

# ARIZONA TRANSITION GUIDE FOR CYSHCN



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Making Lifelong Connections 2017

# Transition

- What is health care transition?
- What is the goal of transition?



# Children and Youth with Special Health Care Needs (CYSHCN)

- 20% of children 18 and under have a special health care need
- 90% of children with special health care needs live to adulthood
- Multiple systems
- Maternal and Child Health (MCH) Transition to Adulthood



# Background

- What is known?
- Current Status of Transition Preparation Among Youth With Special Health Needs in the United States
- The 2020 Federal Youth Transition Plan
- Clinical Report- Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home



# FloridaHATS

- Florida Health and Transition Services
- Tool Box



# UA PPC

- The University of Arizona Pediatric Pulmonary Center (PPC)
- Cystic Fibrosis Transition Passport Program
- ArizonaLEND



# Objective

- To improve the successful transition from pediatric to adult care of children and youth with special health care needs by providing comprehensive educational information to patients, parents, and caregivers



# Methods

1. Create a transition flowchart with state specific resources for patients and parents/caregivers
2. Send flowchart to be reviewed by selected sample consisting of patients, parents/caregivers, providers, and MCHB professionals
3. Post flowchart with applicable links on the PPC and LEND websites for patients and parents/caregivers





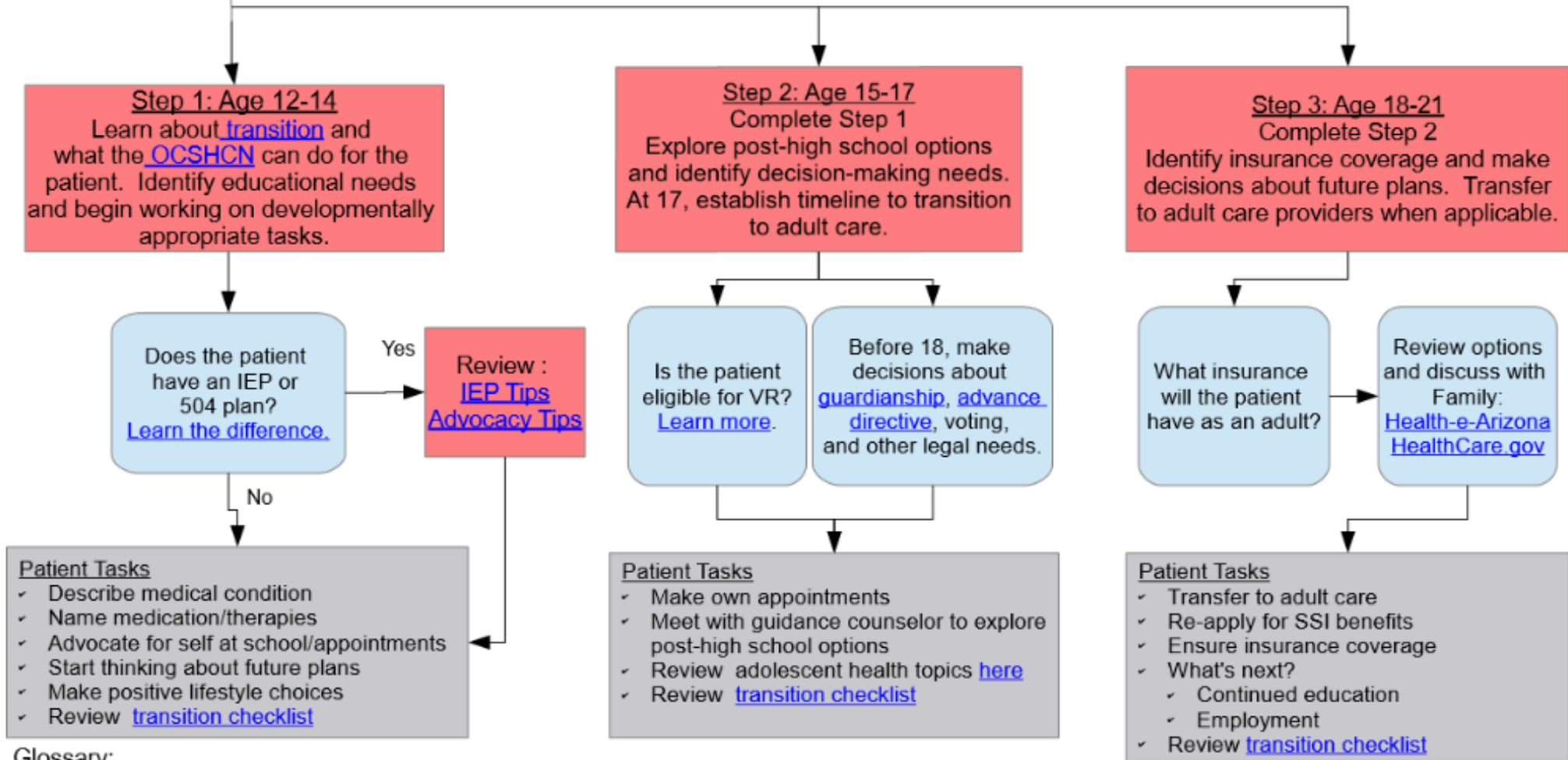
