



Easy Read Policy Brief: **Health Transitions**

What is this resource?

This is an Easy Read version of an ASAN policy brief called “The Transition to Adulthood for Youth with I/DD: A Review of Research, Policy and Next Steps.”



You can read the original brief at <http://autisticadvocacy.org/policy-advocacy/reports-and-brief-materials/the-transition-to-adulthood-for-youth-with-idd-a-review-of-research-policy-and-next-steps>.

A **policy brief** is a summary of a particular issue and the policy options that can deal with this issue. **Policy** means actions that the government can take, like passing a new law. Easy Read policy briefs are accessible summaries of the same information.



This policy brief is about [health care issues young people with disabilities face when they grow up](#). It will give you background information on the different parts of the issue. Then it will give recommendations for what should be done about the issue.

You will see some words in **bold** when you read this policy brief. These words are explained in more detail in the Glossary at the end of the policy brief [on page 37](#).

1. Introduction

- Transition is an important time for youth with special health care needs.

- This is because insurance changes.



- Health insurance is very important for youth with **special health care needs**.

- A person with special health care needs has a higher risk for long-term physical or mental health conditions. This means that they also need more health care services than other people usually would need.



- Many youth with special health care needs have a **developmental disability** (DD).¹
- Developmental disabilities are identified before the age of 22. Developmental disabilities will usually last through a person's lifetime.
- Autism, Down syndrome, and cerebral palsy are examples of developmental disabilities.



- Youth with developmental disabilities (DD) face challenges in keeping effective and active health care in adulthood.

- They have to make sure they get **health insurance**.



- Then they have to keep it. They can do this through public insurance programs such as **Medicaid**, or private insurance.



- They must manage their own health care.
- They must get health care fitting their age.

2. Background



Youth aging out of public aid and private health insurance must find other coverage.



- Most youth have **insurance coverage**.² Coverage is usually subject to age-related cutoffs.



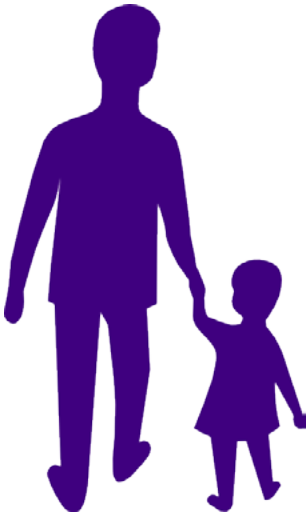
- Youth with health care coverage through parents must get their own coverage by the age of 26.³



- The **Children's Health Insurance Program** (CHIP)'s cutoff is age 19.⁴



- Medicaid's cutoff is age 18. This is unless they qualify for Medicaid as adults.⁵



- These issues have added to wide loss of insurance when youth reach adulthood.



- Youth of color and youth in rural areas who are in need of public health benefits may also be at risk of losing coverage.⁶



- Because most forms of coverage end at a certain age, lots of youth lose coverage.



- Lack of coverage leads to poor health outcomes.



The Affordable Care Act will help young adults with DD get continued insurance coverage.

2010



- **Patient Protection and Affordable Care Act of 2010 (ACA) passed.**

1. =
2. =

- ACA has rules about public and private insurance. This may smooth the transition to adulthood for youth with DD.

2014



- Adults with disabilities can buy health insurance through the state. This is even if their employers do not give health insurance.



- Youth with DD can get insurance despite their **pre-existing diagnoses**.



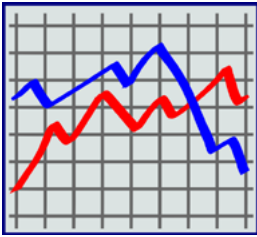
- The ACA also expands Medicaid coverage to childless adults with incomes below 133% of the **poverty line**.
- States can choose whether to offer coverage to these people. This is called **Medicaid expansion**.⁷



- In states that expand coverage, youth who had Medicaid coverage before may be able to keep some health coverage. This is even if they do not qualify for **SSI**, or have not finished applying for SSI.



