

## Introduction

Encourage your team to consider how everyone in your setting can better understand and support young people who have special health care needs.

## Objectives

By the end of this Spark training, participants will be able to:

- Define what a special health care need is and provide examples of special health care needs
- Understand key issues and challenges faced by youth with special health care needs in health care settings
- Identify strategies for best supporting youth with special health care needs

## Supplies

Prepare these supplies prior to facilitating this Spark.

- Laptop
- Projector

## Additional Resources

If you would like to learn more about this Spark topic, or want to find health care services to refer teens to, take a look at these additional resources.

- [Children and Youth with Special Health Care Needs](#)
- [HRSA: Children with Special Health Care Needs](#)
- [Sexual Behaviors of Physically Disabled Adolescents in the United States](#)
- [Got Transition](#)
- [Standards and Systems of Care for Children and Youth with Special Health Care Needs](#)

## Citation

If you plan to modify this resource, please cite or credit as: Understanding and Supporting Youth with Special Health Care Needs. Spark Training developed by the Adolescent Health Initiative at Michigan Medicine; May 2019; Ann Arbor, MI.

## Key of Icons

 = Slide change     = Estimated duration of topic     = Script for facilitator     = Note for facilitator

Intro/Hook  (5 minutes) 1 – TITLE SLIDE

 Today we are going to do a 15-minute mini-training, also called a Spark. Today's Spark training will teach us more about youth with special health care needs and help us start to become more comfortable working with them. This training was developed in collaboration with the Teen Advisory Council from Mott's Children's Hospital in Ann Arbor, MI.

 Introduce yourself/yourselfes, and explain how this fits into your organization's practices/practice improvement plans, if applicable.

 2 – WHAT COUNTS AS A SPECIAL HEALTH CARE NEED?

 It's likely that we all have different levels of knowledge about what could be considered a "special health care need" or even what youth with special health care needs might be like or look like. Take a moment and think to yourself – how would I define a "special health care need"?

 Pause to give people a moment to think.

 What are some examples of special health care needs that come to mind?

 Allow participants time to share a few of their examples. Then click to reveal the different special health care need examples.

 A broad range of conditions can result in special health care needs and it can be helpful to think of "special health care needs" as an umbrella term for many different physical, developmental, behavioral or emotional conditions. You can see some examples listed here on the slide but this list is far from complete. As you briefly review this list are there any conditions here that surprise you?

 Pause to allow a few participants to respond.

 3 – DEFINITION

 Youth with special health care needs are defined as youth who *"have or are at increased risk for chronic **physical, developmental, behavioral** or **emotional** conditions and who also require health and related services of a type or amount beyond that required by adolescents generally."*

Often when people think about "special health care needs" they might initially think of one or sometimes two of these types of conditions. Maybe they have experience with young people with a physical disability or a developmental disability, but it's important to recognize that the umbrella of "special health care needs" encompasses physical, developmental, behavioral and emotional conditions and needs.

On the previous slide, when I asked you to think of special health care needs, which of these 4 areas – physical, developmental, behavioral or emotional - came to mind first?

 Pause to allow a few participants to respond.

 Why do you think that was?

 Pause to allow a few participants to respond.

 Most people tend to be familiar with just one aspect of special health care needs which is why it's helpful to keep this definition in mind.

## Content (7 minutes)

### 4 – YSHCN MYTH OR FACT?

 To learn a little more about youth with special health care needs, let's start with an activity to dispel some myths about these young people. I will be reading four statements. I will be asking you whether you think each is a myth or a fact.

 Statements are animated to appear one after each click, with the answers showing after each click. Read each statement aloud and allow time for the audience to respond before providing the correct answer and advancing to the next one.

