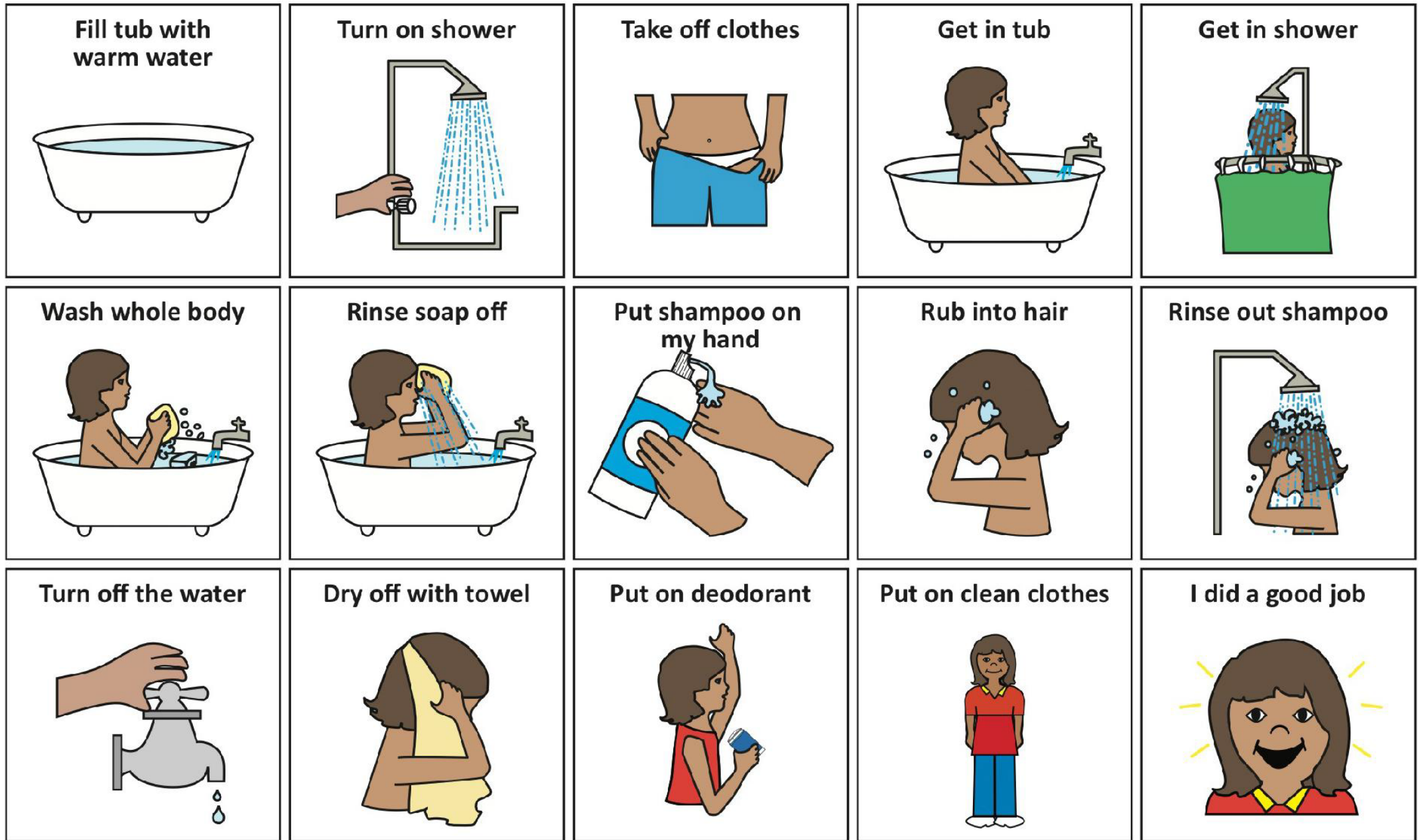


Transition to Adulthood

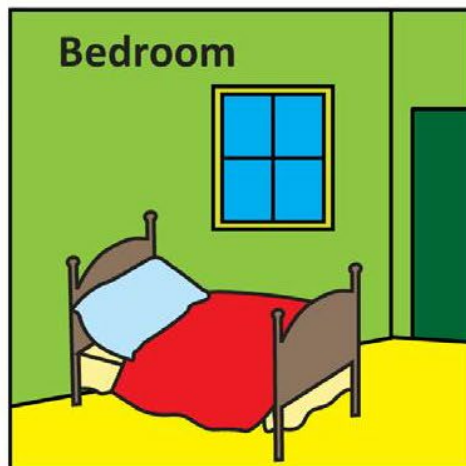
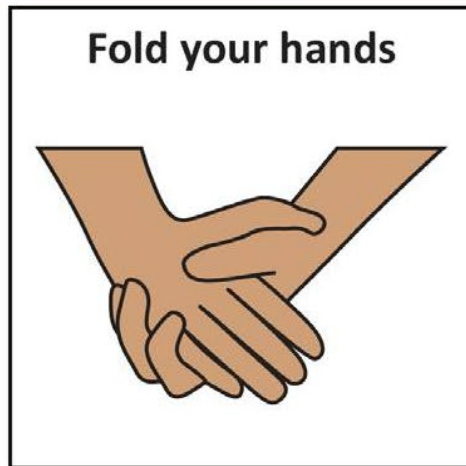
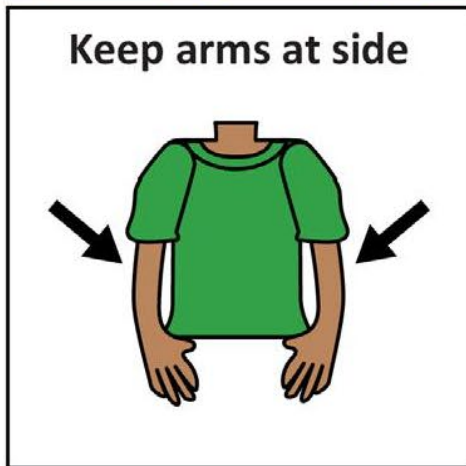
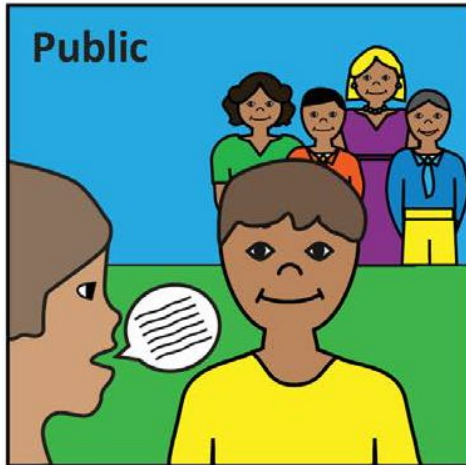


GROWING UP IS HARD

- Puberty and hormones
- Personal boundaries
- Sexual boundaries
- Hygiene
- Social demands
- Aggression
- Mental health



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**It helps to be
concrete... don't
assume that
families have
thought through
these steps.**

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BEGIN IN EARLY ADOLESCENCE

- Medical issues
- Educational issues
- Social issues
- Legal issues
- Documentation issues

Age 12 is not too early to begin these conversations, and goal is to have a rough plan in place by age 14.