# Methods

4. Create and post a needs assessment survey within the PPC and LEND transition links so patients and parents/caregivers can provide feedback as to which areas they would like further information
5. Execute online or in-person transition fair and/or online modules to address CYSHCN transition needs based upon needs assessment results



Start Here to Begin!

## Transition Guide for Children and Youth with Special Health Care Needs in Arizona



Glossary:

OCSHCN: Office for Children with Special Health Care Needs

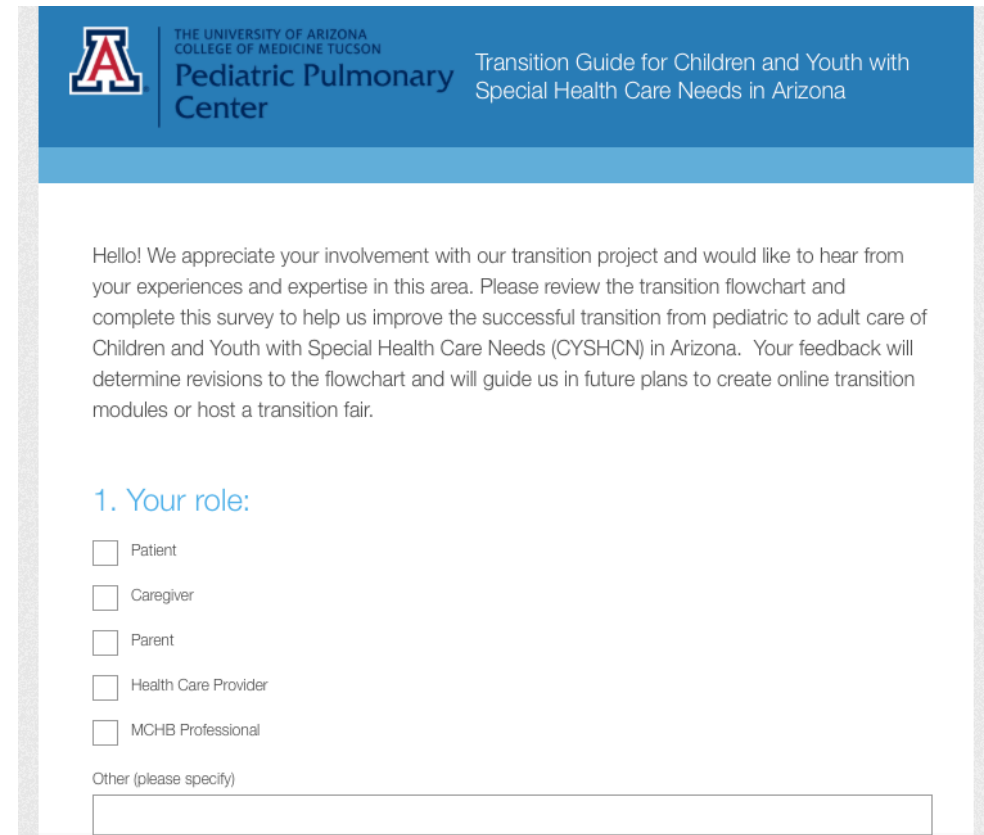
VR: Vocational Rehabilitation

\*Based off of the FloridaHATS transition program.



# Survey

- Sample
  - Patients, parents/caregivers, health care providers, MCHB professionals
- Questions



The survey form has a blue header with the University of Arizona logo and text: 'THE UNIVERSITY OF ARIZONA COLLEGE OF MEDICINE TUCSON Pediatric Pulmonary Center' and 'Transition Guide for Children and Youth with Special Health Care Needs in Arizona'. Below the header, the introductory text reads: 'Hello! We appreciate your involvement with our transition project and would like to hear from your experiences and expertise in this area. Please review the transition flowchart and complete this survey to help us improve the successful transition from pediatric to adult care of Children and Youth with Special Health Care Needs (CYSHCN) in Arizona. Your feedback will determine revisions to the flowchart and will guide us in future plans to create online transition modules or host a transition fair.'

