



**Change Package for Primary Care  
Teams to Guide Youth Transitions to  
Adult Care Systems**

## Funding Statement:

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Oral health content was created in collaboration with the Partnership for Children's Oral Health and University of New England.

## Introduction to the Change Package to Guide Youth Transitions to Adult Care

Adolescence is a critical developmental period of transition from childhood to adulthood. The American Academy of Pediatrics (AAP), American Academy of Family Physicians and the American College of Physicians agree that health care providers address transition planning by engaging youth and their families in developing self-care skills for an adult model of care and support the transfer care by ensuring a smooth handoff to adult health care providers. This transition is challenging for many young adults and even more-so for youth with special needs.

Since 2018, Quality Counts has been working on how to improve adolescent transitions with the Maine AAP as part of the Developmental Systems Integration Project funded by the Maine CDC Maternal and Child Health Block Grant. A group of medical and community stakeholders worked with family organizations to develop sample office policies around adolescent transitions, electronic medical record templates, and resource lists for families.

This change package includes tools and resources for Primary Care Practices to adapt their policies and workflows to better support the youth and families they serve. We aim to improve the content of this document and encourage suggestions for additions or edits based on use of the materials, please contact [QCforKids@qualidigm.org](mailto:QCforKids@qualidigm.org).

### **Change Package Resources (Click on the text below to be directed to the resource):**

- Key Driver Diagram and Measures for Success
- Sample Clinic Policy on Adolescent Transition to Adult Care
- Transition Information for Staff and Providers & Office Checklist
- Adolescent Transition Patient Visit Checklists
- Sample Adolescent Confidentiality Clinic Policy
- Sample Workflows to Implement Adolescent Transition Checklist
- Transitioning to Adulthood Timeline for Teens and their Families
- Resources for Families and Youth in Maine with Special Healthcare Needs
- Supported Decision-Making Information Resource

### **Other Resources to Support Adolescent Health Transitions:**

- [AAP EQIPP - Online Improvement Modules: Bright Futures](#)
- [Maine Parent Federation Services Map](#)
- [Got Transition Resources for Healthcare Providers](#)
- [AYAH National Resource Center Change Package to Improve Preventative Visits](#)
- [MaineCare Primary Care Health Homes List](#)
- [MaineCare Behavioral Health Homes List](#)

# Project Overview

## Primary Care: Improved Transitions for Adolescents to Adult Care

**Global Aim** To improve transition to adult care for children and youth with special healthcare needs



### Primary Drivers

1. Leaders as Champions for Change
2. Informed and Engaged Parents, Caregivers and Youth, especially those with Special Healthcare Needs
3. Empowered and Informed Pediatric Primary Care Teams
4. Access to Adult Service Providers

### Specific Aims

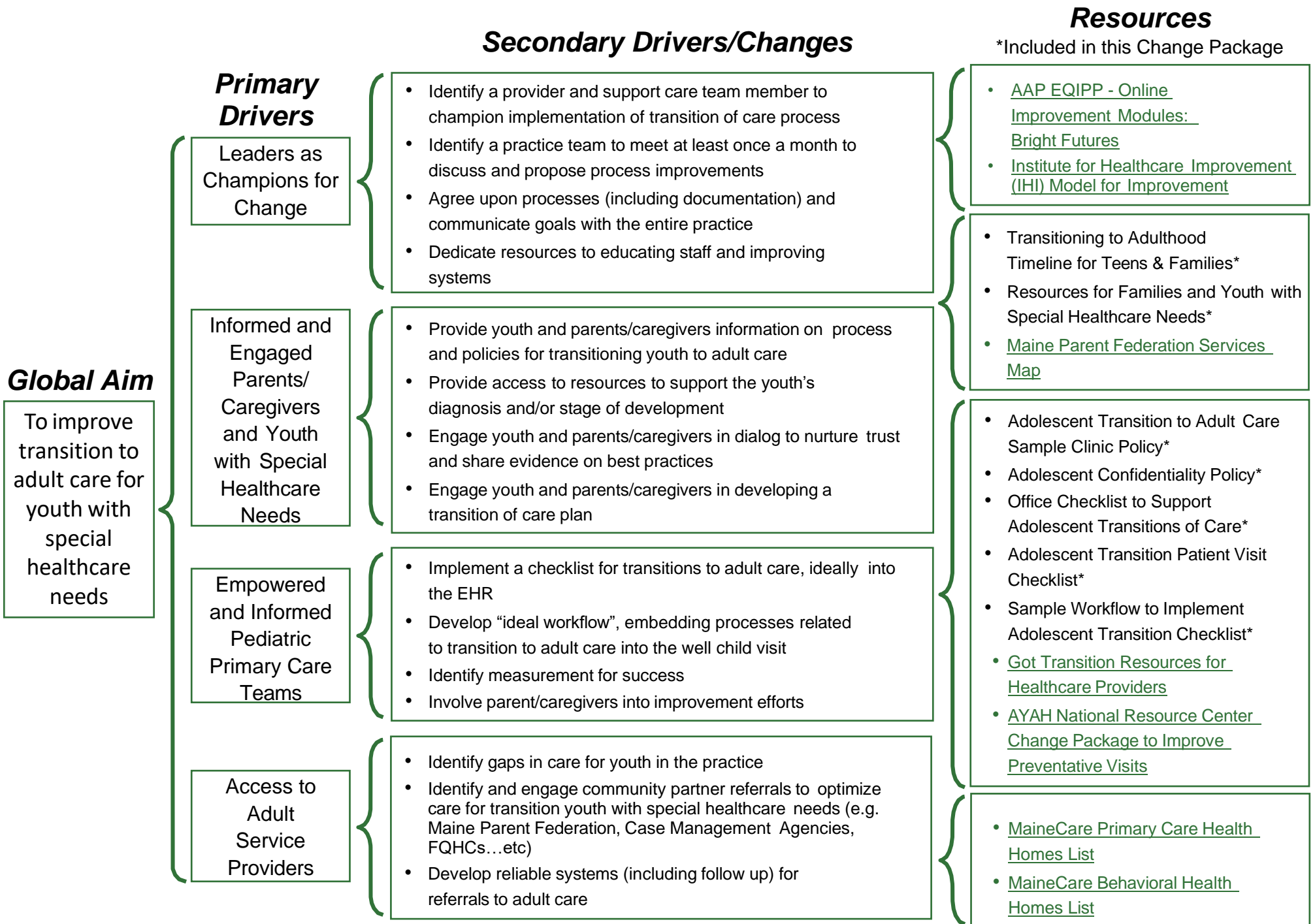
*Improved transitions to adult care will result in increased:*

- Proportion of adolescents receiving preventative screenings and referrals to needed services
- Health education for parents/caregivers and youth
- Referrals to adult providers starting at 17 years (or as appropriate)

### Measurement for Success

- Well-care visit in the past year
- Well-care visits with confidentiality review
- Private visit in the past year
- Youth who receive needed transition services
- Documented transition plans
- Youth who have transferred to Adult Care