ACCESS TO HEALTHCARE SURVEY

55-64%

of providers rarely/never give information related to transition and adult services

ACCESS TO HEALTHCARE SURVEY

73%

of providers rarely/never review legal changes with patients

ACCESS TO HEALTHCARE SURVEY

44-66%

of providers rarely/never share medical summary with patients

ACCESS TO HEALTHCARE SURVEY

74-90%

of providers rarely/never used standardized assessment tool with teen

ACCESS TO HEALTHCARE SURVEY

43%, 56%

of pediatric/adult providers (respectively) rarely/never
communicated with the next/last provider about transfer
of care

ACCESS TO HEALTHCARE SURVEY

~70%

of transition planning started around 16 or 17 years of age

SETTING UP GOALS

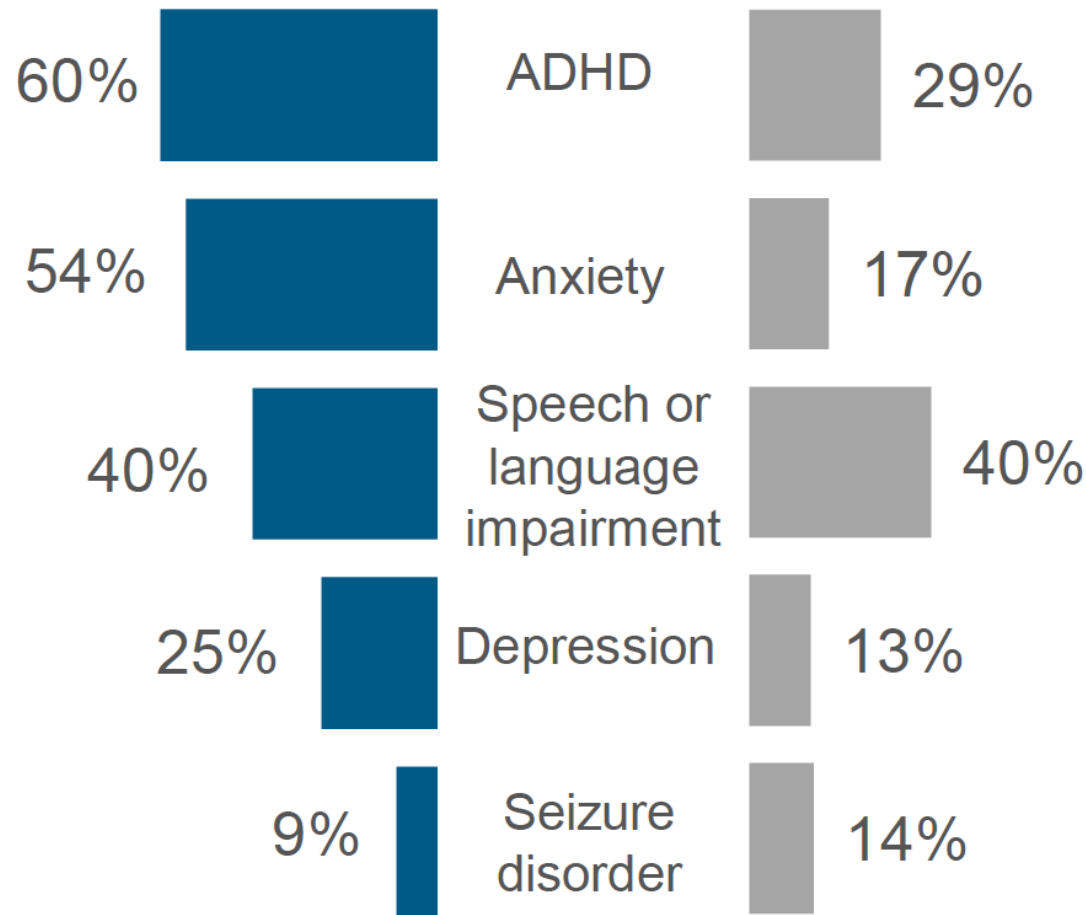
- Think about long and short term
- Start planning for this by age 14 years and think about increments of 2-3 years (ie 14 years, 16 years, 18 years, 21 years...)
- Involve all members of the team

THERAPIES AND TEAMS

- A primary care provider
- Social worker or care coordinator
 - Clinic
 - Department of health
 - DSPD, SSI, other health agencies
- Possibly a psychiatrist
- Therapy team ie ABA, OT, speech
- Family therapy
- CBT if appropriate
- School resources

Teens with ASD were more likely to be diagnosed by a health care professional with ADHD, anxiety, or depression than teens with ID.

NSCH 2016

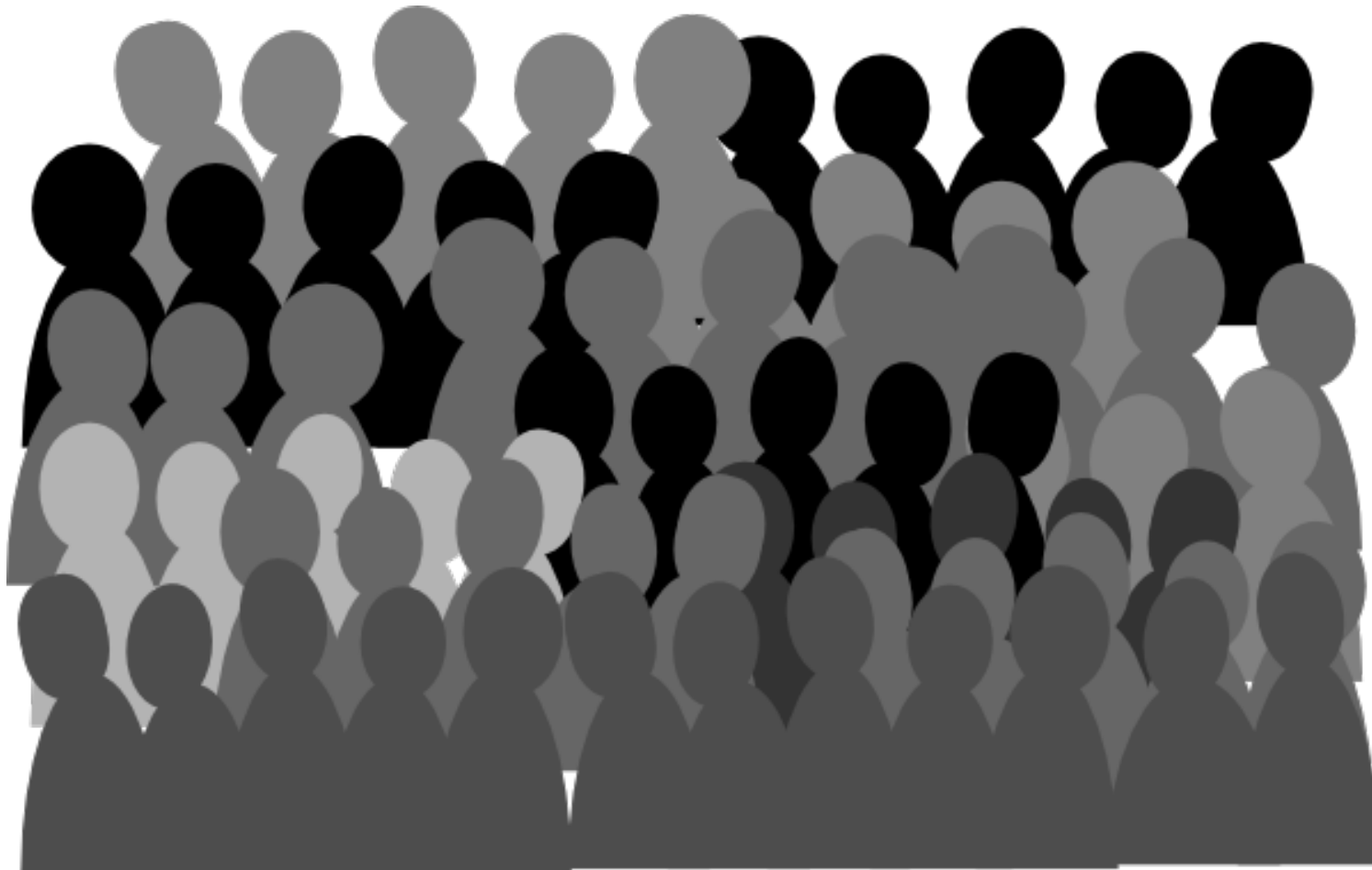


Source: National Survey of Children's Health 2016

MENTAL HEALTH TRANSITION

- Issues of insurance
- Can be difficult to find providers who meet with adolescents/adults with ASD
- Finding the right fit can be challenging when adult providers are not as familiar with ASD