- People whose disabilities prevent them from major life activities may qualify for Medicaid. This is even if they are not eligible for SSI.⁸
- Some examples of major life activities:
 - Bathing
 - Getting dressed
 - Feeding yourself
 - Moving from place to place



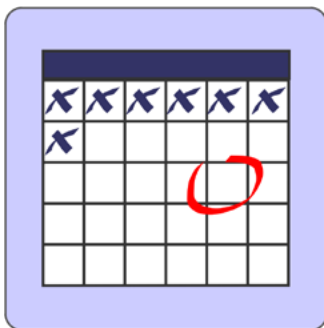
Increased rates of qualifying for coverage may not result in increased rates of coverage.



- Youth who rely on Medicaid need to plan for the future.



- Young adults who live in certain states may need to apply for SSI to receive Medicaid. These states may have rejected Medicaid expansion.



- Youth should begin preparing application materials before they turn 18. They may also need temporary coverage while their application is waiting.



- Young adults who are not qualified for Medicaid also need to plan for the future. They need to be aware of options. These options are statewide exchanges and Medicaid buy-in programs.



- States offer **exchanges** funded by federal money.
- **Medicaid buy-in** programs offer low cost Medicaid health services to people who work.



- Some youth can stay on their parents' insurance until they are 26. If these youth do not expect to work, they should apply for SSI before they turn 26.

Adults with DD must go to self-directed care.



- When youth go to adulthood, many think that they will begin managing their health care. As legal adults, they usually can make their own treatment decisions. They can enjoy privacy about their medical appointments and records.⁹ Youth with I/DD should have these same rights.



- Young adults with DD may need support to manage being in charge of their health care. Poor preparation for this may lead to unmet health care needs.



Stereotypes about DD are a barrier to young adults going to self-directed care.



- Many people believe that youth and young adults with DD cannot make their own decisions.



- This can happen when the young adult needs support from family members to manage their health care.¹⁰



- Other difficulties may come from adult-based doctors' failure to give supports.

Youth may need preparation or help to do many things. These include:



- scheduling their own medical appointments



- filling prescriptions



- having one-on-one conversations with medical providers



- and giving information about their medical histories.¹¹

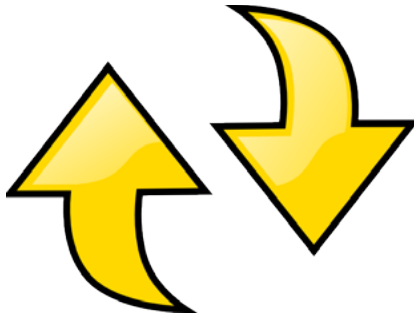


- Doctors may not want to work with adult patients as much. This is even if it is to decide how the adult patients' support networks can help them meet their needs.¹²



- Stereotypes can lead to bad health outcomes for young adults. This is especially true for those with special health care needs.¹³

Adults with DD have changing health care needs.



- Youth have changing needs as they reach adulthood. Youth with DD are no exception. They must go from child-focused doctors to **adult-based doctors**.¹⁴



- Youth with DD and other special health care needs may have a hard time finding adult-based doctors.



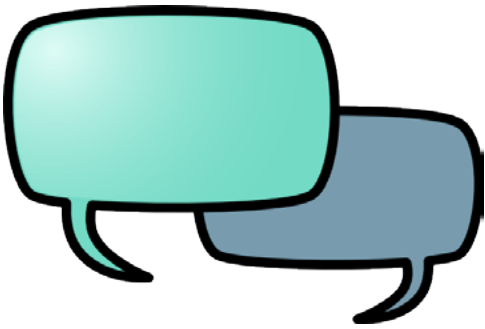
- Assuming an adult with DD is incapable may prevent treatment for adult health issues.