# Key Driver Diagram: Improved Transitions for Adolescents to Adult Care



# Suggested Measures for Success - Defined

<i>Measure Description</i>	<i>Numerator</i>	<i>Denominator</i>	<i>Source</i>	<i>Comments</i>
% of youth w/ at least one comprehensive well-care visit in the past year	# of patients (age 12-21) w/ at least one well-care visit in the past year	# of patients ages 12-21 who are “active” in the past year	National Committee for Quality Assurance (NCQA) in their Healthcare Effectiveness Data and Information Set (HEDIS 2018 Vol2 pg.327)	MaineCare Health Homes are required to track this measure
% of youth well-care visit where Confidentiality Policy is reviewed	# of patients, age 11 - 21, seen for a well-care visit for whom the practice’s confidentiality policy was reviewed during the defined measurement period	# of patients, ages 11 – 21, seen for a well-care visit during the defined measurement period	National Improvement Partnership Network (NIPN)	
% of youth who have a private visit with the primary care provider	# of patients, ages 11 - 21 seen for a well-care visit who had private time during the defined measurement period	# of patients, ages 11 - 21 seen for a well-care visit during the defined measurement period	American Academy of Pediatrics, Bright Futures Preventative Services Quality Improvement Measures	
% of youth who have a dental home by the time they transition to adult care	# of patients, ages 13-20 seen for a well-care visit who have a dental home	# of patients, ages 13-20 seen for a well care visit during defined measurement	Partnership for Children’s Oral Health Suggested Measure	No current national measure found

## Suggested Measures for Success – Defined, cont.

<i>Measure Description</i>	<i>Numerator</i>	<i>Denominator</i>	<i>Source</i>	<i>Comments</i>
% of youth, age 12-17, <b>with</b> special health care needs whose families report receiving services needed for transition to adult health care services	# of patients, ages 12-17, with special health care needs whose families report receive services needed for transition to adult health care services	# of patients with special healthcare needs, ages 12-17	Maternal and Child Health Bureau, Health Resources & Services Administration	Maternal & Child Health Block Grant Program: 16.5% national performance in 2016 (from National Survey of Children's Health)
% of youth, age 12-17, <b>without</b> special health care needs whose families report receiving services needed for transition to adult health care services	# of patients, ages 12-17, without special health care needs whose families report receive services needed for transition to adult health care services	# of patients, ages 12-17, without special healthcare needs	Maternal and Child Health Bureau, Health Resources & Services Administration	Maternal & Child Health Block Grant Program: 14.2% national performance in 2016 (from National Survey of Children's Health)
% of youth with a documented Transition Plan	# of patients, ages 12 – 26, who have a documented transition plan	# of patients, ages 12 – 26	DSI Suggested Measure	No current national measure found
% of youth who have transferred to adult care	# of patients who have transferred to adult care	# of patients ages 17 - 26	DSI Suggested Measure	No current national measure found

# Adolescent Transition to Adult Care

## (Sample clinic policy)

We are committed to helping our teenage and young adult patients make a smooth transition from pediatric to adult health care.

As our patients enter their teenage years, we will give them more responsibility for their health maintenance and encourage them to advocate for themselves. We teach them how to care for their bodies and talk to their providers about their questions and concerns. This is a gradual process that starts early and evolves as one grows into early adulthood.

- 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.
- In the teen years, we gradually encourage the youth to become actively involved with their own healthcare. For example, teen patients will be encouraged to:
  - Check themselves in and out from their appointments
  - Learn about their diagnosis and medications
  - Learn who their providers are and how to reach a provider if issues come up
  - For older teens, participate with refilling and accurately taking medications with some degree of supervision
- There will be time during many visits with the teen when the parent will be asked to leave the room to allow the provider to talk with the patient alone. This assists the youth in becoming more independent in their health care and sometimes allows the youth to be more open about their health. Confidentiality is provided in this setting according to our Adolescent Confidentiality Policy. Regardless of what the teen shares with us, we always advocate for teens and young adults to include their parents in their health when possible and especially when important decisions are being made which impact their wellbeing.
- As the teen gets older, parents may choose to sign a form that allows a minor to come to the office and be seen independently for their entire visit. As above, we still advocate for the patient to include their parents in their health when possible. [THIS MAY OR MAY NOT BE PERMITTED BASED ON YOUR INSTITUTION]
- At age 18, youth legally become adults. At that time, the patient’s consent will be required to discuss any personal health information with family members. A young adult may choose to sign a form that allows us to have ongoing communication with a parent.
- If the youth has a significant health condition that does not allow them to advocate for their own health and financial needs, the parent may want to consider legal options to become responsible for their youth’s decision-making. This should be done before age 18.
- For young adults at college, we will be happy to work with the school’s health center to effectively manage their health and wellness.



- We will work in partnership with youth and families regarding the age for transferring to an adult provider. This may vary based on the individual patient and the doctor involved with their care, typically between age 22-25yrs old. Our adolescent and young adult providers will see patients up until age 25. We are experienced with providing young adults all of the care they need that would be found in an adult office, including well exams, birth control, gynecologic care, substance abuse, eating disorders, mental health, and more.

[THE AREAS MARKED IN RED SHOULD BE ADJUSTED TO MATCH THE SPECIFIC CLINIC SITE.]

- When it is time for transferring to an adult provider, we help our patient's through every step of the process. We will help:
  - Find an adult provider that meets the patient's needs and accepts the patient's insurance
  - Send medical records to the adult provider
  - Communicate with the adult provider about the unique needs of the patient.
- As always, if you have any questions or concerns, please feel free to contact us.

# Information for Staff and Providers - thinking about Oral Health! (Maine Data)

## Background:

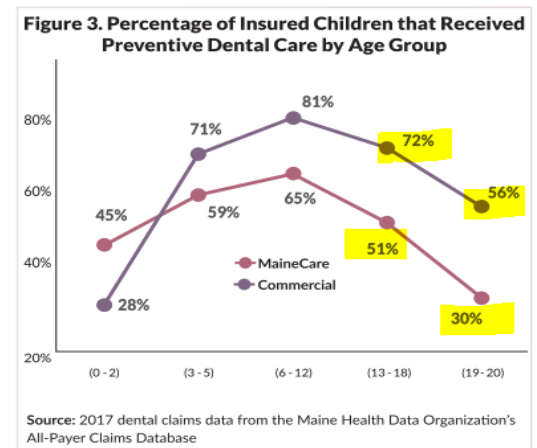
Young people with any form of chronic disease, including **oral diseases** face even greater challenges, since they also must deal with important changes in the care they need and the way it is provided<sup>1</sup>.