TRANSITION TO ADULTHOOD



~72,800 youth with ASD turned 18 in 2018

~728,000 youth with ASD will enter adulthood in the next decade

2018 NATIONAL AUTISM INDICATORS REPORT High School Students on the Autism Spectrum



TOPICS/AREAS OF TRANSITION

- Self Advocacy
- Independent/Interdependent Living skills
- Legal matters
- Community living
- Employment
- Postsecondary
- Housing and residential
- Health
- Safety



The Services Cliff

Autism does not end when children reach adulthood. Most will continue to need some type of services or supports - even among those who are the most cognitively able. When special education services end, many do not qualify for adult services. Families often refer to this as “falling off a cliff” — referring to the dramatic decline in access to services during the transition to adulthood.

Our key findings:

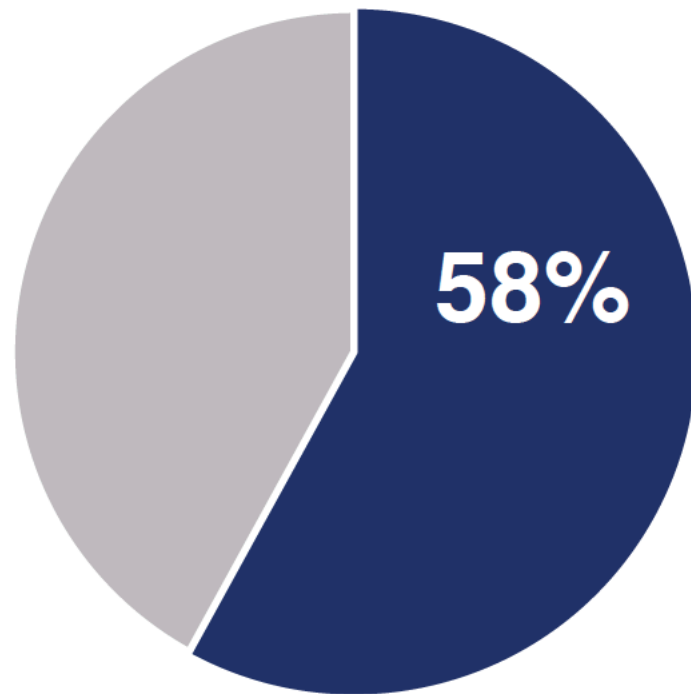
- During high school, over half of youth received speech-language therapy, occupational therapy, social work, case management, transportation and/or personal assistant services.
- However, receipt of these services decreased dramatically for youth between high school and their early 20s.
- **Approximately 26% of young adults on the autism spectrum received no services** – services which could help them become employed, continue their education, or live more independently.
- 28% of young adults who were not employed and also not attending higher education had no services.



TRANSITION PLANNING

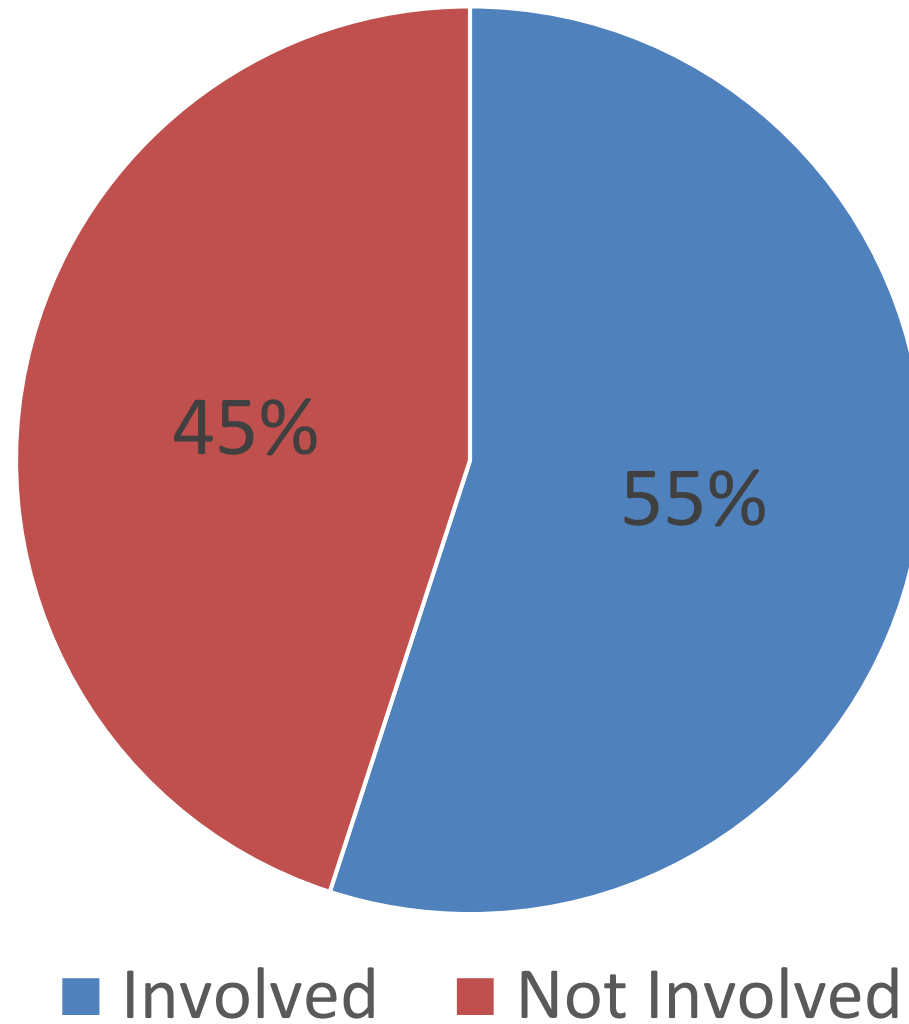


Federal law requires schools to have a transition plan for every special education student exiting high school.



