## Sheppard Pratt & Professional Education

**Registration is open on ETHOS for:**

**Social Work Lecture Series: Do No Harm: Working with Survivors of Sexual Violence**

Friday, October 23, 2020, 9:00 am – 12:15 pm, Online Broadcast, Presented by: Mothyna James-Brightful, M.S. & Elisabet Martinez, MSW, LCSW-C, LICSW

**Social Work Lecture Series: Clinical Supervision: The Tool for Enhancing the Ethical Practice of Those You Supervise**

Friday, November 13, 2020, 9:00 am – 12:15 pm, Online Broadcast, Presented by: Gisele Ferretto, MSW, LCSW-C

**Psychology Workshop: Clinical Work with African Americans: Moving Beyond Cultural Competence**

Friday, November 6, 2020, 10:00 am – 11:00 am, Online Broadcast, Presented by: Danice Brown, PhD

Log into your Ethos account to register to attend this event for credit.

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1. Remember to take the pretest when you get the reminder email for the lecture on Monday.
2. Set a reminder for the lecture using the reminder email. Save the reminder email in your calendar or copy and paste it into your calendar. Set the reminder 10 minutes early to download and/or print the slides before the lecture.
3. Download the slides anytime from the day before to right at the beginning of the lecture. (The link to download the slides is in Venue in the activity page on Ethos. You don't have to be logged in to access it.)
4. Click on the link to watch the online broadcast. (The link is in Venue in the activity page on Ethos. You don't have to be logged in to access it.)
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## Learning Objectives

**After attending this program, participants will be able to:**

1. Distinguish the difference between transition and transfer.
2. Recognize barriers to transition and develop successful solutions.
3. Discuss how superimposition of intellectual disability adds a significant layer of complication to the goals of transition.

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# *Prepare to Launch:*
## *Transition from Pediatric to Adult Care for Youth with Neuropsychiatric Disorders*

Lawrence W. Brown, MD
Pediatric Neuropsychiatry Program
The Children's Hospital of Philadelphia

## OVERVIEW

1. Introduction – The importance of transition
2. Considerations for transition for youth with neuropsychiatricf disorders
3. Steps to transition
4. Barriers, solutions and resources

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## WHY FOCUS ON TRANSITION?

- Adulthood is inevitable
- All young adults need to establish independence to the best of their potential
- Youth with neurological (and neuropsychiatric) disabilities also have general medical issues that are best managed by adult physicians
- Delays in transition simply "kick the can down the road"

- Despite awareness of these imperatives, child neurologists and psychiatrists are often unfamiliar with, unwilling to, or unable to successfully transition patients to adult providers and adult providers are often uncomfortable with accepting these patients



## WHAT DO WE MEAN BY (MEDICAL) TRANSITION?

- Transition is the process beginning in early adolescence to prepare children and their parents/caregivers with chronic conditions
- Transition must be distinguished from transfer - the formal act of handing over care from pediatric to adult health system
- Transition may look different for every patient, depending on medical complexity and whether a patient has intellectual or physical disability



## THE BIG PICTURE

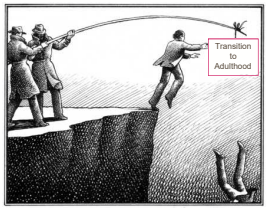
- 2 million young adults in US will be moving into adult healthcare system in 2020
- 1 in 6 U.S. children live with neurologic disorders (or 300,000 transitioning each year)
- At least that many youth have psychiatric disorders, often co-existing
- Only 40% of youth report (or per caregiver report) discussing transition with a healthcare providers

## WHEN INTELLECTUAL DISABILITY IS COMPOUNDED BY PSYCHIATRIC DISORDERS

- 30-50% of individuals with mental illness have IDD (3-4 x general population)
- Emotional/behavioral disorders are a special problem during transition
  - Increasing rate of mental illness in adolescence
  - Higher rates in females than males
- Psy illness is a key driver of morbidity and mortality of people with IDD



## THE GOAL: PREVENTING THE TRANSITION CLIFF




## MY PERSONAL TRANSITION AGENDA: THINKING GLOBALLY AND ACTING LOCALLY

- It all started in 2010 with the American Academy of Neurology Palatucci Advocacy Leadership Program, and kept on growing
- Initial goal was to establish a local transition program in collaboration with adult epilepsy and primary care providers
- Evolved into broad national initiative under auspices of CNF, AAN and AAP

## CONTEXT: FROM PRIMARY CARE TO SPECIALISTS

- 2011 consensus statement by the AAP, AAFP and ACP addressed role of primary care providers in health care transition
  - Practical guide to planning/implementing transitions for all patients
  - Integration into medical home care with chronic care management
- Report challenged all pediatric specialties to develop unique responses to transition challenges

*Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 128:182-200, 2011*



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## TRANSITION TIMELINE FROM 2011 AAP/AAFP/ACP CLINICAL REPORT

| | |
|---|---|
| Age 12 | • Youth and family aware of transition policy |
| Age 14 | • Health care transition planning initiated |
| Age 16 | • Preparation of youth and parents for adult approach to care and discussion of preferences and timing of transfer to adult health care |
| Age 18 | • Transition to adult approach to care |
| Age 18-22 | • Transfer of care to adult medical home and specialists with transfer package |



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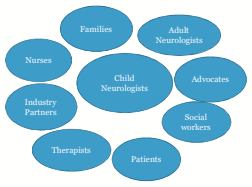
## MEETING THE CHALLENGE: TRANSITION PRACTICES ADVISORY COMMITTEE



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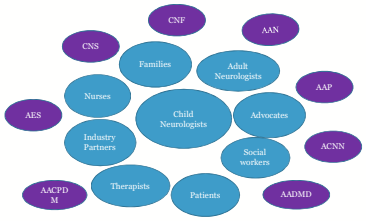


Importance > Considerations > Steps > Solutions

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## MEETING THE CHALLENGE: OUTCOME


CONTEMPORARY ISSUES

The neurologist's role in supporting transition to adult health care

A consensus statement

ABSTRACT

*Brown L.W, Camfield P, Capers M, Cascino GD, et al. The Neurologist's Role in Supporting Transition to Adult Health Care: A consensus statement, Neurology, 87:835-840, 2016.*



Importance > Considerations > Steps > Solutions

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## CNF'S 8 PRINCIPLES OF GOOD TRANSITION

1. Expectation of transition
2. Yearly self-management assessment
3. Annual discussion of medical condition and age-appropriate concerns
4. Evaluation of legal competency
5. Annual review of transition plan
6. Child neurology team responsibilities
7. Identification of adult provider(s)
8. Transfer complete when provider accepts patient and appointment made and kept

Importance > Considerations > Steps > Solutions



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## PRINCIPLES OF GOOD TRANSITION

1. **Expectation of transition**
   - Time for patients and families to prepare for eventual need to transfer to adult care
   - Time to gradually increase competency in disease knowledge, self-management, advocacy
   - Time to learn about differences in adult care models and health insurance
   - Time to coordinate with school transition under IDEA (Individuals with Disabilities Education Act)



## PRINCIPLES OF GOOD TRANSITION

2. **Yearly self-management assessment**
   - Understanding of diagnosis and any related limitations
   - Necessity of making informed decisions
   - Importance of self-advocacy

3. **Annual review of medical condition and age-appropriate concerns**
   - Separate appointment vs incorporation into non-acute visit
   - Age-specific concerns - puberty, driving, risky behaviors
   - Recognition of patient drift



## PRINCIPLES OF GOOD TRANSITION

4. **Evaluation of legal competency**
   - Legal consequences if youth unlikely to achieve independent financial/medical decision making
   - Recognition that guardianship often long and expensive process and avoiding discussion can lead to delays and emotional challenges if family unprepared
   - If competency unclear, consider formal neuropsychological evaluation
   - Note: schools are not responsible for addressing this area

## PRINCIPLES OF GOOD TRANSITION

5. **Annual review of transition plan**
   - Assurance that appropriate plan exists
   - Identification of primary responsible provider
   - Preparation and update of neurologic component

6. **Child neurology team responsibilities**
   - Assessment of disease knowledge and self-management skills; guardianship/power of attorney planning for those with significant intellectual or physical disabilities
   - Preparation of transition packet including history, current treatment and emergency protocol



## PRINCIPLES OF GOOD TRANSITION

7. **Identification of adult provider(s)**
   - Importance of "medical home"
   - Recognition that adult neurologists may be willing to treat primary neurologic problem but not co-morbidities
   - Some conditions are not typically managed by adult neurologists (i.e. ADHD, autism, Tourette syndrome) and may require alternative provider – typically primary care or psychiatrist



## PRINCIPLES OF GOOD TRANSITION

8. **Transfer as final stage of transition**
   - Child neurology team responsible for contacting new provider to confirm transfer acceptance and receipt of packet plus to offer to serve as a resource a necessary
   - Transfer completed only after $\geq 1$ health care visit
   - At that point, other providers can be notified and transfer documented in medical record