- Oral Diseases include *Dental caries (cavities), Periodontal (gum) disease, Cleft lip and palate, Oral and facial pain, Oral and pharyngeal (mouth and throat) cancers*
- Prevalence of **untreated** dental caries in permanent teeth among adults 20-64 years of age is 27%, with **no change in rate in the last 20 years**<sup>3</sup>
  - Much of this dental disease starts in early childhood: Among Maine 3rd graders, about 40% have a history of dental decay, and about half of these children had visible cavities that remained untreated at the time of the screening.<sup>1</sup>
- Asthma is the second most common chronic disease among children, and there are many children who suffer the combined consequences of asthma and dental disease. Research has demonstrated that children with asthma are more likely to develop dental caries, an interaction that is driven by both disease process and use of inhaled corticosteroids<sup>2</sup>
- If unchecked, oral health can deteriorate progressively and adversely impact an individual's general well-being. It also has a financial bearing at family and community levels<sup>2</sup>.
- These conditions may be prevented with regular visits to the dentist; however, there is a downward trend in **preventive** oral health care utilization as youth begin the transition to adulthood

## Why:

**Age Group:** There is a steep and continual decline after age 12 years in the percentage of patients who receive preventive dental care

- **Insurance/socioeconomic status:** The decline is even steeper for youth with MaineCare compared to youth with commercial dental insurance
- For more detailed data on dental care utilization among Maine children, see <https://mainepcoh.org/publications/databrief.pdf>



<sup>1</sup> Maine Integrated Youth Health Survey - 2019 results.

[https://data.mainepublichealth.gov/miyhs/2019\\_reports\\_results](https://data.mainepublichealth.gov/miyhs/2019_reports_results). Accessed April 30, 2020.

<sup>2</sup> Asthma's Effects on Oral Health - Decisions in Dentistry. <https://decisionsindentistry.com/article/asthmas-effects-on-oral-health/>. Accessed April 30, 2020.

<sup>3</sup> In the 2020 legislative session, the legislature is considering a bill that would provide comprehensive dental benefits for adults with MaineCare so this could change if LD 1955 passes

## Call to Action: What can Pediatricians and Adolescent Providers Help Young People Transition to Adult Dental Care?

- Use the Transition Toolkit to guide the process of transitioning pediatric patients to adult systems of dental care as well as primary care:
  - Improve a young person's knowledge of their oral health condition and their own appropriate use of oral health services → **share the Patient Adolescent Transition Checklist during well check visits**
  - Understand how MaineCare dental benefits work and what happens when someone with MaineCare turns 21 years old (MaineCare Benefits Manual, <https://www.maine.gov/sos/cec/rules/10/ch101.htm>)
    - For patients <21 years old, covered services currently include:
      - Clinical Oral Examination, 2 per calendar year
      - Preventive services including prophylaxis (removal of plaques), fluoride treatment, pit and fissure sealants, oral hygiene instruction, smoking cessation counseling
      - Restorative services including amalgam and composite restoration, crowns
      - Endodontic services (i.e. root canals)
      - Orthodontic services with granted prior approval
      - Necessary extractions and surgical interventions
    - Patients >21 years old: adult dental benefits are currently limited<sup>34</sup> to interventions for pain, infection and services considered medically necessary, and do not include comprehensive preventive care
  - Note that Commercial dental plans vary as to when a child ages out of their parents insurance plan can vary, some are as early as 18-19 years old

**For these reasons, it is important to ensure that young adults have a dental home established and have completed all restorative care needed prior to aging out of comprehensive benefits.**

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## References

1. Oral Health | Healthy People 2020. <https://www.healthypeople.gov/2020/topics-objectives/topic/oral-health>. Accessed February 8, 2020.
2. Arora A, Khattri S, Ismail NM, Nagraj SK, Eachempati P. School dental screening programmes for oral health. *Cochrane Database of Systematic Reviews*. 2019;2019(8). doi:10.1002/14651858.CD012595.pub3
3. Rozier RG, White BA, Slade GD. Trends in Oral Diseases in the U.S. Population. *Journal of dental education*. 2017;81(8):eS97-eS109. doi:10.21815/JDE.017.016
4. Henshaw MM, Garcia RI, Weintraub JA. Oral Health Disparities Across the Life Span. *Dental Clinics of North America*. 2018;62(2):177-193. doi:10.1016/j.cden.2017.12.001
5. <https://www.maine.gov/sos/cec/rules/10/ch101.htm> MaineCare Handbook

# Transition Information for Staff and Providers

Transition is a gradual process that extends from about age 12 years until when the patient transfers to another clinic.

Considerations for Adolescent Transitions:

- If your office is going to see older teens and young adults, it is important that you be able to screen for and provide the services that the age group needs.
- Different providers have different comfort levels with and skill sets for older teens and young adults. This may impact the ages for which a provider transfers his/her patient to adult care. Local adult primary care availability may also limit transfer of patients at times.
- The Maine Parent Federation is a good resource to include when patients have cognitive or medical challenges. They are particularly helpful with designing transition plans for complex patients or addressing Supported Decision-Making or Guardianship plans.

## Office Checklist to Support Adolescent Transitions of Care

### Transition Policy

- Developed an office transition policy with input from youth and families. Include privacy and consent information.
- Educated staff about practice's approach to transition and roles of the youth, family, and healthcare team.

### Access to Care

- Developed permission form for minor patient to seek care without parent (check with your institution to see if this is permitted locally)
- Developed permission form for parent to seek information on their 18+ child.
- Front desk encourages patient to do check-in/out with parent back up (early/mid adolescence).
- Rooming person takes history from patient with parent back up (early adolescence).
- Consider calling some lab results to the teen, and then to parent.
- Educate staff and providers on laws about consent and ability to treat minors.
- Developed relationship between adult providers and pediatric providers
- Educate office about partial vs full guardianship options.

### Quality Care

- Adult providers who meet the needs of the young adult patient must be able to address:
  - Well care
  - Mental health
  - Contraception services
  - STI screening
  - Substance use knowledge
  - Sports medicine skills
  - Immunizations.
  - Protects confidentiality as requested

These providers may be in pediatrics, family practice, med-peds, or internal medicine.

- Integrated patient transition check list into EMR for tracking progress over time.
- Referrals to ensure a dental home is established prior to transition to adult Primary Care Provider

### Resource Partners

- Maine Parent Federation
- Case management

### Patient Adolescent Transition Checklist

The following checklist was developed to support healthcare teams in adolescent transitions to adult care over several years, as relevant to the patient. Every teen grows up at a different rate and these supportive tools are meant to be guidelines, rather than a strict template. Every patient is unique, and appropriateness of the topic should be assessed before engaging in discussion.

- Consider storing the checklist within the problem list.
- Aim to talk about 1-3 topics at each visit.
- Status comments can be written anywhere on this living document. Ex. You could write the date the topic was discussed or add a comment line with where the patient stands.
- Not all topics have to be discussed, and some topics may be discussed more than once during the age group.