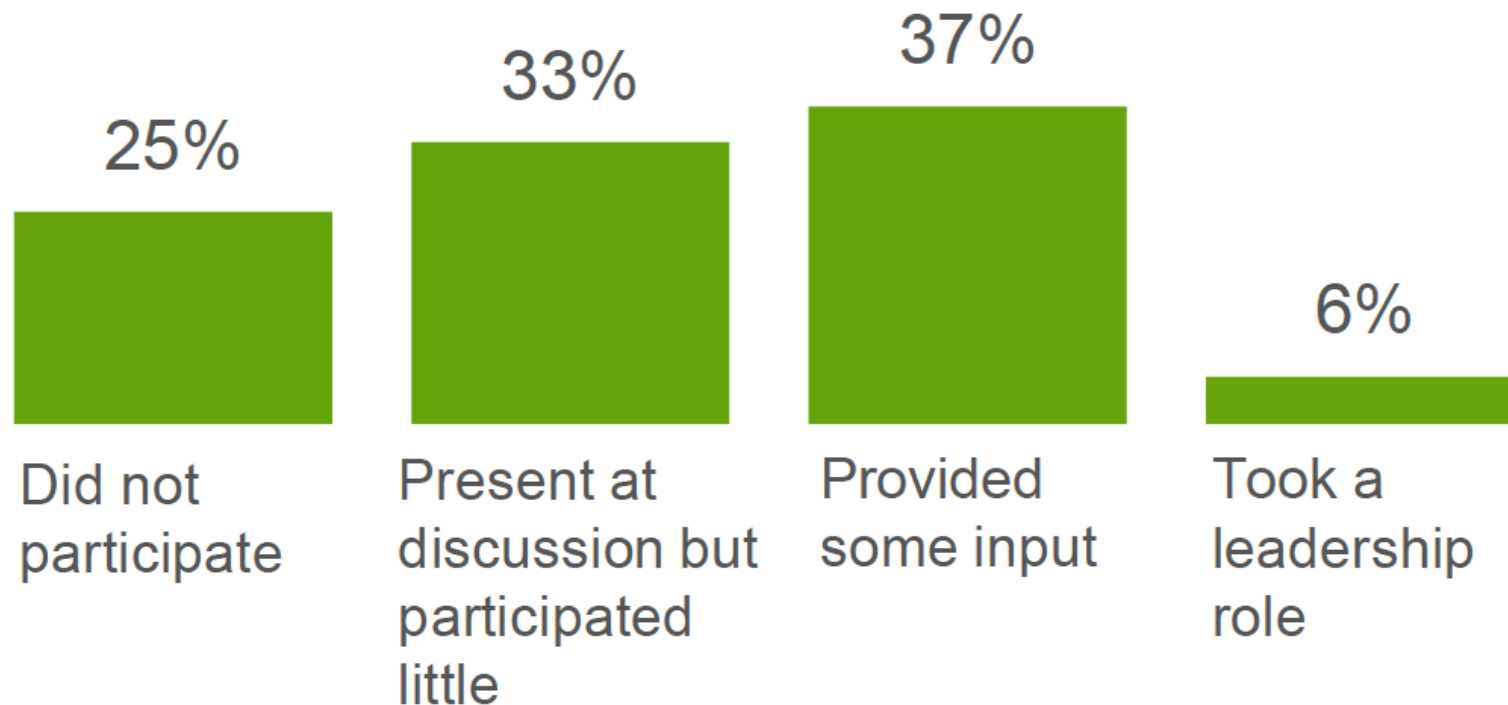
of youth with autism had a transition plan by the required age according to their teachers.

Parent Involvement in Transition Planning



One-quarter of teens with ASD ages 16-18 did not participate in transition planning.