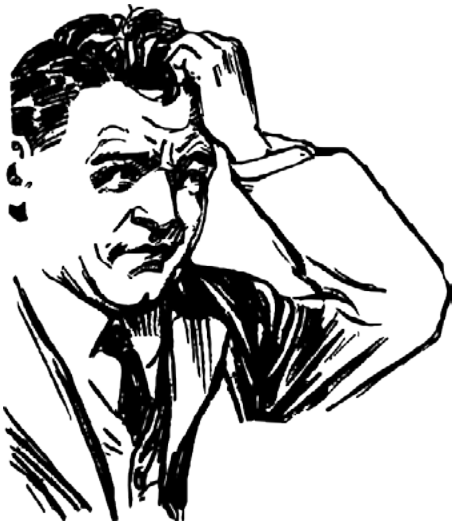
- For example, some doctors do not want to discuss sexual health.¹⁵



- Youth with disabilities may also not want to leave their familiar child doctors.



- Communication between the old doctor and new doctor is important.



- Adult-based doctors often have difficulty caring for young adults.

Youth with DD need health care transition support services to go to adulthood.

- Health care transition services help to make sure youth:



- keep access to health care,



- can take control of their own care as adults,

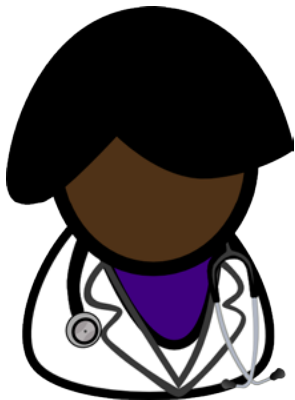


- and transition well to adult providers.

Necessary elements of transition support services



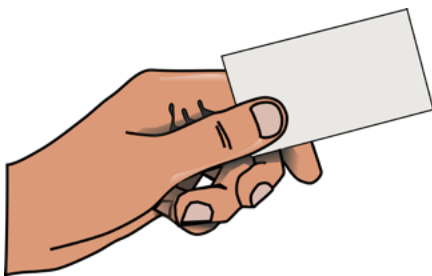
- Transition services should touch on a range of topics. At the least, health providers should discuss:



- going to an adult main doctor (or, in the case of a family doctor, an adult model of care);



- changes in the person's health care needs as an adult;



- making sure of health insurance coverage as an adult; and



- using **self-directed care** as the individual reaches adulthood.¹⁶



- Other important topics are continuing education, employment, and independent living needs.¹⁷

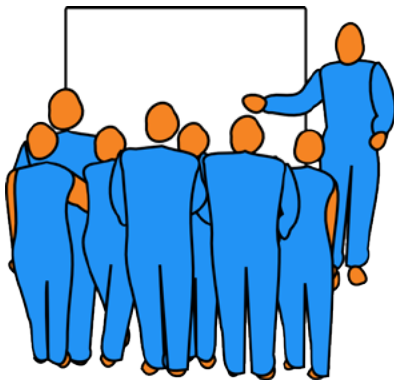


- Planning for transition should start when the youth is 12. There should be more intense planning every year. Make sure planning is happening by the time someone is 14.¹⁸

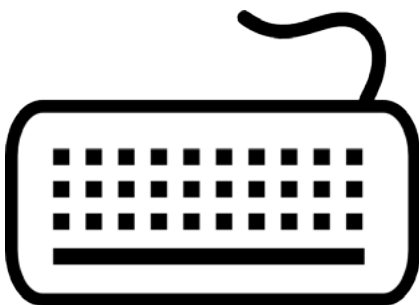
- Transition team should make a **“portable medical summary.”**¹⁹ This includes:



- emergency treatment plans

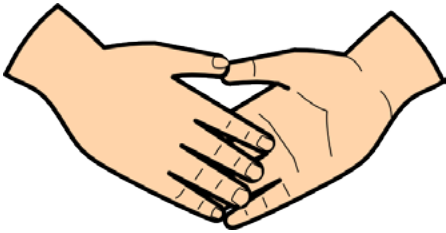


- the patient’s health education history

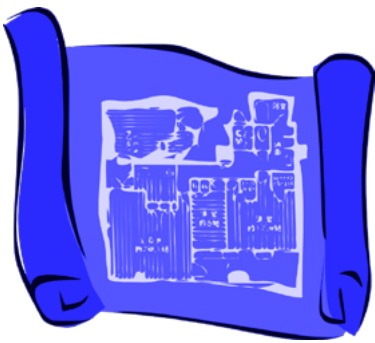


- the patient’s preferred method of communication and other needs.²⁰

Most youth with DD lack good transition support services



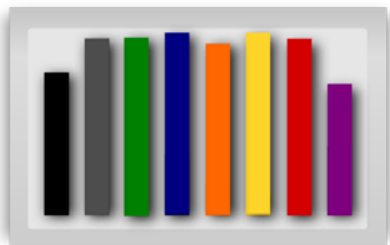
- Youth with special health care needs may need preparation and support to keep insurance.