Approximate Ages	12-14	14-17	17+	Any age
<b>Knowledge of Care</b>				
Understands diagnosis & disease process*	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands treatments, meds, and allergies	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands pts family medical history	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Jointly developed <u>annual</u> goals for self-care w/ pt. including behavioral and oral healthcare	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	
<b>Access to Care</b>				
Understands providers/specialists/dentists involved w/ care.		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands how to schedule/reschedule appts.		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands medications and refill process		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands when and who to call w/ health concerns (including mental and oral health)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Before 18 - Consent to see pt independent of parent	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained
After 18 - Consent to communicate with parent			<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained
<b>Health Planning (Consider spending 1:1 time w/ pt.)</b>				
Assessed guardianship, or Supported Decision- Making (partial guardianship), as		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Plan in Place
Understands risks of substance use (including smoking and vaping)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered

Understands reproductive and sexual health.	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands healthy media and screen use.	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands importance of good oral health including risks of oral habits (snacking/teeth grinding)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Discussed safe relationships, gender, and orientation	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands career and/or education goals and plan		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Plan in Place
Transition Process				
Understands insurance process including dental insurance			<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands adult approaches to care (privacy, legal changes, self-advocacy)			<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands adult healthcare team and optimal transition timing		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Identified adult provider <input type="checkbox"/> Made appointment
Charting is set to assist transition (Maine Parent Federation may help with writing summary transition plan)			<input type="checkbox"/> Discussed	<input type="checkbox"/> Problem list updated <input type="checkbox"/> Transition summary letter created
Follow up visit w/ pediatric provider (for complex pt)			<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained

\*Communication is likely with patient, may be with guardian when appropriate.

***Easy to manipulate and copy this form into EHR Systems.  
If using Epic, you can find this checklist by visiting the Smartphrase Manager and searching for Fanburg, Jonathan. The list is titled "JFTransitionChecklist"***

## Patient Adolescent Transition Checklist

The following checklist was developed to support healthcare teams in adolescent transitions to adult care over several years, as relevant to the patient. Every teen grows up at a different rate and these supportive tools are meant to be guidelines, rather than a strict template. Every patient is unique, and appropriateness of the topic should be assessed before engaging in discussion.

- Consider storing the checklist within the problem list.
- Aim to talk about 1-3 topics at each visit.
- Status comments can be written anywhere on this living document. Ex. You could write the date the topic was discussed or add a comment line with where the patient stands.
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Understands treatments, meds, and allergies	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands pts family medical history	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Jointly developed annual self-care goals w/ patient Including behavioral and oral healthcare	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	
<b>Access to Care</b>				
Understands providers/specialists/dentists involved in care		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands how to schedule/reschedule appts		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
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Understands when/who to call w/ health concerns (including mental and oral health)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Before 18 – Consent to see pt independent of parent	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained
After 18 – Consent to communicate with parent			<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained
<b>Health Planning (Consider spending 1:1 time with patient)</b>				
Assessed guardianship/supported decision-making (partial guardianship)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Plan in Place	
Understands risks of substance use (including smoking/vaping)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands reproductive and sexual health	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands healthy media/screen use	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered

Understands importance of good oral health Including risks of oral habits (snacking/teeth grinding)	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Discussed safe relationships, gender, and orientation	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands career and/or education goals and plan Place		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Plan in
<b>Transition Process</b>				
Understands insurance process including dental insurance			<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands adult approaches to care: Including privacy, legal, self-advocacy			<input type="checkbox"/> Discussed	<input type="checkbox"/> Mastered
Understands adult healthcare team and optimal transition timing		<input type="checkbox"/> Discussed	<input type="checkbox"/> Discussed	<input type="checkbox"/> Identified
Adult provider		<input type="checkbox"/> Made Apt		
Charting set to assist transition (Maine Parent Federation may help with writing summary transition plan)				
	<input type="checkbox"/> Discussed	<input type="checkbox"/> Problem list updated		<input type="checkbox"/> Transition summary created
Follow up visit with pediatric provider (for complex pt)			<input type="checkbox"/> Discussed	<input type="checkbox"/> Obtained



# Adolescent Confidentiality Clinic Policy

(Sample)

Adolescence is a time of change when teens start to gain independence. In order to keep teens healthy, we focus on physical growth and development, social and academic success, emotional well-being, risk reduction, and violence and injury prevention. As such, we routinely ask parents to allow a brief one-on-one visit between their teen and medical provider to better serve their needs.

- **Independent Visits:** Having time alone with their physicians fosters an environment in which adolescents become comfortable speaking with healthcare providers and provides an opportunity for them to express medical concerns confidentially.
- **Confidentiality:** When teens share information with us that they ask to remain confidential, we will honor that request unless they plan to hurt themselves or someone else, or someone else is going to hurt them. We encourage patients to be open and honest with their parents, but we also want to offer a safe place for our teens to talk about their health questions and concerns. Some topics that may be addressed are dating, drugs, alcohol, mood, stress, and safety. Our goal is to give the best guidance and care in these situations.
- **Telephone Calls:** We maintain the patient's confidentiality in all types of communication, including office visits, phone calls, and online portals. This includes discussions about some lab/imaging evaluations and results.
- **Parents:** Parents are welcome to speak privately with the patient's healthcare provider about any concerns they may have about their child. We will, however, not share information that the patient has asked us to keep private.

This policy is consistent with Maine State Law surrounding adolescent confidentiality and with the policies of the Society for Adolescent Medicine and the American Academy of Pediatrics.

We consider it a privilege to take care of our teens and look forward to working together as our teens grow up!

## Adolescent Confidentiality Information for Staff and Providers

1. Where possible, involving parents/legal guardians with all healthcare issues of a minor is preferred. However, there are times when doing so prevents a minor from seeking or getting healthcare. We want to create an effective and trusted partnership with minors and their parents/guardians.
2. Based on Maine Law, minors can seek care confidentially, without parent knowledge or consent for 5 things:
  - a. contraception (all forms including emergency and implantable contraception)
  - b. family planning services (pregnancy testing, possibly pregnancy)
  - c. sexually transmitted infections
  - d. emotional health (depression/anxiety/etc)
  - e. substance abuse.All other healthcare services require permission from their parent/legal guardian.
3. Rarely, minors are emancipated from their parents (typically when living separately from their parents without parental support for >60 days or if emancipated by the court). In this setting, they may seek care confidentially and without parent consent or knowledge for all types of healthcare services.
4. Where a minor has ability to consent for care, they have an ability to receive care.
5. A provider has a right to break confidentiality and disclose confidential information if the minor is at serious risk of harming themselves or someone else. This may change in the course of the treatment relationship.
6. In the State of Maine, there are no specific ages associated with the confidentiality laws. However, most experts believe that privacy EMR tools need to be in place starting at about age 12yrs old.
7. Confidentiality extends to all types of communication, including verbal, written, telephone, emails, texts, and EMR communication (like MyChart or appointment reminder calls). Careful attention should be noted with lab results, after visit summaries, medications (and refills), appointment reminders, and release and scanning of medical records.
8. Explanation of Benefits (EOB's) and billing needs to be addressed with confidential services, as some insurance companies may disclose visit diagnosis or lab tests if the insurance is billed for these services.
9. Alone time with adolescents is encouraged to start at about age 12yrs old, but this may vary based on the cognitive development of the adolescent. As well, younger adolescents are more likely to have briefer periods of alone time than older adolescents.  
During the independent visit, the provider should assess the adolescent patient in a non- judgmental manner for strengths as well as risks associated with HEADS
  - (H) home
  - (E) education