NLTS-2012

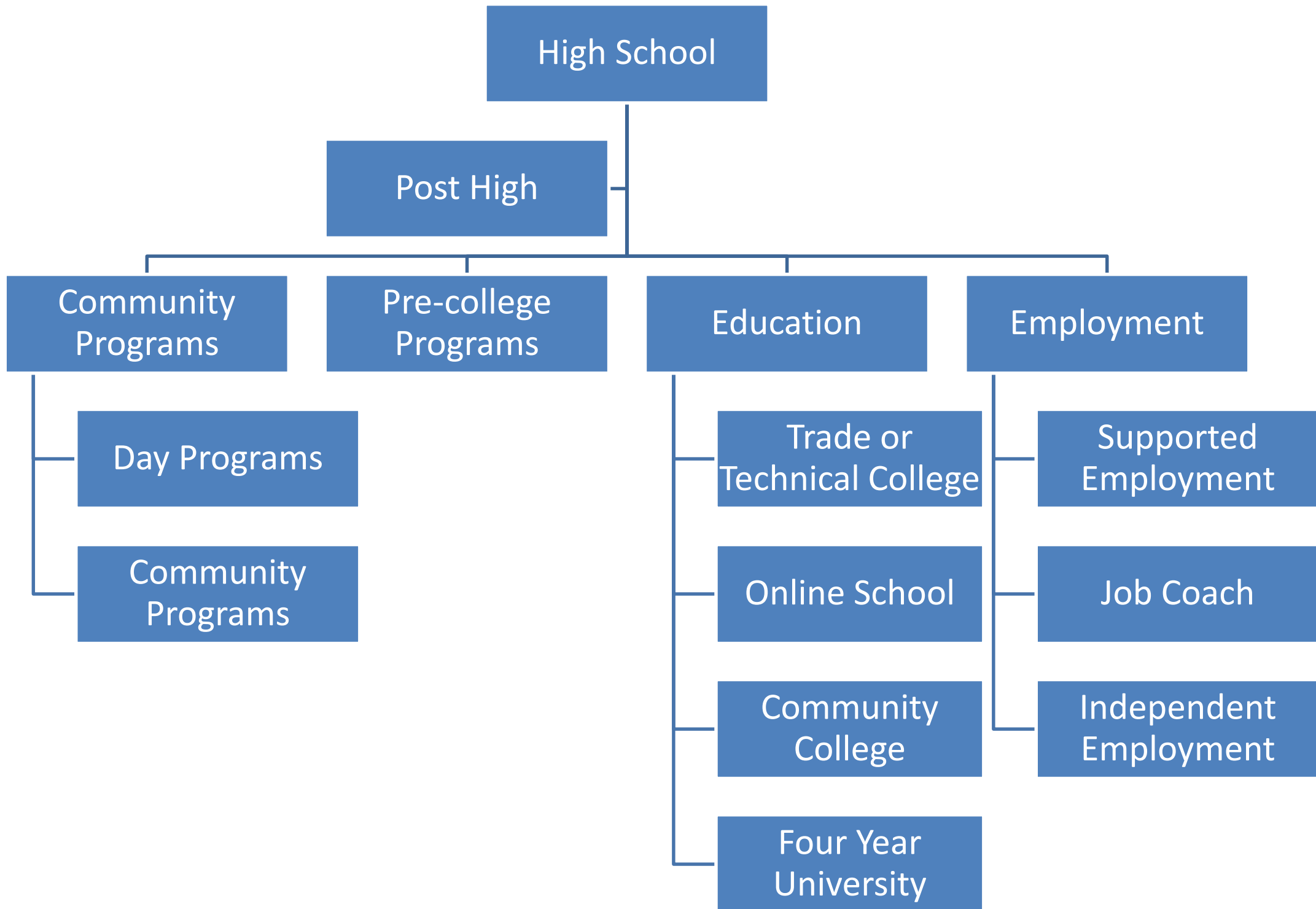


Source: National Longitudinal Transition Study-2012

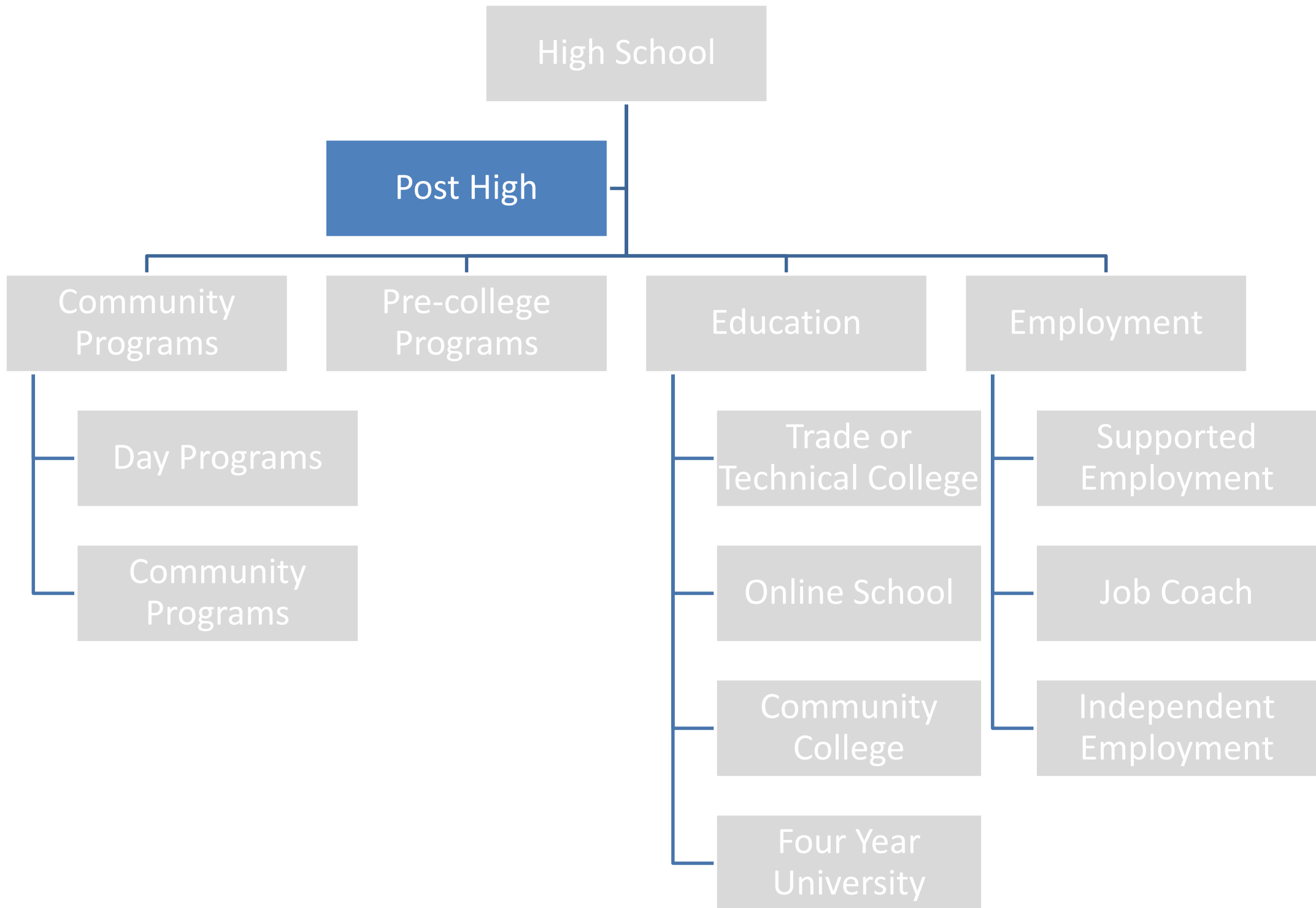
WHEN DOES TRANSITION PLANNING START?