-  1. One in five U.S. families have a child or young person with a special health care need. – **FACT** – Keep in mind that this may mean that some families include more than one young person with a special health care need.
2. Topics such as sex and sexuality are less of a priority when working with youth with special health care needs. – **MYTH** – Many young people with special health care needs are sexually active just like their peers without special health care needs and this aspect of their health should be prioritized just as it would with any other adolescent.
3. The care and resources that youth with special health care needs and their families require is commonly available from a single provider or health center. – **MYTH** – Youth with special health care needs and their families often need services from multiple systems – health care, education, mental health, and social services. Having to coordinate care with multiple different systems can be especially challenging and health centers should make efforts to address care coordination for these young people.
4. Youth with special health care needs can be competent and capable of self-management when provided the necessary tools and supports. – **FACT** – While some youth with special health care needs may have complex care needs, require multiple medications, and need the support of parents and caregivers, it's important to empower them in their health care and recognize that they can be competent and capable of self-management.

 5 – DO'S AND DON'TS

 Young people with special health care needs can often be treated differently than their peers by friends, family, teachers, and health care professionals. As health care professionals, we can play a role in providing a safe and welcoming space for all youth to receive the services they need.

The next couple of slides review some quotes from a focus group of youth with special health care needs on what they do and don't want from their health care providers. As we walk through these do's and don'ts, consider how you have seen some of these behaviors play out in our health center or in your individual interactions with young people.

 6 – DO'S AND DON'TS

 Don't define me by my condition alone – I have a social life too...

 7 – DO'S AND DON'TS

 Learning about my condition can sometimes be a lot to take in. I need time to digest what you're saying and what it means for me.

 8 – DO'S AND DON'TS

 Don't make assumptions about me based on my chart or what you know about my illness. Get to know me and my condition on an individual basis.

 9 – DO'S AND DON'TS

 Don't assume that just because I "look fine" that I feel fine. My outward appearance doesn't dictate how I'm really feeling.

 10 – DO'S AND DON'TS

 Trust that I'm an expert on my own health experiences. Don't treat me like a child.

 11 – DO'S AND DON'TS

 As you review these quotes from youth with special health care needs, what stands out to you?

 [Pause to allow a few participants to respond.](#)

 12 – TRANSITION

 Another important aspect to consider when working with youth with special health care needs is health care transition from pediatric care to adult care, especially since many youth with special health care needs see multiple providers and specialists. Many have established trusting relationships at their pediatric practices, and parents often have a much bigger role in their teen's care, so it can be a big adjustment to change practices.

 13 – PREPARING FOR TRANSITION

 It's important for all of us as health care professionals, whether we're in a pediatric or family medicine setting, to do what we can to support adolescent patients and their families to prepare to move into adult-oriented care. The process on this slide shares some steps that we should keep in mind for all of our adolescent patients, including those with special health care needs. As you review this process, how might this look different if the patient has a special health care need?

 Pause to allow a few participants to respond.

 The organization, *Got Transition*, has some great additional resources for health centers who want to work more on transition, and more in depth information is listed in the facilitator script.

**Application**  (3 minutes) 14 – STRATEGIES

 Now that we've covered some of the basics of providing patient-centered care to youth with special health care needs, it can be helpful to assess how well we're doing in providing that care.

Find a partner and review this list of strategies. Discuss which items you think you're already doing well and which items where you think you could improve.

 If time allows have participants share one item they're doing well and one item they thing they could improve on.

 15 – VOICES OF YOUTH WITH SPEICAL HEALTH CARE NEEDS

 As we wrap up our session today, let's take a moment to reflect on the voices of some youth with special health care needs. I'm going to show you a few more quotes. Again, I'll ask for a few volunteers to read the quotes out loud.

 Reveal the quotes one at a time. Ask audience members to read each one as it appears.

"I'm more than my illness"

"I've already been forced to grown up fast – listen to me."

"Inform ME on everything so I understand"

“We’re individuals”

“Our voices are powerful, even if we’re not fully grown adults”

“We appreciate the work you’re doing and we are so grateful.”

 16 – THANK YOU!

 To keep this conversation going over the next month, I will share Sparklers, or small posters, that relate to this topic. I’ll post the Sparklers around the office in places that you all can easily see them. Thank you for your participation!