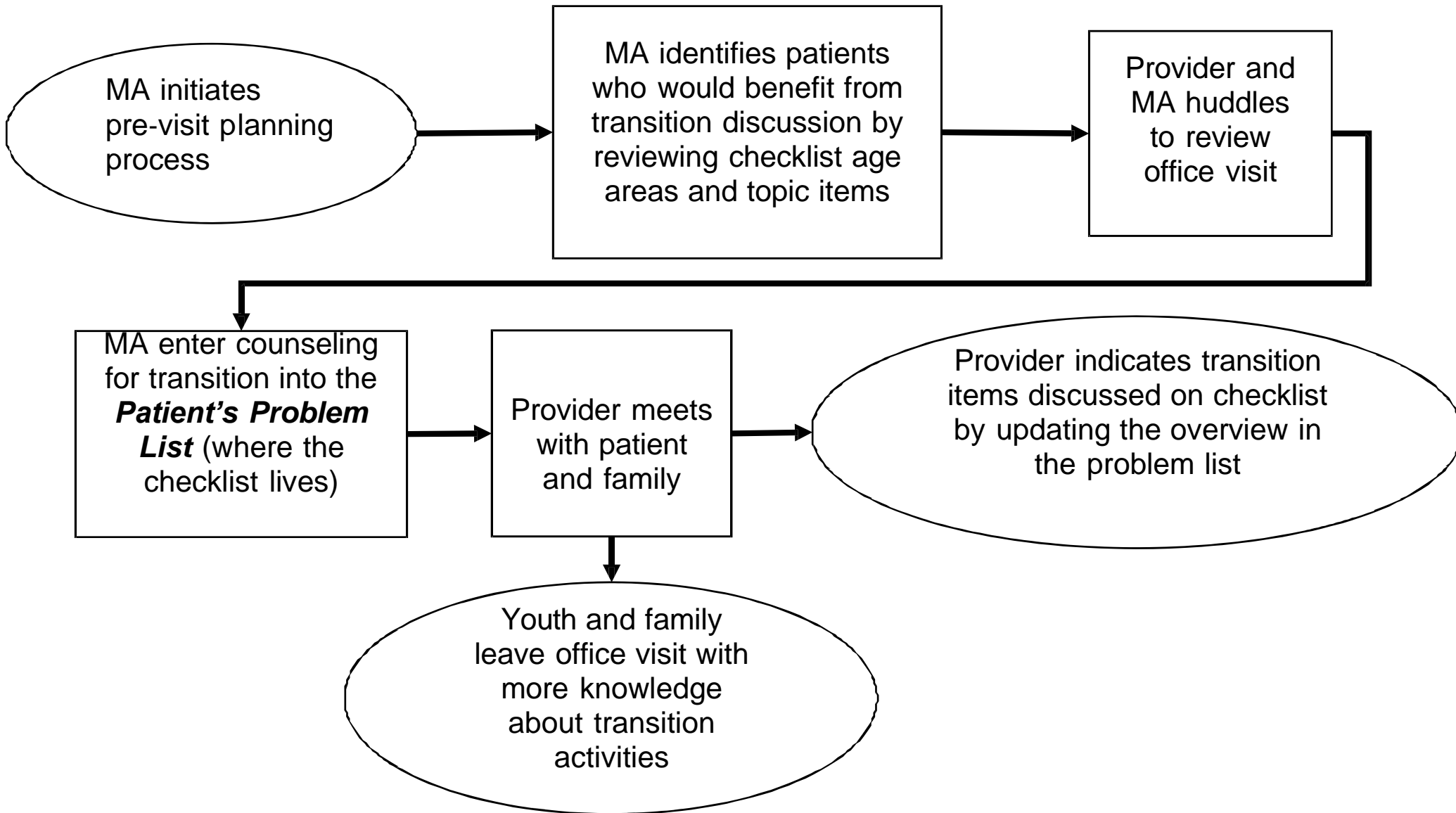
- (A) activities
- (D) diet, drugs
- (S) sex, suicide, safety

10. Explaining at the beginning of the visit about the structure of the office visit along with why you are talking alone with the minor is an effective means for helping parents and minors understand their roles in an office visit. Offices vary as to if the rooming person vs physician does this.
11. Confidentiality as it relates to HPV vaccine is not clearly defined by Maine law. However, some health systems have interpreted the law to include administering HPV vaccine as a confidential service.
12. Confidentiality as it relates to abortion is not included within this document. However, there are specific Maine laws that allow for confidentiality for abortion provided that certain conditions exist.
13. Specific to EPIC at MaineHealth – New adolescent confidentiality tools are available in EPIC that allow for the following:
  - a. Adolescent Order Set –
    - i. Allows for confidentially ordering select labs, medications, and procedures.
    - ii. Flags medical record and front desk staff related to release of medical records.
    - iii. Highlights select lab results that they are confidential and what to do with the results (like call pts cell phone).
    - iv. Notifies the pharmacist that select medications are confidential.
    - v. Prints an After Visit Summary that removes select labs, medications, or diagnosis.
    - vi. Blocks select diagnosis from being seen in MyChart and highlights confidential next to the diagnosis in the problem list.
    - vii. Flags billing to redirect bills to a different guarantor if confidentiality cannot be protected in the billing process.
  - b. Adolescent Confidential Box –
 

Creates a boxed in area within the note for which anything written in the box is blocked from being released in the medical record, but visible with caution labeling for other physicians.