ASAP

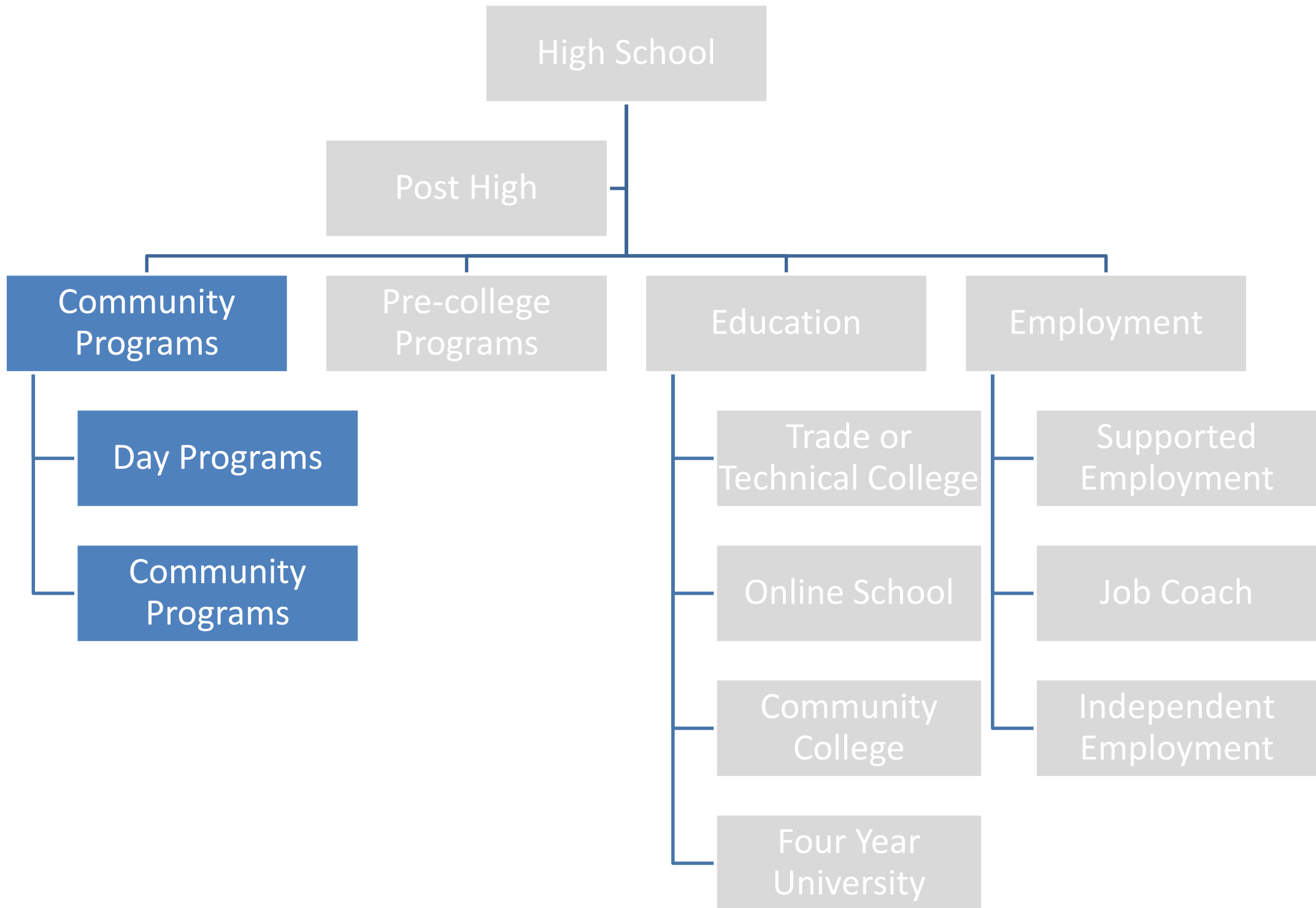




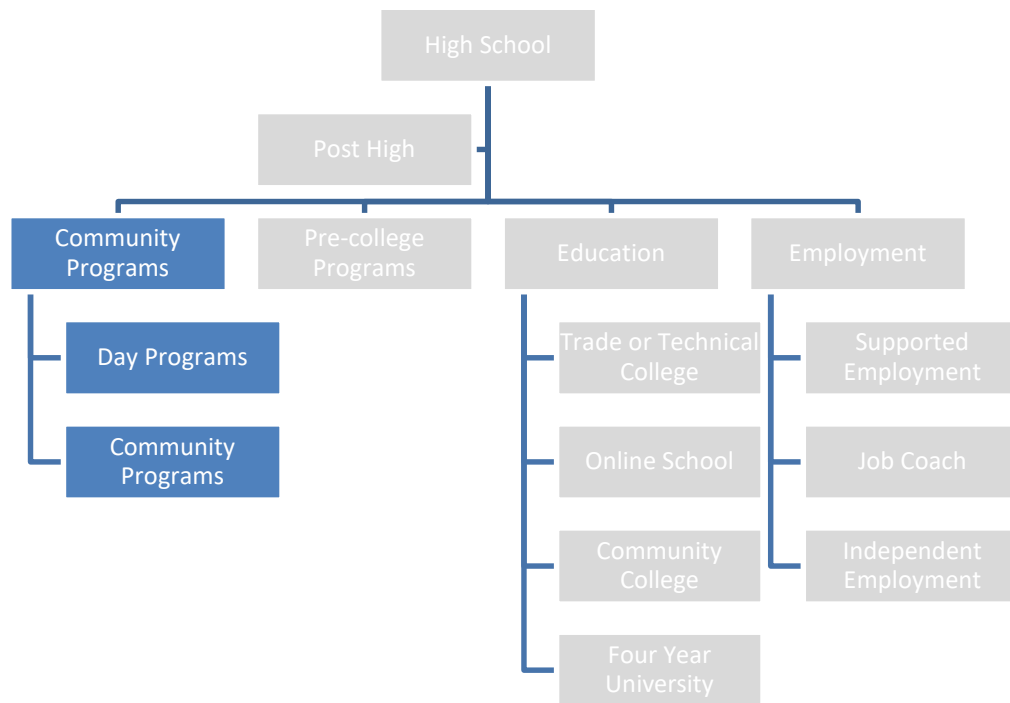
<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



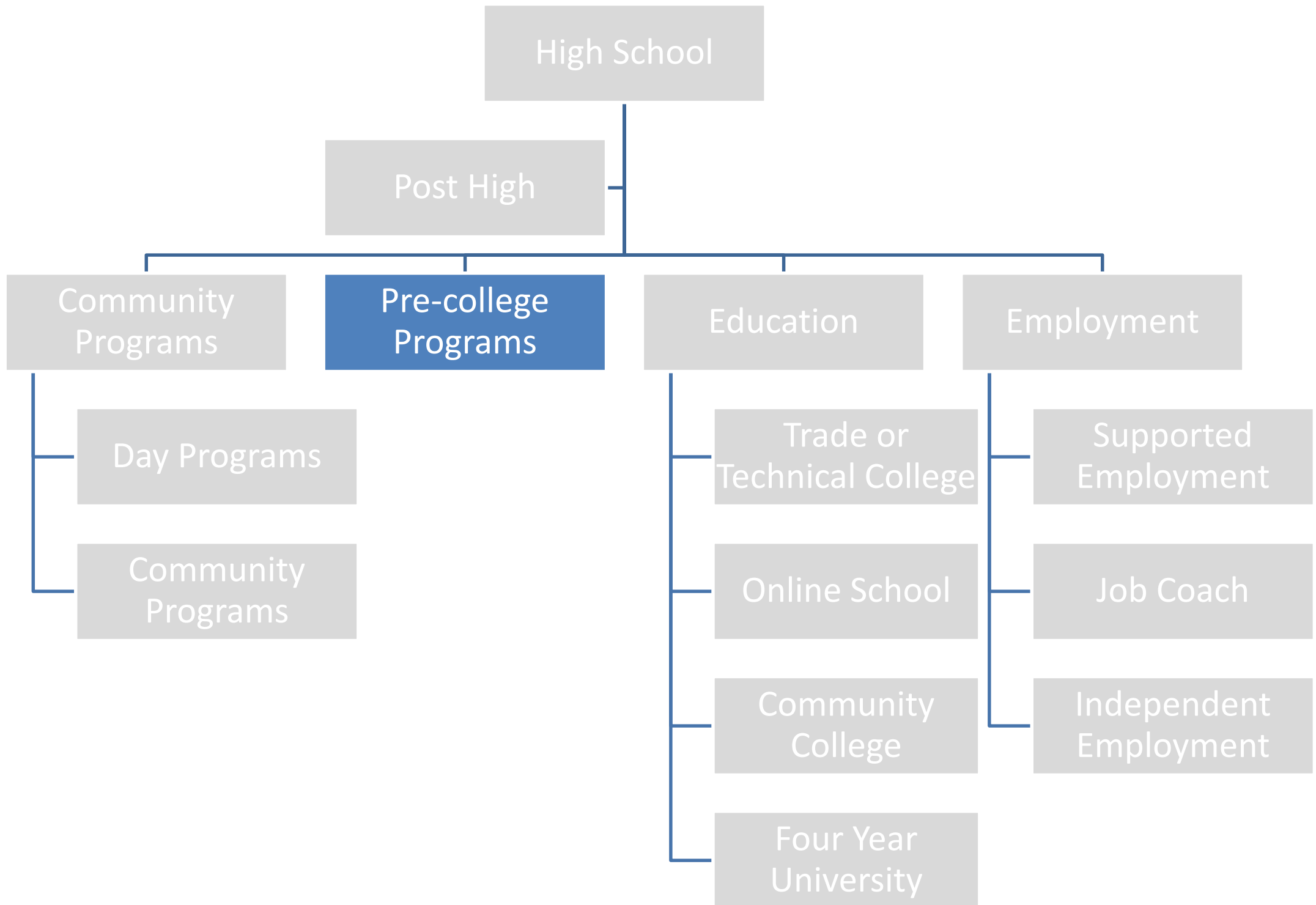
What: Day and independent living programs provide support in daily living by providing health and supportive services (e.g., physical therapy, speech therapy, medical supervision, etc.), as well as activities to engage in with peers. These tend to be for individuals who are significantly impacted by ASD and/or ID