- A study found that only 40% of youth with special health care needs had good support for health care transition.²¹

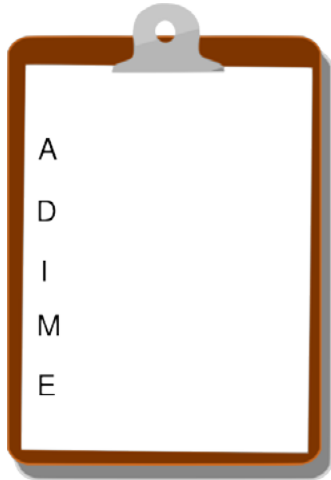


- Few youth with special health care needs had a discussion with a doctor about keeping insurance. Few discussed going to an adult provider.²²



- Efforts over the past several years have resulted in few increases in the amount of youth with special health care needs who are getting good transition support services.²³

The “medical home” model increases access to detailed transition support services

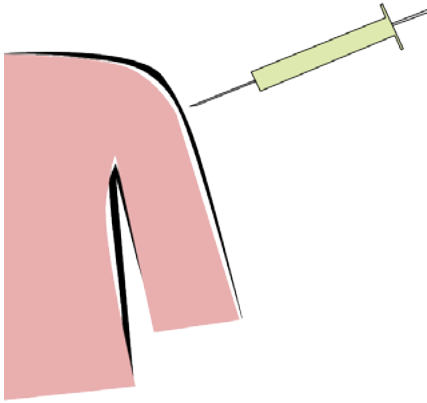


- The medical home is not a physical location at which health care services come. It is a health care model.



- The model involves a personal doctor who leads a team of providers.²⁴

- The medical home model must include three things:



1. preventive care,



2. sudden illness management,

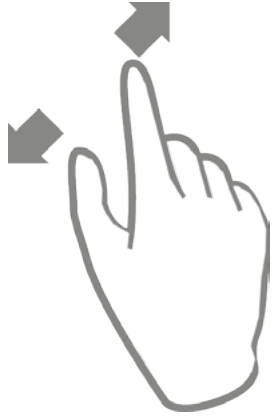


3. and chronic condition management.²⁵



- Youth who receive care through medical homes are more likely to receive transition services.²⁶

3. Recommendations



1. Expand funding for medical “homes” and transition services.



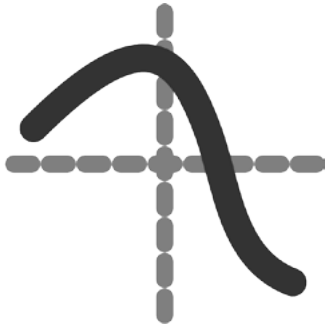
- Evidence shows that the medical home model increases access to planning for youth.



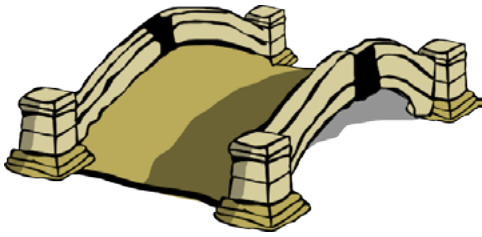
- Youth covered by Medicaid need transition support. They are less likely to get this support.



- We recommend that more states include refunds for “health home” services.