1. Your role:

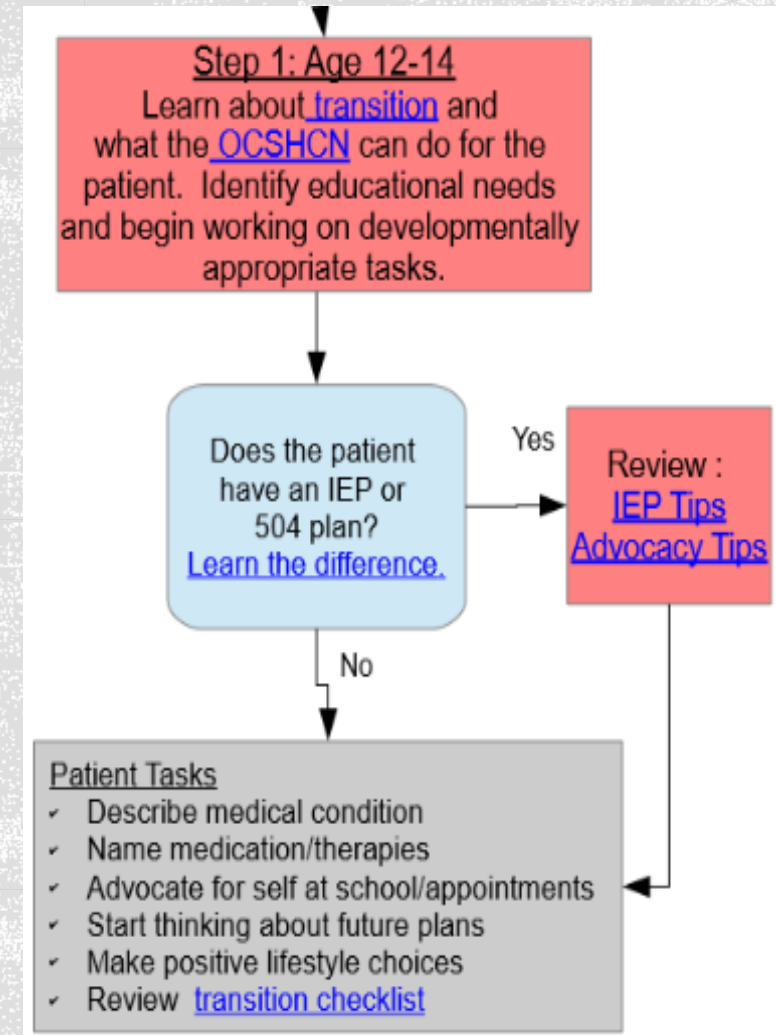
- Patient
- Caregiver
- Parent
- Health Care Provider
- MCHB Professional

Other (please specify)



