

# HCT BARRIERS WITH YSC INPUT

## Barriers to Health Care Transition

Health care transition is the process of getting ready for health care as an adult.

Part of health care transition is learning to take care of your own health. Some parts of health care transition can be tough. Below are some of the feelings young people have about health care transition, gathered from the Youth Steering Committee and academic journal articles.

1. I am nervous about being an adult.
2. My doctor only talks to my family and not to me.
  - Doctors are not educated about disability.
  - I am not included in discussions or planning with my doctor.
  - Doctors do not have the patience to listen to me.
  - There are no text communication options.
  - I am not respected as a person by my doctor. They only see my disability.
3. I do not have enough information about self-advocacy.
  - I am unprepared to advocate for my health.
  - I did not have information about patient advocates.
4. I have not had time alone with my doctor in order to self-advocate without my parent or caregiver.

5. I have not seen my pediatric doctor in a long time because I am too old.
6. My doctor's office is far away or hard to get to.
  - It can be expensive and inconvenient to transport to my doctor's office.
  - I do not know how to access public transportation to get to my doctor's office.
  - It is hard to make plans to get to my doctor's office because it takes a lot of executive functioning skills.
7. I am not ready to leave my pediatrician.
  - I feel my needs won't be met in adult care.
  - I am not ready for these changes. Change is disruptive.
  - I worry that my new adult doctor will not listen to me.
8. It is hard to find an adult doctor....
  - ...because I live in a rural area.
  - ...that is the right fit for me.
  - ...because there is not a good way to navigate lists of doctors.
  - ...because the information is not already organized in a way I can understand.
  - ...because I don't know where to look.
9. The transition process is hard when you have lots of doctors. There are so many portals to keep track of.

10. The transition process is hard because it is a lot of added work to my life and takes lots of extra time and energy.
11. No one explained how my health care would change when I become an adult.
  - Doctors should be trained and responsible for easing health care transition so they can explain these changes when I become an adult.
  - Doctors should prepare us for transition beforehand, so we are not pushed into it.
  - Doctors should prepare us before the visit, so we have time to look up information and ask questions during the visit.
  - Doctors should tell us their policy about the age we need to leave their practice.
12. There is not a clear age for when youth ends and when young adulthood starts.
13. Doctors should not assume parents or caregivers are responsible for explaining transition.
14. The young person should be heard correctly, in a nice and kind way.
15. I do not know how to ask or who to ask questions about health care transition to.
16. I do not feel comfortable asking a doctor about health care transition.

17. My doctor does not know or is not accepting of my cultural, identity, or language preferences.
  - The doctor may not be able to provide an ASL interpreter.
  - I feel like my doctor may not be culturally competent.
18. My doctor's office does not know how to handle my disabilities.
  - There are accessibility issues.
  - Doctors are not educated about disability.
  - Doctors need to support a patient according to the patient's disability, symptoms, and needs.
  - Doctors need to understand and accept that patients come from different situations and process information differently.
  - Doctors should not assume that patients know medical or technical terms and it is uncomfortable to ask them to explain.
  - Doctors who use cursive make it difficult to read medical summaries.
19. I do not know how to keep my insurance.
  - I cannot afford my own insurance or co-pay and have trouble budgeting for this.
  - I don't have a way to make insurance payments.
20. My adult doctor did not have my new health information.
  - We do not always know how to get our health information to the new adult doctor.

- I don't know how to contact my pediatrician to get this information. It can be especially hard if they don't have text communication options.
21. There can be challenges with telehealth such as difficulties accessing internet or a smartphone or time limits with virtual appointments.