2. States must expand Medicaid to adults with incomes below 133% of the Federal Poverty Line.

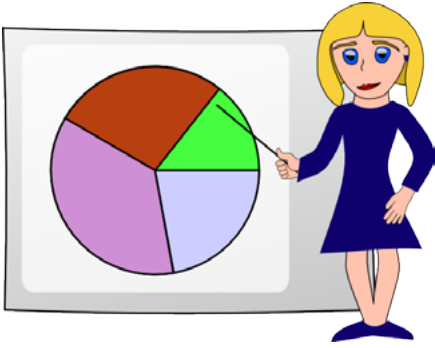


- Expanding Medicaid will reduce youth with DD having gaps in or loss of coverage.



- This will help people whose disability prevents them from taking part in activities of daily life.

3. Increase education on transition planning.



- Parents and doctors often do not know the importance of transition planning.



- A barrier for young adults with I/DD is the belief that they cannot go to self-directed care.



- Education for parents and doctors should focus on the importance of going to an adult model of care.

- Efforts should also focus on groups of youth with I/DD who have more risk for not getting services. This includes:



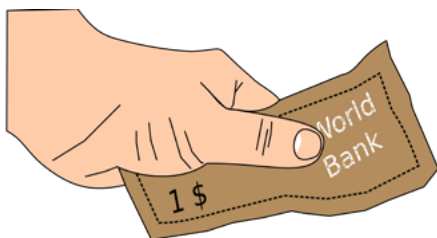
- youth with behavioral disabilities,



- youth of color,



- youth who live in homes in which English is not the primary language,

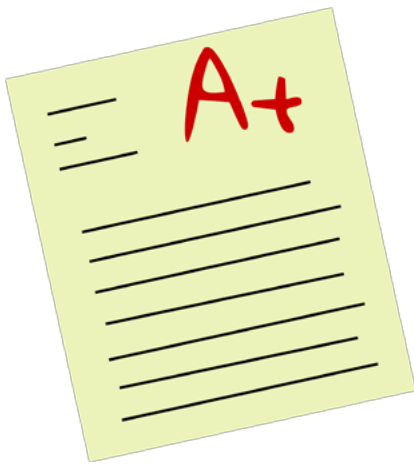


- and low-income youth.²⁷



4. Further research on outcomes of transition support programs

Outcome-focused research



- Research should focus on the outcomes of services. Research has only focused on how many people are getting services.

Research on the needs of youth and young adults with I/DD



- Much of the research on transition supports has focused on people with special health care needs as a whole.²⁸



- Youth with I/DD may have unique needs. These needs include accommodations, preparation, and support.



- Research must occur to find the best ways of supporting these youth as they reach adulthood.

Research on the experiences of youth and young adults with I/DD



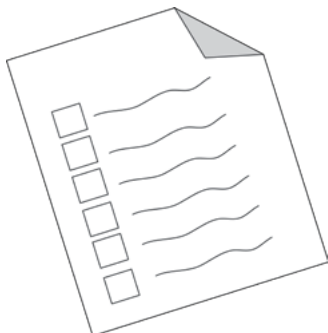
- Studies have focused on reports by parents. This is rather than the youths and young adults themselves.²⁹ Many of these studies use data from the National Survey on Children with Special Health Care Needs. (NS-CSHCN)



- They collect data only from parents and caregivers.³⁰

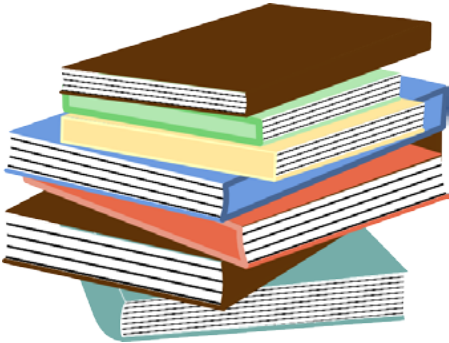


- Youth and young adults have their own views.



- The NS-CSHCN should include youth and adults with special health care needs in surveys.

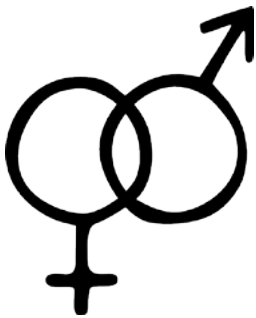
Research on more transition support services, including nutritional and sexual health



- There is a need for increased research on certain transition services. These include:



- advanced care planning,



- sexual health counseling,



- and nutritional counseling.