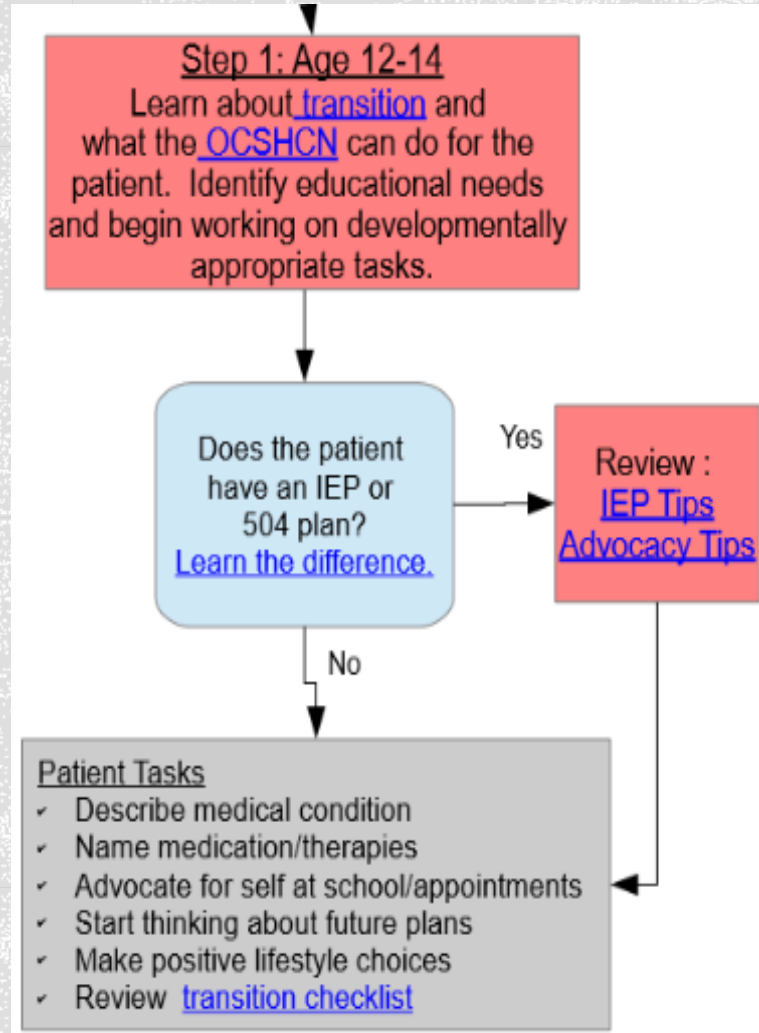
# Questions

1. Do you feel that the information provided in this step is age/developmentally appropriate?
2. If no, what information would be more helpful to include?
3. Do you feel that the resources provided on IEP and 504 plans, IEP Tips, and Advocacy Tips are useful to prepare patients/families for transition?
4. If no, what information or resources would be helpful to include?



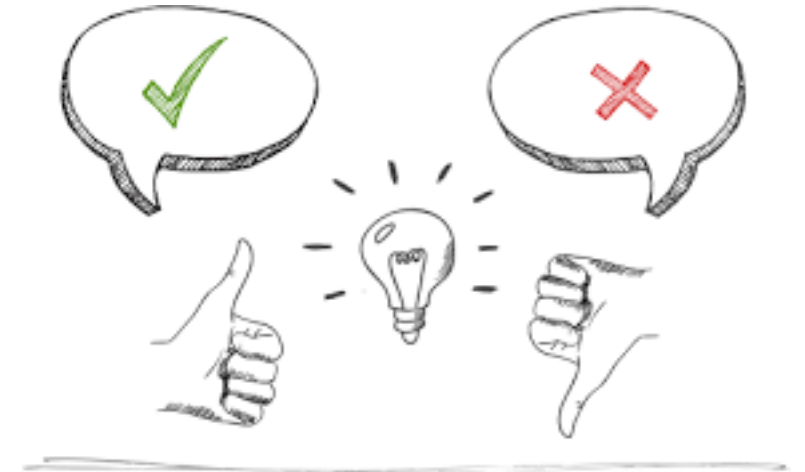
# Questions

5. Are there other resources or topics you believe should be addressed in this step? If yes, please provide feedback and comments below.
6. Do you believe the tasks listed in this section are appropriate for this age group?
7. If no, what tasks would be helpful to include or change?



# Results

- Age/developmentally appropriate
- Resources
- Tasks
- Formatting
- Grammar/ phrasing



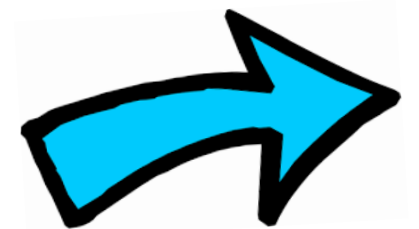
# Conclusion

- Potential Revisions
  - Insurance
  - Medications
  - Grammar/phrasing



# Next Steps

- Post flowchart with applicable links on the PPC and LEND websites
- Needs assessment survey
- Online or in-person transition fair and/or online modules





# References

- Children with special health care needs. (2016). Health Resources & Services Administration. Retrieved from <https://mchb.hrsa.gov/maternal-child-healthtopics/children-and-youth-special-health-needs#>
- Clinical report: Supporting the health care transition from adolescence to adulthood in the medical home. (2011). American Academy of Pediatrics. 182-200.
- For youth & families. (n.d.) FloridaHATS. Retrieved from <http://www.floridahats.org/for-youth-families/>
- Lorenzo, S. B. (2014). Transition to adulthood. National Center for Education in Maternal and Child Health. Retrieved from <https://www.ncemch.org/evidence/NPM-12-transition.php>
- McManus et al. (2013). Current status of transition preparation among youth with special needs in the United States. American Academy of Pediatrics, 13(6), 1091-1097.
- McPherson et al. (1998). A new definition of children with special health care needs. American Academy of Pediatrics; 137-140.
- The 2020 federal youth transition plan: A federal interagency strategy. (2015). Federal Partners in Transition Workgroup.
- Youth & families. (2017). Got Transition. Retrieved from <http://www.gottransition.org/youthfamilies/index.cfm>



# THANK YOU!

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