How: Individuals tend to qualify if they have DSPD funding

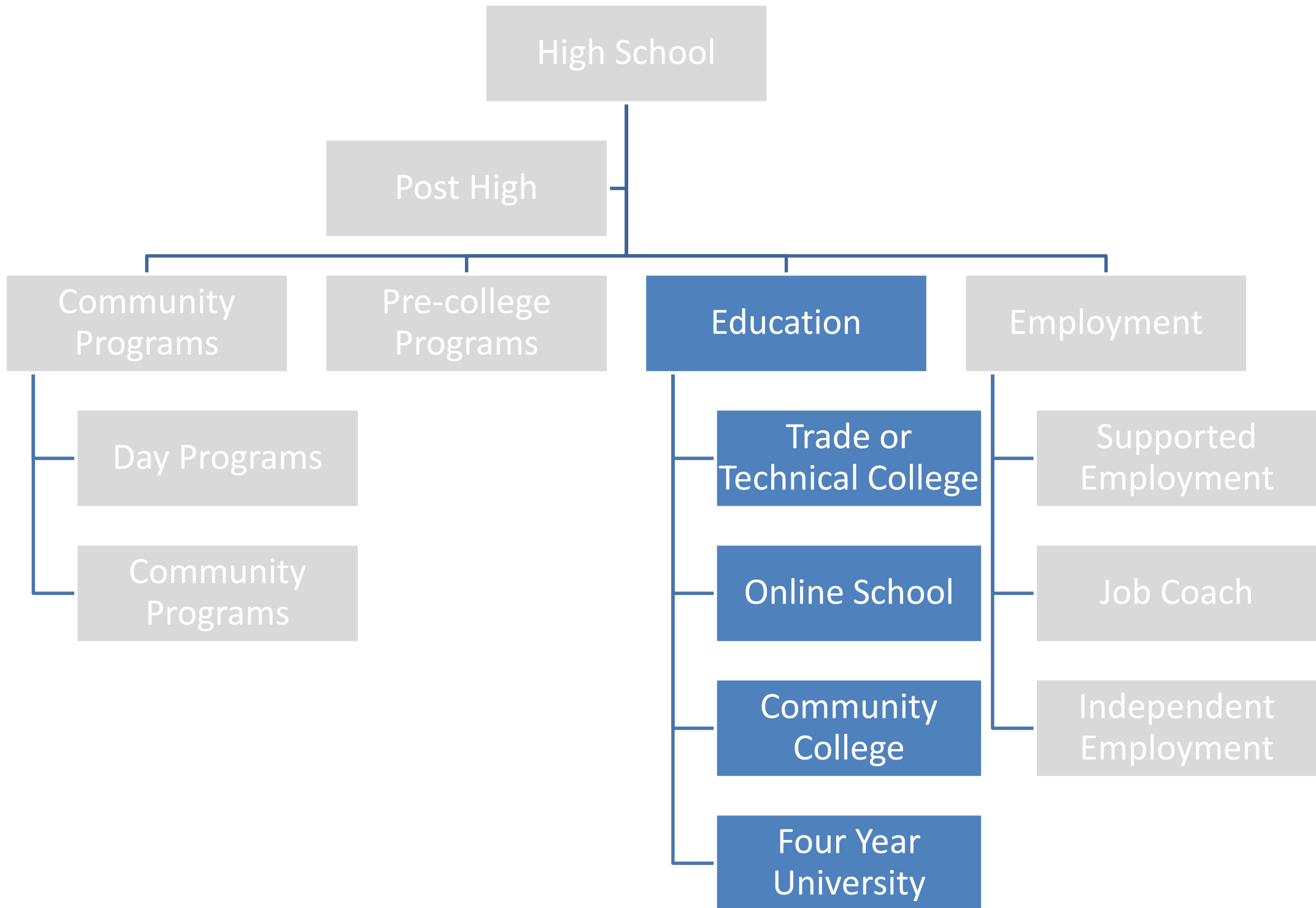
Strengths: Provide support and activities for adults with ASD who would otherwise be limited to their home environment without peers

Limitations: Highly dependent on funding and do not always provide opportunities for adults to work and earn a wage

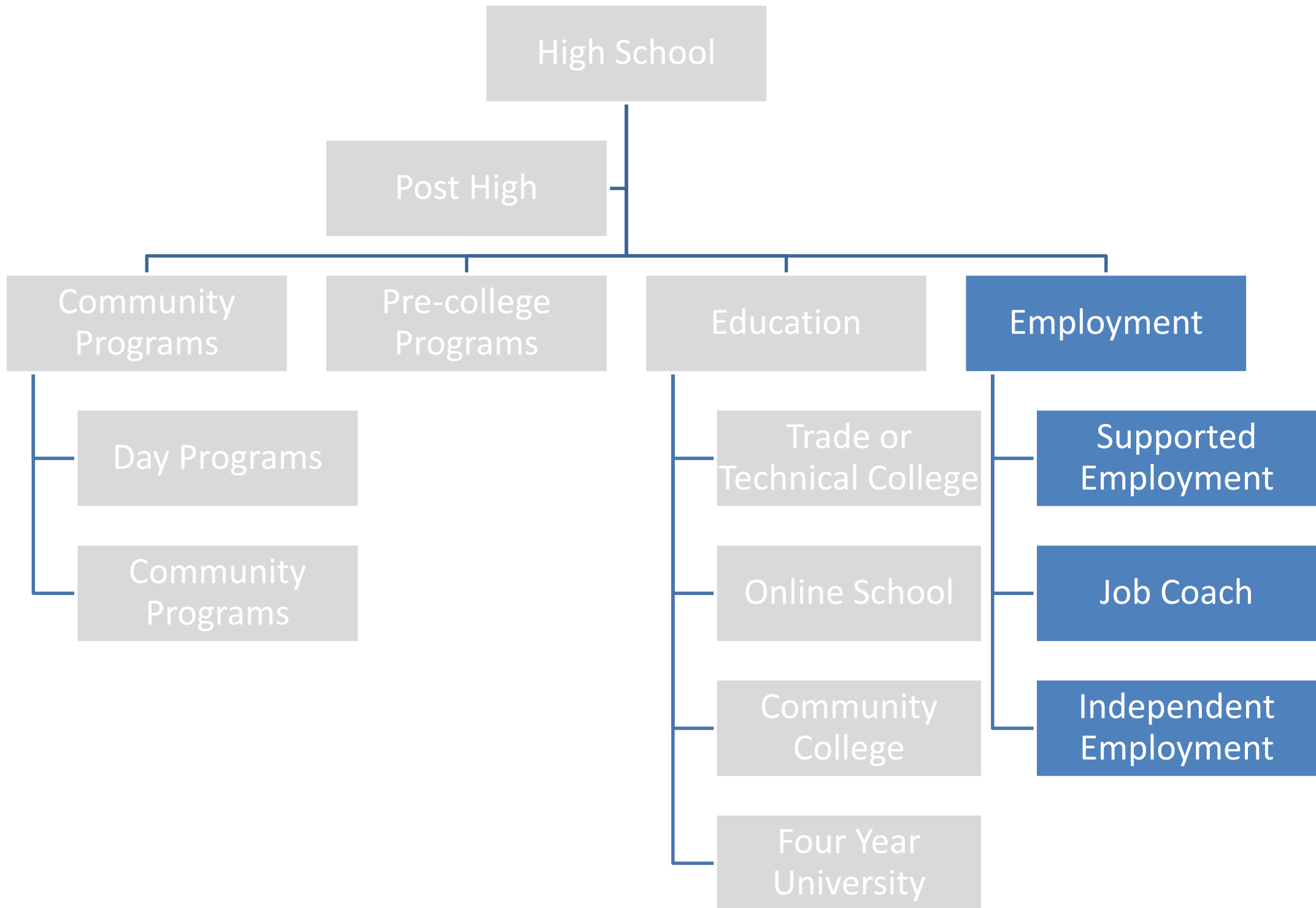
<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



