 39 adult women with the syndrome found that only 24 (63%) received regular follow-up and only 17 (44%) had adequate health surveillance, even though 87% were identified with one or more associated disorders.
  - The study concluded that adult care was suboptimal and sporadic.
  - A questionnaire survey of 160 young women with Turner syndrome in Belgium, who had all been identified and treated during childhood, found that 41 of 102 responders (40%) reported health problems, yet 13 (13%) did not receive regular medical care.
  - Of the 76 women with primary amenorrhea and induced puberty, 11 (14.5%) were no longer taking estrogen. The average age of this cohort was 23 years.

M. C. Davies (2010). 'Lost in transition: the needs of adolescents with Turner syndrome', *BJOG: An International Journal Of Obstetrics And Gynaecology*, England, vol.172, no.2, pp. 134-136.

TURNER SYNDROME

- There is significant morbidity and early mortality among adult women with Turner syndrome. Reduced life expectancy is mainly caused by cardiovascular disease. Hypertension is common. The risk of atherosclerosis is shared by other women with ovarian failure.
- Transition is a staged process. During adolescence, the focus of medical care changes from growth to feminization and then to the maintenance of health. When final height is achieved and pubertal induction is completed, clinic visits become less frequent and the emphasis shifts to health surveillance, review of existing conditions (e.g. hormone replacement), and early identification and treatment of new ones (e.g. hypothyroidism).

M. C. Davies (2010). 'Lost in transition: the needs of adolescents with Turner syndrome', *BJOG: An International Journal Of Obstetrics And Gynaecology*, England, vol.172, no.2, pp. 134-136.

TURNER SYNDROME (CARDIOLOGY)

- Cardiology review may be appropriate at the time of transition to adult care, at the onset of hypertension, and in women considering pregnancy.
- Magnetic resonance imaging of the aortic arch and valve may be more sensitive than echocardiography.

M. C. Davies (2010). 'Lost in transition: the needs of adolescents with Turner syndrome', *BJOG: An International Journal Of Obstetrics And Gynaecology*, England, vol.172, no.2, pp. 134-136.

TURNER SYNDROME (FERTILITY)

- Discussing plans for fertility is important: maternal deaths from aortic dissection have been reported in Turner syndrome, and assisted reproduction (egg donation) should not be offered without adequate pre-pregnancy assessment.
- Some women with structural cardiac anomalies may be advised against pregnancy. There is also an increased risk of pregnancy-induced hypertension and gestational diabetes, and caesarean section delivery is the norm.
- Multiple pregnancies should be avoided.

M. C. Davies (2010). 'Lost in transition: the needs of adolescents with Turner syndrome', *BJOG: An International Journal Of Obstetrics And Gynaecology*, England, vol.172, no.2, pp. 134-136.

TURNER SYNDROME

- During the transition period, there is a change in emphasis from treating the child within the family, using the parents as intermediaries, to supporting the adolescent in developing independence and taking responsibility for her health. These young women will require life-long care; it is crucial that they have a good relationship with their health professionals and a full understanding of their condition, as these factors contribute to compliance and minimize drop-out.

M. C. Davies (2010). 'Lost in transition: the needs of adolescents with Turner syndrome', *BJOG: An International Journal Of Obstetrics And Gynaecology*, England, vol.172, no.2, pp. 134-136.

PEDIATRIC ENDOCRINE SOCIETY: RESOURCES

- https://www.pedsendo.org/patients_families/transition_toolkit/index.cfm

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TRANSITION OF CARE

CONGENITAL ADRENAL HYPERPLASIA

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CONGENITAL ADRENAL HYPERPLASIA

- Patients aged 16+ years with CAH who had attended the adrenal clinic at Royal Manchester Children's Hospital between 1992 and 2009 were identified.
  - A total of 61 patients (27 men) were identified. Thirty-six patients were referred to specialist adult services from the pediatric service; eighteen of these (50%) were lost to follow-up (two were never offered an appointment). Only 53% of the whole group attended their first new and subsequent second appointment (i.e. good early attenders). Good early attenders were less likely to get lost to follow-up compared with poor early attenders (11–33% lost to follow-up compared with 63–71%).

Gleeson H et al. The challenge of delivering endocrine care and successful transition to adult services in adolescents with congenital adrenal hyperplasia: experience in a single centre over 18 years. Clin Endocrinol (Oxf). 2013 Jan;78(1):23-8.