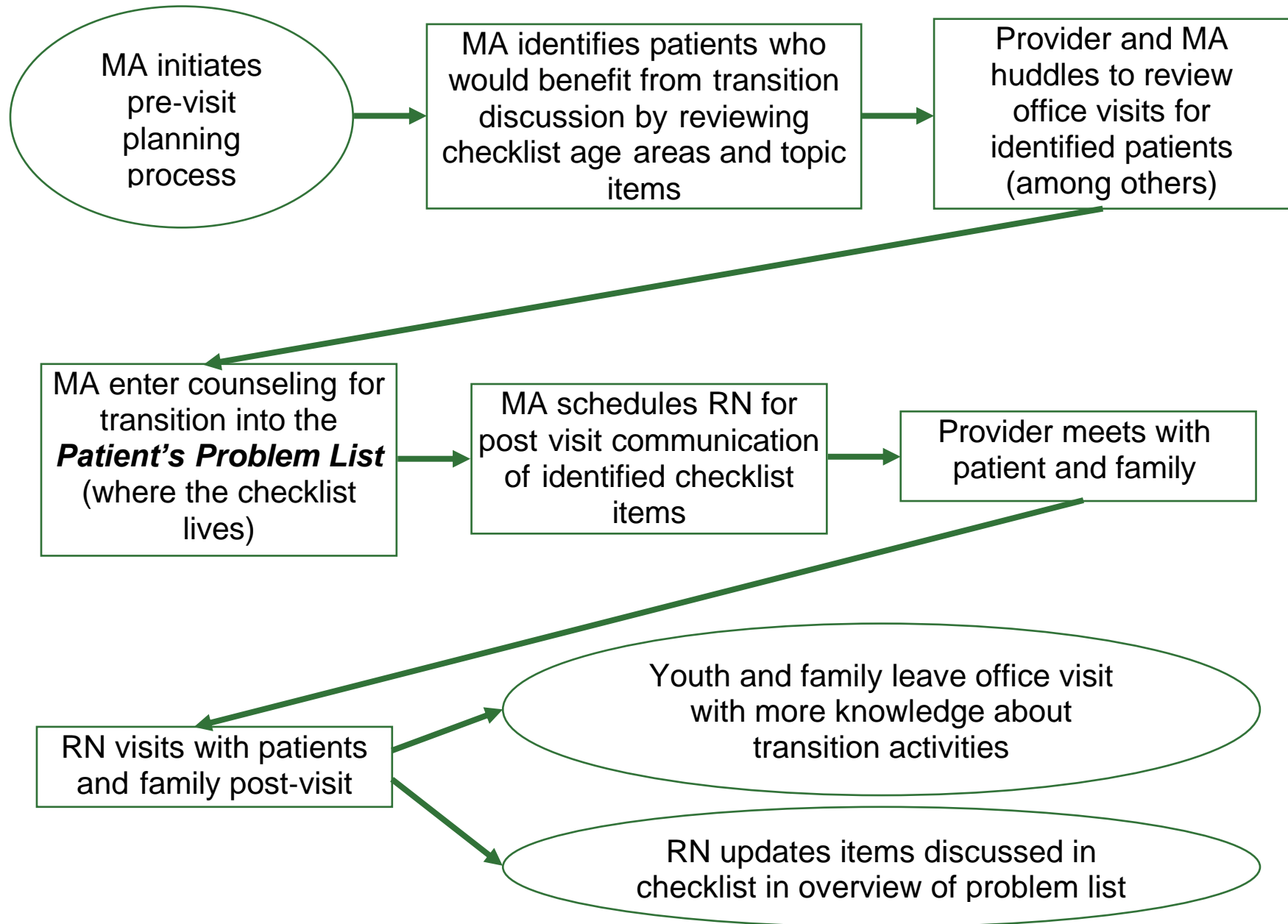
# Pre-Visit Planning Process Workflow to Implement Youth Transition Checklist

This workflow can be used to support implementation of the Adolescent Transition Checklist into a practice's processes. Pre-visit planning and consistent communication strategies are key to the success of the implementation.



# Team-Based Workflow to Implement Youth Transition Checklist

This workflow can be used to support implementation of the Adolescent Transition Checklist into a practice's processes. This workflow in particular engages the MA and the RN, in addition to the medical provider, as pivotal roles in the process. Pre-visit planning and consistent communication strategies are key to the success of the implementation.



# Transitioning to Adulthood

## Timeline & Checklist for Teens and Their Families

This handout is to help teens, parents, and guardians as you start making the transition from child to adult care systems. Everybody is unique and these transitions can happen at different ages and stages. Some items listed on this handout may or may not be relevant to you.

### Early Transition Skills

Typically ages 13-14 years

During this time, you are starting to take responsibility for your own needs. Some of the examples may be relevant to you at earlier or later ages.

#### Examples for you include:

- Schedule appointments for yourself.
- Meet with your doctor alone, for at least part of your appointment.
- Be a part of the IEP (Individualized Education Program) team.
  - Remember that transition services are part of the IEP!
- Learn about supported decision-making.
  - Look at 'Disability Rights Maine Supported Decision-Making' handbook:  
<https://drme.org/assets/brochures/DRM-SDM-Handbook-Rev.-01.09.19.pdf>

#### Examples for parents include:

- Connecting with support organizations, like the Maine Parent Federation.

#### Questions to ask yourself:

- Do I speak for myself at appointments?
- Do I talk with my family and doctor to help make health care decisions for myself?
- Do I talk with my doctor during appointments without my family or parents in the room?
- Do I know how to explain my health conditions or disabilities to other people?
- Do I know how my health conditions or disabilities affect my daily life and oral health?
- Do I wear or carry a medical alert (for allergies or other health conditions)?
- Do I know how to follow a healthy lifestyle with foods, exercise, dental hygiene, etc.?
- Do I know how using tobacco, alcohol, drugs, or medicines that aren't prescribed for me can affect me?
  - o Make symptoms worse, interact with your medicines, etc.
- Do I know what the signs are for sadness or depression?
- Do I know where to find help for mental health and substance use services, if I ever need them?
- Do I understand what healthy and proper relationships with the people around me are?

- Do I have adults in my life that I feel comfortable talking to?
- Am I connected with a support organization?
- Do I know how to properly brush my teeth and floss as well as take care of my orthodontic appliances?

## Middle Transition Skills

Typically ages 15-17 years

During this time, you have started to take responsibility for your own care needs and are ready to take on a bit more responsibility. Some of the examples may be relevant to you at earlier or later ages.

### Examples include:

- Think about how and when you will transition from pediatric to adult health care.
- Get work experience by volunteering, job shadowing, part-time employment, or vocational rehabilitation and apply to the Division of Vocational Rehabilitation, if needed.
- If you decide that you want to get a driver's license, think about driver's education and the types of adjustments you might need.
- Apply to the Office of Aging and Disabilities Services for adult services, if needed.
  - Learn about services that are available to you as a young adult, including adult long-term care.
- Look for resources and tools that may help you plan your life after school.
  - Look at 'High School and Beyond Guide' from the Office of Child and Family Services: <https://www.maine.gov/dhhs/ocfs/cbhs/documents/5-2-18Youth%20Transition.pdf>
- Think about how you will make big decisions when you turn 18.
  - When you turn 18 you will have the right to make all your own decisions. You can decide you want someone to help you make decisions, such as a power of attorney for health care, power of financial attorney, or medical directives.

### Questions to ask yourself:

- Do I know how to schedule my own appointments?
- Do I usually call my doctor's or dentist's office if I have a question or problem?
- Do I know the names of my medicines, how to take them, and why I take them?
- Do I know what might happen if I decide to skip my medicines or treatments?
- Do I know what to do if I have any side effects from medicines or treatments?
- Do I know how to get my medical and dental records?
- Do I know my rights to keeping my health information private and secure?
- Do I know how to use my health and dental insurance benefits?

- ❑ Do I know what my sexual identity and interests are?
- ❑ Have I talked about healthy & consensual relationships?
- ❑ Do I know who to talk to about birth control and safe sex?
- ❑ Do I know how to snack properly?
- ❑ Do I know if I have enough fluoride in my diet?
- ❑ Do I know what I want to do after high school?
  - Get a job, more education, volunteering, recreational options, etc.
- ❑ Do I know how my condition might affect my options and choices for jobs?
- ❑ Do I know where to find resources that can help me find a job, transportation, assistive technology, etc.?