- Many parents have reported a need for such services.³¹

Research on health care transition support through non-medical providers



- There is not enough research on transition support from non-medical groups.



- Places like public schools should include health care in transition plans.



- A high school student may be getting transition support from a doctor. They should work with the student's Individualized Education Plan team.

The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that every sale, purchase, and payment must be properly documented to ensure the integrity of the financial statements. This includes recording the date, amount, and purpose of each transaction.

The second part of the document provides a detailed breakdown of the company's revenue streams. It identifies the primary sources of income and analyzes their contribution to the overall financial performance. This section also includes a comparison of current revenue trends with historical data to identify any significant changes or patterns.

The third part of the document focuses on the company's operating expenses. It details the various costs incurred in the course of business operations, such as salaries, rent, utilities, and marketing. This analysis helps in understanding the efficiency of the company's cost management and identifies areas for potential savings.

The fourth part of the document discusses the company's financial position and liquidity. It examines the balance sheet and cash flow statement to assess the company's ability to meet its short-term obligations and fund its long-term growth. This section also includes a discussion of the company's debt levels and its overall financial health.

The fifth and final part of the document provides a summary of the key findings and conclusions. It highlights the strengths and weaknesses of the company's financial performance and offers recommendations for future improvement. This section is crucial for providing a clear and concise overview of the company's financial status to stakeholders.

Glossary

Glossary



Adult-based doctor

Adult-based doctors treat adult patients. Children and adolescents may go to a pediatrician, which is a doctor that specializes in treating younger patients.

Affordable Care Act (ACA)

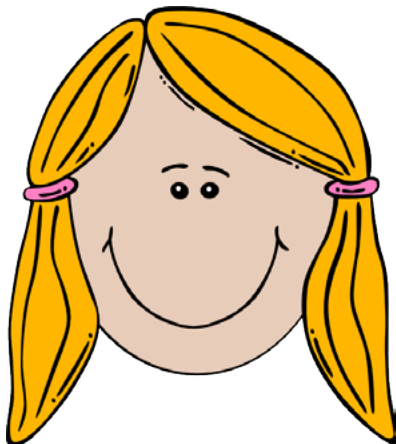
see Patient Protection and Affordable Care Act (PPACA)

Benefits

see Insurance benefits

Buy-in program

see Medicaid buy-in program



Children's Health Insurance Program (CHIP)

CHIP is a government program that provides insurance coverage for people under age 19 who do not qualify for Medicaid but who also cannot afford to buy insurance from a private company.



Chronic condition

A chronic condition is a health condition that is long-lasting. Long-lasting usually means that it lasts for more than three months at a time. Diabetes, asthma, and depression are examples of chronic conditions.

Coverage

see *Insurance coverage*



Developmental disability

Developmental disabilities are identified before the age of 22. Developmental disabilities will usually last through a person's lifetime. Autism, Down syndrome, and cerebral palsy are examples of developmental disabilities.

Exchange

see *Health care exchange*

Federal poverty line



- The federal poverty line or federal poverty level (FPL) is a set amount of money that a family needs to buy food, clothes, housing, and other important things during the year.
- It is the lowest amount of money that is needed to buy these things.
- For example, in 2015 the FPL for a two-person family is \$15,930. That means if you live with another person, when you add up how much money you both make, if it is more than \$15,930 you are above the FPL.
- The FPL is used to decide if you are able to get certain benefits from government programs.
- Usually government programs are for people making less than the FPL.



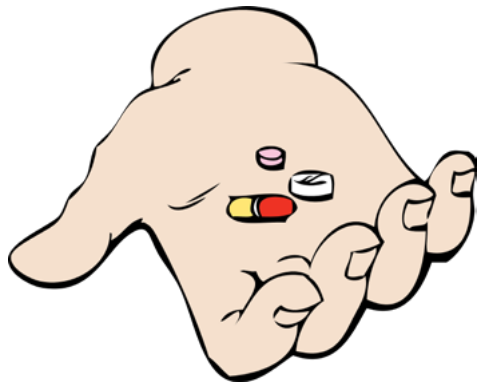
Health care exchange

- The exchange is a government website of insurance plans with different levels of coverage.
- People without health care coverage can get health insurance from the exchange.
- The health care exchange makes it easy to compare different insurance plans.