## PRACTICAL CONSIDERATIONS TO REMEMBER THROUGHOUT THE TRANSITION PERIOD

- Clear office transition policy
- Goal to for adolescent to accept responsibility for self-care and self-advocacy
- Transition care responsibility of neurology team, not just neurologist
  - Nurse, social worker, transition coordinator
- Ongoing process: need for periodic reevaluation
- Guardianship/power of attorney, as indicated
- Medical home important for all, but critical for complex or challenging patients
- Transition model is just as valuable even if provider is unchanged



## PARENTS CAN ALSO SUPPORT TRANSITION

- Parents can encourage teen knowledge of medical disorder
  - Name of condition, medications, emergency plan, when to seek medical attention
  - Importance of healthy habits and making good choices
- Parents can "let go" and move from youth's "advocate" to "ally"
  - Need to remember that it's about the youth and not about them
  - Abandon idea that the youth will make same choices as parents would
  - "Letting go" might look different in each case



## DEVELOPMENTAL ISSUES IN ADOLESCENCE

- Personal responsibility
- Autonomy
- Body Image
- Personal identity

## DEVELOPMENTAL ISSUES IN ADOLESCENCE: IMPACT OF NEUROPSYCHIATRIC DISORDERS

- Personal responsibility
  - "Why do I have to take medication? nobody else does."
- Autonomy
  - "I am not supposed to do most of the things that my friends do—drinking, drugs, sex."
- Body Image
  - "The pills will make me fat."
- Personal identity
  - "No one will go on a date with me."



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## SPECIAL CONSIDERATIONS WITH TOURETTE SYNDROME

- Tics define the disorder, but co-morbidities often more disabling and longer lasting
  - Only 12% have isolated tics, according to survey of 3500 patients by the Tourette International Consortium
  - ADHD (60-75%), OCD (20-30%), anxiety disorders (20-30%), IDD and learning disability (20-25%), autism (5%)
  - Mood disorders, emotional lability, aggression, rage attacks – near 100% at some point
- Even if tics and behavior are outgrown or under control, must anticipate risk of sub-threshold problems leading to academic challenges, difficulty maintaining job, substance abuse



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## SPECIAL CONSIDERATIONS WITH EPILEPSY

- 60% of children age 5-16 with epilepsy meet DSM criteria for at least one psychiatric disorder
- Psychiatric diagnosis most common in individuals with IDD
  - Mood disorders (15-30%, anxiety disorders (20-30%), ADHD 20-40%
- Psychotropic and behavioral medications in affected individuals
  - 54% take at least 1 medication
  - Of those, 69% take 1-2 medications, 25% take 3-4, 6% take 5-10
- Only 23 % have behavioral plans



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## CLINICAL PEARLS FOR ADVISING YOUTH WITH EPILEPSY ABOUT MENTAL HEALTH

| | |
|---|---|
| ASK | • All adolescents with epilepsy should be screened for depression, suicidal ideation, and other mental health conditions at least once yearly<br>• Adolescents should be given the opportunity to talk with their healthcare provider without others in the room |
| TREAT | • Patients with epilepsy should be started on appropriate AEDs, even if they have depression or other mental health conditions<br>• Patients with suspected co-morbid mental health conditions should be referred for psychiatric evaluation and treatment |
| FOLLOW-UP | • Check that patients with psychiatric needs are being appropriately treated, particularly during times of transition (e.g. moving to college, transfer to adult care)<br>• Whenever AED medications are changed, patients should be asked about mood and behavioral side effects |



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## FROM PRINCIPLES TO PRACTICE:
## RESOURCES FROM CHILD NEUROLOGY FOUNDATION

- Office transition policy
- Transition checklist
- Self-care assessment
  - Separate forms for individuals with intellectual disability
- Transition packet
  - Transfer Letter Sample
  - Plan of Care
  - Medical Summary



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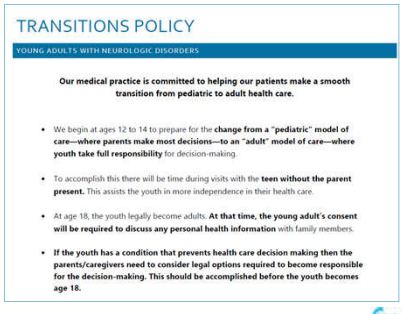
## CNF MODEL TRANSITION POLICY



TRANSITIONS POLICY

YOUNG ADULTS WITH NEUROLOGIC DISORDERS

**Our medical practice is committed to helping our patients make a smooth transition from pediatric to adult health care.**