## Late Transition Skills

Typically age 18 years or older

During this time, you are actively involved in caring of yourself. You are ready to take on most of the responsibility for your own needs. Some of the examples may be relevant to you at earlier or later ages.

**Examples include:**

- Arrange supported decision-making team and decide if you would like to pick a power of health care attorney, power of financial attorney, and/or a guardian.
- Take responsibility for managing your health insurance.
  - You can stay on your parent's health insurance plan until you turn 26.
- Make plans for where you will work and live.
- Register to vote.
- Register for Selective Service, if eligible.
- Complete the transition to adult healthcare providers
- Apply for SSI, Medicaid, and an adult long-term care program, if eligible.

**Questions to ask yourself:**

- ❑ Do I have an updated portable medical summary?
  - This should include a list of your medical conditions, medicines, immunizations, and care plan.
- ❑ Do I have an adult healthcare and dental provider?
- ❑ Do I have a doctor's and/or dentist's office that I can go to while I'm away at college or post-secondary school?
- ❑ Do I know how to take my medicines the right way?



- ❑ Do I know when and how to fill my prescriptions?
- ❑ Do I know how to wear/care for my retainers?
- ❑ Do I know how to use and take care of my medical equipment and supplies?
- ❑ Do I know when I should go to urgent care or the emergency room?
- ❑ Do I know who to call if I have questions about my health or dental insurance?
- ❑ Do I know at what age my medical and dental insurance ends?
- ❑ Do I know about my options for supported decision-making, guardianship, or power of attorney for health care?
- ❑ Do I know when I should call 9-1-1?
- ❑ Do I know what government benefits I might be eligible for?
  - SSI, SSDI, Health Benefits for Workers with Disabilities, Home & Community Based Services, etc.
- ❑ Do I know what my options are for housing as an adult?
  - Living on my own, in a group home, etc.
- ❑ Do I know how to manage my money and make sure I have enough to pay my bills?

You can find more information at this website: <http://illinoisap.org/wp-content/uploads/TEEN-CHECKLIST.pdf>

## These organizations & resources are available to help young adults and their families navigate the transition from child to adult services.



AccessMaine helps people with disabilities and their families find local & statewide resources that can support their development and independence.

They offer:

- Information about adaptive resources for living in the community
- A list of resources to help find equipment & tools for people with disabilities
- A detailed explanation of services offered through the State of

Maine Website: [http://www.accessmaine.org/living\\_parents\\_ME.htm](http://www.accessmaine.org/living_parents_ME.htm)



The Autism Society of Maine supports people with Autism Spectrum Disorder, their families, members of the community, and the professionals who work with them.

They offer:

- Workshops and 1-on-1 support for parents and individuals
- Help with Individualized Education Plans (IEP)
- Referrals services, including to primary care providers

Website: <https://www.asmonline.org/>



G.E.A.R. Parent Network offers support for parents and caregivers of children with behavioral health needs.

They offer:

- 1-on-1 support for parents
- Education about positive parenting skills
- Family-centered trainings
- Social events to reduce isolation and increase resiliency

Website: <https://crisisandcounseling.org/services/gear/>



Maine Parent Federation offers support to parents of children with disabilities or special health care needs. Services are offered for free to parents and caregivers and are available statewide.

They offer:

- Referrals to resources
- Telephone support
- 1-on-1 peer support
- Trainings for parents and caregivers

Website: <http://mpf.org/index.html>

## Resources for Families and Youth in Maine with Special Healthcare Needs

**These resources & services are offered through the State of Maine to help support you and your child with special healthcare needs as they transition to adult services.**

**High School and Beyond: A Guide to Transition Services in Maine**

This is a guide to help children and their families with special healthcare needs. It has information about resources and suggestions for successful transitions from high school to adulthood.

Website: <https://www.maine.gov/dhhs/ocfs/cbhs/transition-adulthood.shtml>

**Katie Beckett Program**

This program provides MaineCare benefits for children 18 years or younger with serious health conditions. Your child may be eligible for benefits, based on financial or medical reasons. Families that exceed the financial limit may still qualify.

Website: <http://www.maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html>

**Maine Department of Vocational Rehabilitation**

This program offers a 'Transition Career Exploration Workshop' for students with disabilities. This workshop is for students in 9<sup>th</sup> – 12<sup>th</sup> grade who are eligible, or may be eligible, for vocational rehabilitation services.

Website: [http://www.maine.gov/rehab/dvr/youth\\_transition.shtml](http://www.maine.gov/rehab/dvr/youth_transition.shtml)

**These MaineCare Benefits can support families and youth living with disabilities & chronic medical conditions.** The Maine Department of Health and Human Services website offers a list of agencies that can help you determine your eligibility for these services.

Website: <https://www.maine.gov/dhhs/ocfs/cbhs/provider-list/home.html>

**MaineCare Section 92  
BHH Services for Youth**

This benefit provides community-based care coordination and case management services.

To be eligible for these youth services, a person must meet these requirements:

- 1) Be under the age of 21 years old
- 2) Have a diagnosis of Serious Emotional Disturbance
- 3) Meet medical & financial eligibility requirements through

## Resources for Families and Youth in Maine with Special Healthcare Needs

<b>MaineCare Section 21 &amp; 29 Residential and Community Services</b>	<p>This benefit provides housing and/or community-based services.</p> <p>To be eligible for these services, a person must meet these requirements:</p> <ol style="list-style-type: none"> <li>1) Be age 18 or older</li> <li>2) Have an intellectual disability or autism spectrum disorder diagnosis</li> <li>3) Meet medical and financial eligibility requirements through</li> </ol> <p>MaineCare Website: <a href="http://www.maine.gov/sos/cec/rules/10/ch101.htm">http://www.maine.gov/sos/cec/rules/10/ch101.htm</a></p>
<b>MaineCare Section 13 Targeted Case Management</b>	<p>This benefit provides community-based care coordination and case management services.</p> <p>To be eligible for these services, a person must meet these requirements:</p> <ol style="list-style-type: none"> <li>1) Be age 21 or younger</li> <li>2) Have a developmental disability or a chronic medical condition</li> <li>3) Meet medical and financial eligibility requirements through</li> </ol> <p>MaineCare Website: <a href="http://www.maine.gov/sos/cec/rules/10/ch101.htm">http://www.maine.gov/sos/cec/rules/10/ch101.htm</a></p>

### These additional resources and services can support you and your child with special healthcare needs as they transition to adult services.