Health insurance

- Health insurance is a system that pays for some or all the cost of medical services that a person might need to use.
- You pay a certain amount of money regularly to have insurance. This is called an insurance premium.
- You pay for insurance even if you don't know when you might need it.
- If you have insurance, many medications and medical services are much cheaper than if you were paying the full price.



Insurance benefits

Benefits are what kind of protection you get from your insurance. Free visits to a doctor's office or cheaper medicines are examples of insurance benefits.



Insurance coverage

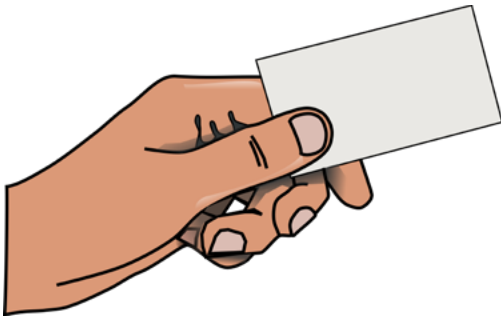
Insurance coverage is the total amount and type of insurance that somebody has. Some insurance might only give you coverage for some medicines or services, but not others. It might pay for the whole cost of a medicine or service, or just pay for part of it.



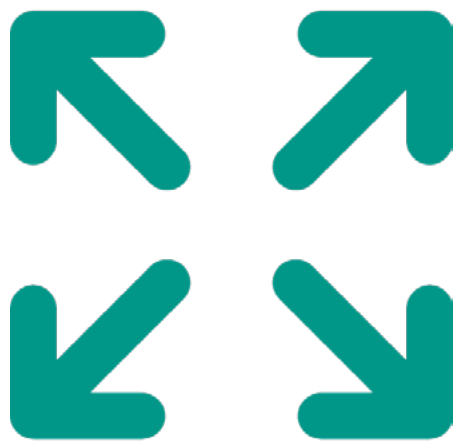
Medicaid buy-in program

- Medicaid buy-in provides Medicaid insurance coverage to people with disabilities who work. This is important because some people who work will end up earning too much money to still qualify for Medicaid.
- Medicaid buy-in programs let working disabled people keep their Medicaid insurance even if they earn more money than the limit.

Medicaid



Medicaid is a government program that provides health insurance to low-income people. There are limits to how much money you can make to be able to get Medicaid benefits.



Medicaid expansion

The Affordable Care Act (ACA) gives states more money to expand their Medicaid programs. If states choose to expand Medicaid, their Medicaid programs will cover adults without children who have an income up to 133% of the federal poverty line.

Medical home

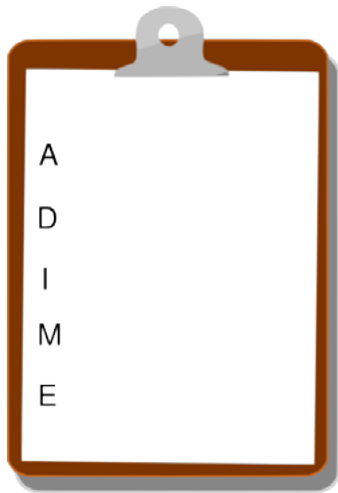


The medical home is a way of organizing health care. A health care provider leads a team of other specialists who work together to provide complete health care to a patient.



Patient Protection and Affordable Care Act (PPACA)

The PPACA is also known as the Affordable Care Act (ACA) or Obamacare. It is a law that President Obama signed in 2010. This law will make health care insurance cheaper and easier to get for more people.



Portable medical summary

A portable medical summary is a document with all of the important health information about a person. "Portable" means it is easy to bring this information to a new doctor, since it is all in one place.