CONGENITAL ADRENAL HYPERPLASIA

- Clinical manifestations in children
  - Salt wasting
  - Ambiguous genitalia
  - Postnatal virilization
  - Short stature
  - Non-classic

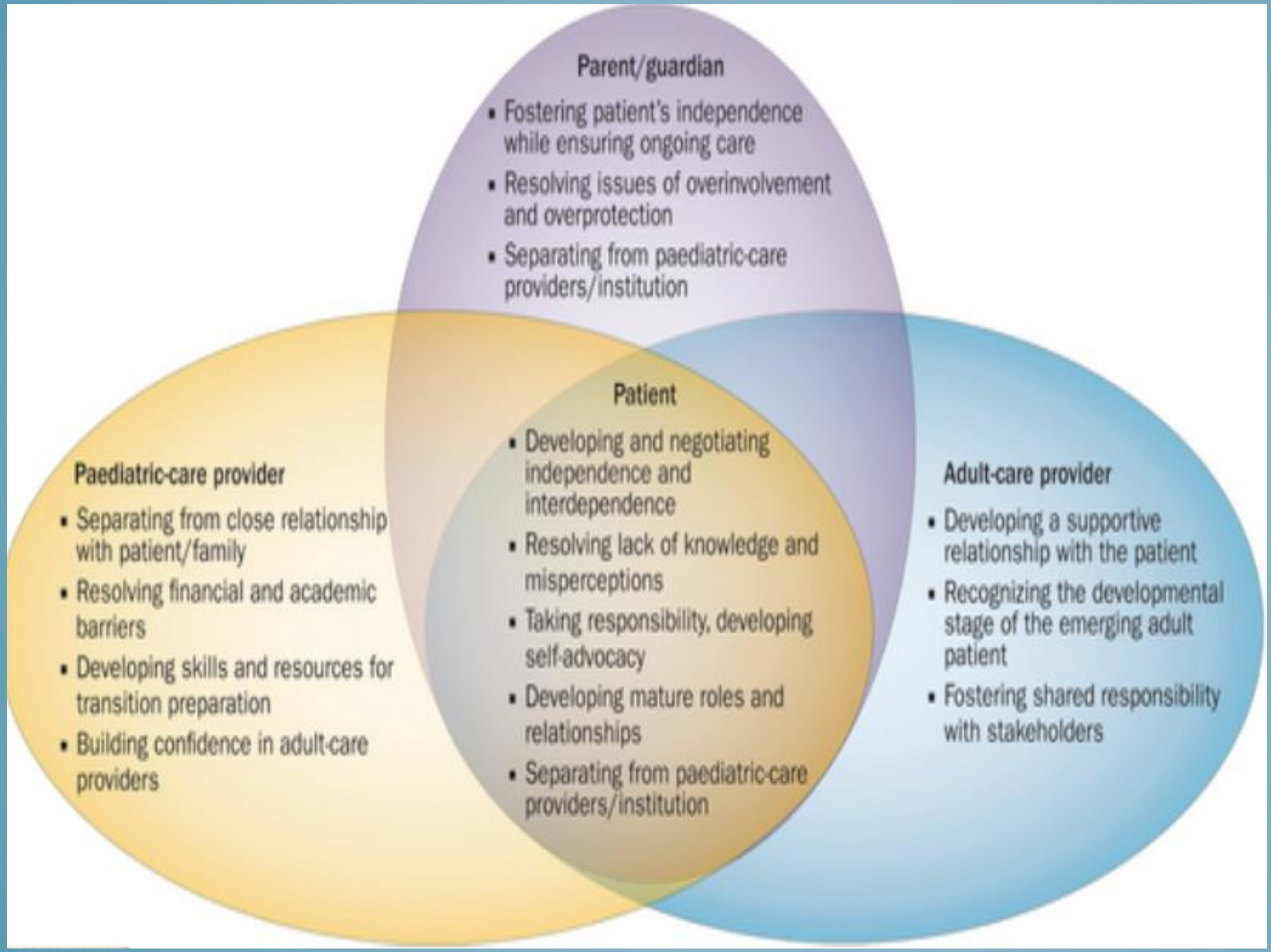
- Clinical manifestations in adults
  - Psychosexual
    - Gender identity
    - Impaired sexual function
  - Infertility
  - Metabolic abnormalities
    - Obesity
    - Diabetes
    - Decreased bone mineral density

Maria Papagianni, Richard Stanhope (2003). 'How should we manage growth hormone deficiency in adolescence? Transition from paediatric to adult care', *Journal Of Pediatric Endocrinology & Metabolism: JPEM*, England, vol.16, no.1, pp. 23-25.

Shared Management Model

Age and Time ↓	Provider →	Parent/Family →	Youth →
	Major responsibility	Provides care	Receives care
	Support to Parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manager
	Resource	Consultant	Supervisor/CEO

Kieckhefer GM, Trahms CM. Supporting development of children with chronic conditions: From compliance toward shared management. Pediatric Nurs 2000; 26: 354–363



ENDOCRINE SOCIETY: RESOURCES

- Provider assessment of patient skills
- Clinical Summary
- Patient self assessment of worries, burdens, concerns of his condition
- Recommended Approach for Transition
- Guideline for Pediatricians for Transition
- Educational Fact Sheets (about condition)
- Welcome Guideline
- Visitor Information Sheet

http://www.endocrinetransitions.org/

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THANK YOU!

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