<b>Benefits Counseling at Maine Medical Center</b>	<p>This resource encourages people with disabilities that work is possible. They offer information about ABLE Accounts and other programs that help individuals work and manage money.</p> <p>To be eligible for this service, a person must meet these requirements:</p> <ol style="list-style-type: none"> <li>1) Be age 14 years or older</li> <li>2) Receive Social Security</li> </ol> <p>Website: <a href="https://mainehealth.org/maine-medical-center/community/vocational-services/benefits-counseling">https://mainehealth.org/maine-medical-center/community/vocational-services/benefits-counseling</a></p>
<b>Disability Rights Maine</b>	<p>This is Maine's protection &amp; advocacy agency for people with disabilities.</p> <p>This program represents people whose rights have been violated or who have been discriminated against based on their disability.</p> <p>Website: <a href="https://drme.org/contact">https://drme.org/contact</a></p>
<b>Exceptional Family Member Program of the US Military</b>	<p>This program is for military families that include a child with special needs.</p> <p>The program offers resources and information to help parents navigate medical and special education services, community support benefits, and entitlements.</p> <p>Website: <a href="https://efmp.amedd.army.mil/">https://efmp.amedd.army.mil/</a></p>

## Resources for Families and Youth in Maine with Special Healthcare Needs

### **NAMI Maine**

This is an education & advocacy organization that is committed to the topic of mental illness.

This resource provides accessible and useful information to those impacted by mental illness. Services include family education, training, and connection to respite services.

Website: <https://www.namimaine.org/>

# Supported Decision-Making: A New Option for Transition Age Youth and Others with Disabilities

**Stephen Meister, MD, FAAP**, Developmental Pediatrician, MaineGeneral & President, Maine Chapter, American Academy of Pediatrics

**Staci Converse, Esq**, Managing Attorney, Disability Rights Maine

## Introduction for Healthcare Teams

Adolescence is a critical developmental period of transition from childhood (dependence) to adulthood (independence). The American Academy of Pediatrics (AAP), American Academy of Family Physicians and the American College of Physicians agree that health care providers address transition planning by engaging youth and their families in developing self-care skills for an adult model of care, transfer care by identifying adult health care providers and ensuring a smooth handoff. This transition has been a challenge for many young adults, and this is even more-so for youth and children with special needs.

The question about guardianship is a common one for primary care practices as children with special health care needs start to make the transition to adulthood. In the past, full guardianship was the primary option for adults with developmental disabilities and other special health care needs who needed decision-making assistance.

Supported Decision-Making is a new alternative to guardianship that is more appropriate for most adults and will be part of Maine's Probate Code (which includes guardianship law) in September 2019. It is important that health care providers understand SDM when advising families on guardianship.

## What is Supported Decision-Making?

Supported Decision-Making (SDM) allows an individual with a disability to work with a team of chosen supporters and obtain needed accommodations to make decisions about his or her own life.

## Supported Decision-Making Steps

1

**The person chooses a team** of people who will be involved in supporting them; including friends, family, and professionals.



2

**The person and their team talk about what support is needed** including decisions about finance, healthcare, and employment. There may be some areas where the person decides support is needed and not others.



3

**The person and their team create a plan** that outlines how the person will be supported in the areas of decision making. The person and the team sign the plan, making it a Supported Decision-Making agreement. The agreement can be revised as needed.



Individuals with disabilities select people they know and trust—friends, family, and professionals—to be part of a support network to help with their decision-making in the areas in which they require help. These supporters help the individual understand the everyday situations and choices they encounter, explaining the pros and cons in a way that makes sense to the person with the disability.

This process enables an individual to make his or her own decisions, promotes self-determination and the person affected retains their fundamental rights. SDM builds on the natural supports in an individual’s life and, in so doing, provides an opportunity for the individual to build decision-making skills. The presence of often more than one and sometimes several supporters (as compared to a single guardian) serves as an important safeguard against the potential for abuse.

Healthcare needs can be addressed using supported decision-making, for example<sup>1</sup>:

<b>Healthcare Task</b>	<b>Supported decision-making options</b>
<ul style="list-style-type: none"> <li>• Taking Medications as needed</li> <li>• Maintaining hygiene and diet</li> <li>• Avoiding high-risk behaviors</li> <li>• Making decisions about medical treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Use apps to help remember to take medication and perform hygiene tasks</li> <li>• Get documented advice from healthcare professions during office visits on prevention and safety</li> <li>• Allow home health aides to assist in daily living tasks</li> <li>• Use HIPAA release forms as needed</li> <li>• Obtain Healthcare Power of Attorney or Living Will</li> </ul>

People who use SDM report that they experience greater community inclusion, improved decision-making skills, and increased social and support networks<sup>2</sup>. In contrast, people under a full guardianship order are more segregated from their communities—they are less likely to choose where they live, less likely to have a job in the community and less likely to have friends<sup>3</sup>.

**Maine’s Supported Decision-Making Landscape**

When Maine’s new Probate Code takes effect in September 2019, it will require that less-restrictive alternatives, including Supported Decision-Making, be attempted before a probate court will consider granting a guardianship. The adoption of this new Probate Code shows that Maine is recognizing the importance of self-determination and that guardianship is to be used only when there are no other options. If a guardian is appointed, Maine law will require that a guardianship be limited to only those areas in which the individual needs assistance.

Maine is not alone; SDM has been gaining substantial momentum in the United States and internationally. In the U.S., SDM has been endorsed and promoted by the American Bar Association, the National Guardianship Association, and several federal advisory bodies and agencies, including the Department of Education, the Department of Health and Human Services, the National Council on Disability, and the Senate Committee on Aging<sup>4,5</sup>.

While it is critical to discuss SDM with patients with developmental disabilities and other special healthcare needs who are approaching the age of majority (age 18) and their families, it is never too early to begin working on supporting individuals to make their own decisions as a part of transitioning from dependency (childhood) to independence (adulthood).

Discussions about Supported Decision-Making should include planning for transition to adult health care. There are many resources for families considering Supported Decision-Making and other alternatives to guardianship and links to some of them are provided below.

## Resources to Inform Families on Supported Decision-Making

- **Disability Rights Maine (DRM)** has produced an interactive SDM handbook and lists resources at: [www.supportmydecision.org](http://www.supportmydecision.org). DRM can be contacted at 1-800-452-1948 and their website is [www.drme.org](http://www.drme.org)
- **Maine Parent Federation (MPF)** has parent navigators who are trained to work with individuals with disabilities and their families when they are interested in pursuing SDM. MPF can be contacted at: 1-800-870-7746 and their website is <http://mpf.org/>

## References:

<sup>1</sup>Disabilities Rights Maine, 2019: <http://supportmydecision.org/assets/tools/DRM-SDM-Handbook-Rev.-3.14.19.pdf>

<sup>2</sup>Pell & Mulkern, Human Services Research Institute, Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report, at 31-34, [http://supporteddecisions.org/wp-content/uploads/2016/11/Evaluation-Year-2-Report\\_HSRI-2016\\_FINAL-2-1.pdf](http://supporteddecisions.org/wp-content/uploads/2016/11/Evaluation-Year-2-Report_HSRI-2016_FINAL-2-1.pdf)

<sup>2</sup>National Core Indicators Project, Adult Consumer Survey data 2013-14, [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

<sup>3</sup>National Council on Disability, Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination, March 2018, [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)

<sup>4</sup>Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans, November 2018, [https://www.aging.senate.gov/imo/media/doc/Guardianship\\_Report\\_2018\\_gloss\\_compress.pdf](https://www.aging.senate.gov/imo/media/doc/Guardianship_Report_2018_gloss_compress.pdf)