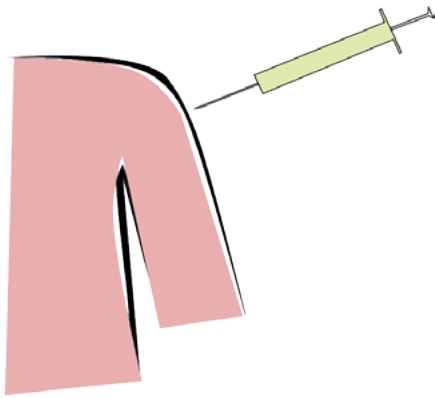
Poverty line

see Federal poverty line



Pre-existing diagnoses

A pre-existing diagnosis is also known as a pre-existing condition. This is a term used by insurance companies. A pre-existing condition is any health condition that a person had and knew about before getting a new insurance plan.



Preventive care

Preventive care is health care that you get when you're healthy to keep you from getting sick. Regular check-ups and getting shots are examples of preventive care.



Self-directed care

Self-directed care means that the patient getting health care services can make decisions about their health care. They can take direct control of managing their care.



Special health care needs

A person with special health care needs has a higher risk for long-term physical or mental health conditions. This means that they also need more health care services than other people usually would need.



SSI

SSI stands for Supplemental Security Income. It is a government program that gives money to low-income adults and children with disabilities. You have to apply for this program.

Endnotes

1. McManus, et al., 2013.
2. Id. Among young adults as a whole, according to the 2009 Commonwealth Survey of young adults, of 61% of all young adults were insured through their parents' employer during high school, 10% were insured through Medicaid, and 5% were insured through individual insurance plans which may have included plans obtained through CHIP. Collins & Nicholson, 2010, p. 19 Table 1.
3. PPACA, sec. 2714, 42 U.S.C. § 300gg-14; Collins & Nicholson, 2010.
4. Gleason, et al., 2009; Collins & Nicholson, 2010.
5. Gleason, et al., 2009; Collins & Nicholson, 2010.
6. Pullman, Heflinger, & Mayberry, 2010; Lotstein, et al., 2010.
7. National Federation of Independent Business v. Sebelius, 567 U.S. ___, 132 S. Ct. 2566 (2012).
8. Final Rule: Medicaid Program; State Flexibility for Medicaid Benefit Packages, 2010 ("Exempt Individuals," (§ 440.315)); National Council for Community Behavioral Healthcare, 2010.

9. American Academy of Pediatrics, et al., 2011.
10. Reiss, Gibson, & Walker, 2005.
11. American Academy of Pediatrics, et al., 2011.
12. Osgood, Foster, & Courtney, 2010; Reiss, Gibson, & Walker, 2005, pp. 27-28.
13. Cheak-Zamora, et al., 2013, p. 116
14. Id.; Gleason, et al., 2009.
15. Osgood, Foster, & Courtney, 2010.
16. Cheak-Zamora, et al., 2013; U.S. Dep't of Health and Human Services, 2007; American Academy of Pediatrics, et al.,
17. American Academy of Pediatrics, et al., 2011.
18. Cheak-Zamora, et al., 2013, p. 451.
19. American Academy of Pediatrics, et al., 2011, p. 291
20. Id.
21. Cheak-Zamora, et al., 2013; Maternal and Child Health Bureau, Data Resource Center for Child & Adolescent Health, 2011; McManus, et al., 2013.
22. McManus, et al., 2013.

23. Maternal and Child Health Bureau, Data Resource Center for Child & Adolescent Health, 2011; Cheak-Zamora, et al., 2013; McManus, et al., 2013; American Academy of Pediatrics, et al., 2011.
24. Gleason, et al., 2009.
25. American Academy of Pediatrics, et al., 2011.
26. McManus, et al., 2013.
27. Id.
28. McManus, et al., 2013; American Academy of Pediatrics, et al., 2011; Lotstein, et al., 2008.
29. Cheak-Zamora, et al., 2013; McManus, et al., 2013; Woodward, Swigonski, & Ciccarelli, 2011.
30. McManus, et al., 2013.
31. Woodward, Swigonski, & Ciccarelli, 2011.
32. American Academy of Pediatrics, et al., 2011.

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