- We begin at ages 12 to 14 to prepare for the **change from a "pediatric" model of care—where parents make most decisions—to an "adult" model of care—where youth take full responsibility** for decision-making.
- To accomplish this there will be time during visits with the **teen without the parent present.** This assists the youth in more independence in their health care.
- At age 18, the youth legally become adults. **At that time, the young adult's consent will be required to discuss any personal health information** with family members.
- **If the youth has a condition that prevents health care decision making then the parents/caregivers need to consider legal options required to become responsible for the decision-making. This should be accomplished before the youth becomes age 18.**



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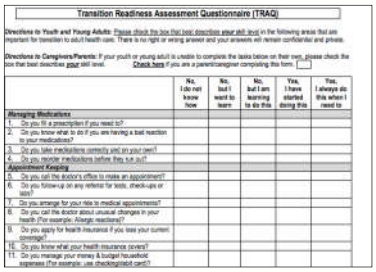
## MONITORING TRANSITION READINESS



Transition Readiness Assessment Questionnaire (TRAQ)

**Directions to Youth and Young Adults:** Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

**Directions to Caregivers/Parents:** If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form.

| | No, I do not know how | No, but I want to learn | No, but I am learning to do this | Yes, I have started doing this | Yes, I always do this when I need to |
|---|---|---|---|---|---|
| **Managing Medications** | | | | | |
| 1. Do you fill a prescription if you need to? | | | | | |
| 2. Do you know what to do if you are having a bad reaction to your medications? | | | | | |
| 3. Do you take medications correctly and on your own? | | | | | |
| 4. Do you reorder medications before they run out? | | | | | |
| **Appointment Keeping** | | | | | |
| 5. Do you call the doctor's office to make an appointment? | | | | | |
| 6. Do you follow-up on any referral for tests, check-ups or labs? | | | | | |
| 7. Do you arrange for your ride to medical appointments? | | | | | |
| 8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)? | | | | | |
| 9. Do you apply for health insurance if you lose your current coverage? | | | | | |
| 10. Do you know what your health insurance covers? | | | | | |
| 11. Do you manage your money & budget household expenses (For example: use checking/debit card)? | | | | | |



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## CNF TRANSFER PACKET

- Contents:
  - Summary of diagnosis/etiology
  - Current medication/laboratory results
  - Previous treatments & evaluations
  - Significant past procedures
  - Protocol for emergency care

- In addition, assessment of youth's knowledge of medical condition, self-management skills and decision-making capacity
- Best completed at age 17-18, or at least one year prior to transfer



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## FROM BARRIERS TO SOLUTIONS:
### NOT YET READY FOR ADULT MODEL OF CARE

Barrier:

- Lack of understanding of difference between family-centered and patient-centered care
- Youth's ignorance of consequences
- Overprotective parents



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## FROM BARRIERS TO SOLUTIONS:
### NOT YET READY FOR ADULT MODEL OF CARE

Barrier:
- Lack of understanding of difference between family-centered and patient-centered care
- Youth's ignorance of consequences
- Overprotective parents

Solution:
- Gradually introduce individual office time beginning in early teens
- Provide training to meet psychosocial needs of young adults
- Utilize local resources such as CHADD or Epilepsy Foundation camp to encourage self-advocacy and independence



## FROM BARRIERS TO SOLUTIONS:
### TEEN ISSUES IN YOUTH WITH NORMAL IQ

Barrier:
- Inconsistent adherence to medical plan
- Driving
- Risk-taking behaviors
- Psychiatric co-morbidities



## FROM BARRIERS TO SOLUTIONS:
### TEEN ISSUES IN YOUTH WITH NORMAL IQ

Barrier:
- Inconsistent adherence to medical plan
- Driving
- Risk-taking behaviors
- Psychiatric co-morbidities

Solution:
- Visits include time with nurse or transition coordinator
- Patients practice 3 sentence summary
- Screen for possible psychosocial problems
- Provide "Health Passport" on flash drive or cell phone

## FROM BARRIERS TO SOLUTIONS:
### UNANSWERED QUESTIONS FOR PSYCHIATRIC ISSUES

- Relationship between mental health and medical systems
  - Diagnosis as barrier
- Accessibility issues
  - Distance, availability
- Caregiver burden
  - Crisis cycle, burnout, mental illness
- Education and training for staff and family
- Payment
  - Financial ownership tied to individual system
  - Cost of guardianship
- Lack of evidence to guide intervention



## FROM BARRIERS TO SOLUTIONS:
### TEEN ISSUES IN YOUTH WITH IDD

Barrier:

- Lack of understanding disease and consequences of non-adherence
- Behavioral challenges make blood work, EEG, MRI difficult
- Adult specialists and ED don't allow family into exam room



## FROM BARRIERS TO SOLUTIONS:
### TEEN ISSUES IN YOUTH WITH IDD

Barrier:

- Lack of understanding disease and consequences of non-adherence
- Behavioral challenges make blood work, EEG, MRI difficult
- Adult specialists and ED don't allow family into exam room

Solution:

- Avoid assumptions - consider individual capacity for self-management
- Educate house staff and encourage family to advocate for patient-friendly environment

## FROM BARRIERS TO SOLUTIONS:
### FEWER RESOURCES IN ADULT SYSTEM

Barrier:

- Integrated care in pediatrics vs fragmented care in adult



## FROM BARRIERS TO SOLUTIONS:
### FEWER RESOURCES IN ADULT SYSTEM

Barrier:

- Integrated care in pediatrics vs fragmented care in adult

Solution:

- Better preparation of expectations for adult model
- Utilize extra services available in pediatric setting as much as possible prior to transfer – community living arrangements, vocational training, respite care



## FROM BARRIERS TO SOLUTIONS:
### LIMITED RESOURCES AT ALL LEVELS

Barrier:

- Lack of time – other more urgent issues
- Lack of compensation - current inability for both neurologists to bill for joint visit

## FROM BARRIERS TO SOLUTIONS:
### LIMITED RESOURCES AT ALL LEVELS

Barrier:

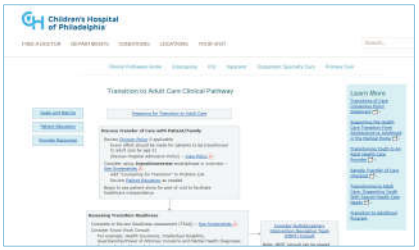
- Lack of time – other more urgent issues
- Lack of compensation - current inability for both neurologists to bill for joint visit

Solution:

- Introduce transition gradually in collaboration with primary care
- Support programs co-sponsored by local advocacy organizations
- Utilize AAN coding initiatives
- Develop new practical approaches that do not add to clinical burden



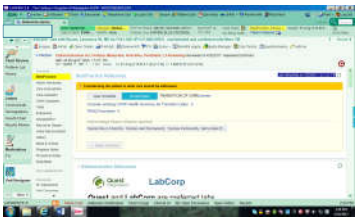
## LOCAL SOLUTIONS:
### UTILIZING THE EMR: PATHWAY FOR TRANSITION



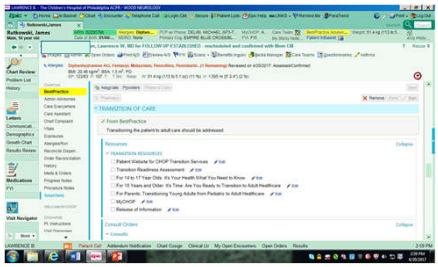

*https://www.chop.edu/clinical-pathway/transition-adult-care-adolescents-and-young-adults-ambulatory-outpatient-specialty*



## LOCAL SOLUTIONS:
### UTILIZING THE EMR: BEST PRACTICE ADVISORY



## LOCAL SOLUTIONS:
### UTILIZING THE EMR: TRANSITION RESOURCES





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## LOCAL SOLUTIONS:
### OTHER RESOURCES FOR PATIENTS WITH PSYCHIATRIC ISSUES

- Adult Transition Clinical Consult Services
  - Complex youths ready to transfer to adult with ≥ 2 specialists and/or IDD
  - Transition coordinators help to identify adult providers and facilitate transfer of medical records
- NJ Transition to Adult Coordinated Care Program
  - Similar service for NJ residents with IDD of any etiology, age 16-26
- Telephonic Psychiatric Consult Service (TiPS)
  - PA funded service for children insured by Medicaid up to age 21
  - 3 regional teams of psychiatrists provide real-time consults to >300 PCP offices; providers do not prescribe medications but will provide in-office training to PCPs
  - Team therapist and care coordinator provide transition care and link families to local mental health providers



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## BEST ON-LINE RESOURCES

www.childneurologyfoundation.org/transitions


www.gottransitions.org/transitions/providers/index.cfm



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## SUMMARY

1. Successful transition to adulthood requires years of preparation and needs to be addressed early and often
2. Transition may look different for every patient, but there are common principles and available resources
3. "Graduation" to adult care should always be the culmination of a process of achieving maximal independence
4. If you are not sure where to start, pick one patient and start the conversation; it gets easier over time

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## EVEN THOUGH IT OFTEN SEEMS THAT SUCCESSFUL TRANSITION IS IMPOSSIBLE….

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## ….ALL PATIENTS DESERVE TO GRADUATE TO ADULTHOOD….

**….AND ALWAYS REMEMBER THE GOAL IS TRANSITION NOT JUST TRANSFER**