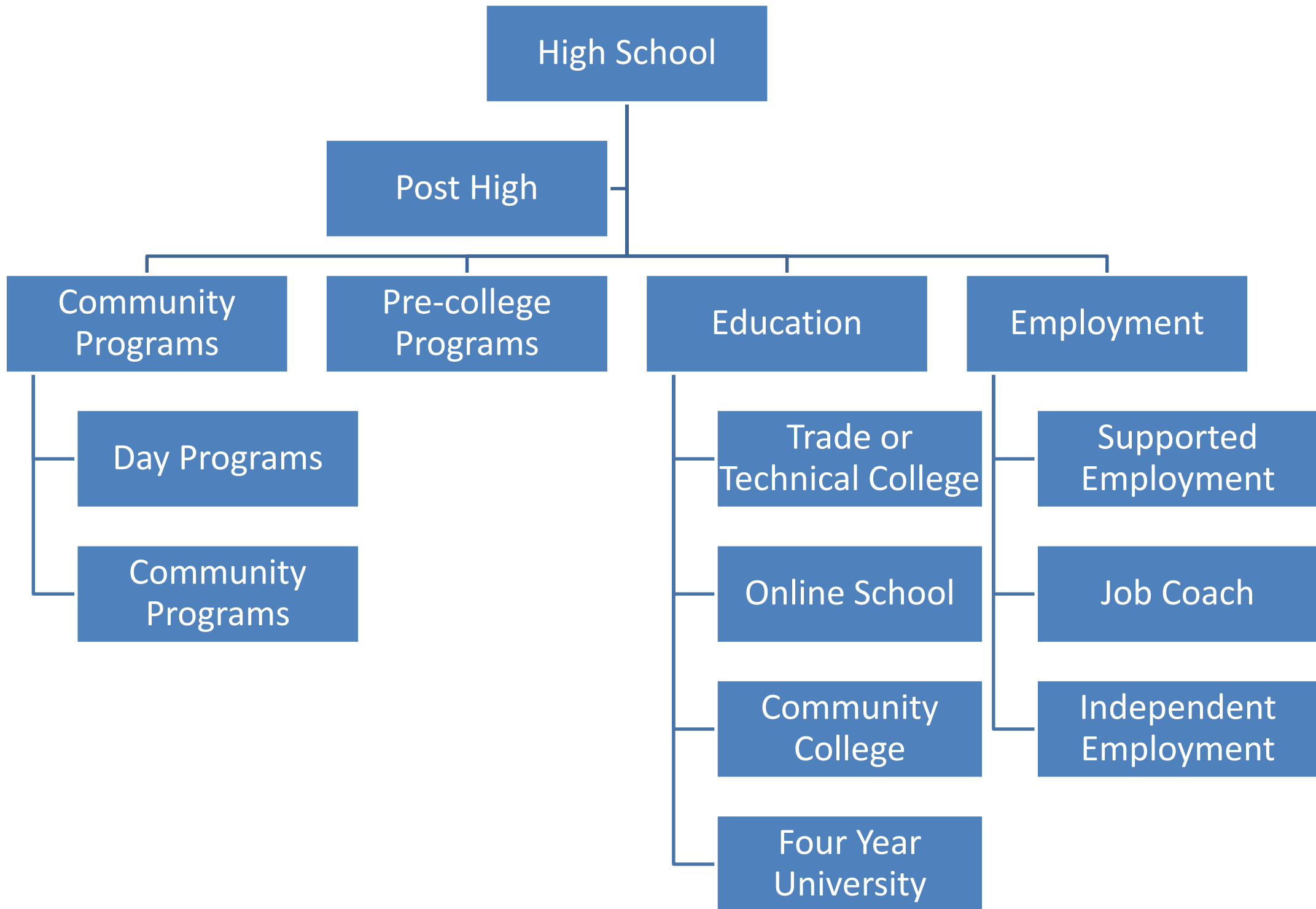
<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>



<https://www.carautismroadmap.org/education-after-high-school-what-are-the-options/>

WHAT IS NEEDED IN TRANSITION?

- Past assessment and educational records
- Updated Assessments
 - Referrals from medical or mental health providers
 - Many services require updated assessments to prove that the individual is still in need of services
 - Intellectual abilities, adaptive abilities, and measures confirming diagnosis of autism spectrum disorder

Note about assessments!

- Can be expensive if parents pay out of pocket
- School can complete necessary assessment measures before graduation
- Medicaid covers assessments but only until age 21

WHERE TO GET SERVICES

- Start with the school!
- Meet with a therapist (e.g., psychologist, LCSW, MFT, etc.)
- Access online toolkits and guides from established resources
Apply, re-apply, re-apply again
- Internet communities and resources
- Talk to other parents

www.utahparentcenter.org



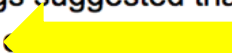
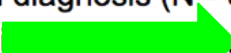


Sexual Orientation in Autism Spectrum Disorder.

George R¹, Stokes MA¹.

Author information

Abstract

Clinical impressions suggest a different sexual profile between individuals with and without Autism Spectrum Disorder (ASD). Little is presently known about the demographics of sexual orientation in ASD. Sexual Orientation was surveyed using the Sell Scale of Sexual Orientation in an international online sample of individuals with ASD (N = 309, M = 90, F = 219), aged (M = 32.30 years, SD = 11.93) and this was compared to sexual orientation of typically-developing individuals (N = 310, M = 84, F = 226), aged (M = 29.82 years, SD = 11.85). Findings suggested that sexual orientation was contingent on diagnosis (N = 570, $\chi^2_{(9)} = 104.05$, $P < 0.001$, $\phi = 0.43$). In the group with ASD, 69.7%  reported being non-heterosexual, while , 30.3% reported being non-heterosexual. The group with ASD reported higher rates of homosexuality, bisexuality and asexuality, but lower rates of heterosexuality. The results support the impression that non-heterosexuality is more prevalent in the autistic population. Increased non-heterosexuality in ASD has important clinical implications to target unique concerns of this population, and suggests a need for specialized sex education programs for autistic populations for increased support and awareness. Autism Res 2018, 11: 133-141. © 2017 International Society for Autism Research, Wiley Periodicals, Inc.

LAY SUMMARY: Research suggests that individuals with Autism Spectrum Disorder (ASD) report increased homosexuality, bisexuality, and asexuality, but decreased heterosexuality. It is important to increase awareness about increased non-heterosexuality in ASD among autistic populations, medical professionals and care-takers, so as to provide specialized care, if needed and increase support and inclusion for non-heterosexual autistic individuals.

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Brief Report: Sexual Orientation in Individuals with Autistic Traits: Population Based Study of 47,000 Adults in Stockholm County.

Rudolph CES^{1,2}, Lundin A³, Åhs JW³, Dalman C^{3,4}, Kosidou K^{3,4}.

+ Author information

Open/close author information list

Abstract

We examined the association between autistic traits and sexual orientation in a general adult population (N = 47,356). Autistic traits were measured with the ten items Autistic Quotient questionnaire using a cut-off score of ≥ 6 . Sexual orientation was assessed by self-report. Multinomial logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (CIs) for sexual orientation categories. Participants with autistic traits were more likely to identify as bisexual (OR 1.73; 95% CI 1.01-2.9) and to feel that their sexual orientation could neither be described as hetero-, homo- nor bisexual (OR 3.05; 95% CI 2.56-3.63), compared to individuals without autistic traits. Autistic traits are associated with minority sexual orientation, and perhaps with uncertain self-identification and/or a defiance of traditional ways of categorizing sexual identity.

Prevalence of the Wish to be of the Opposite Gender in Adolescents and Adults with Autism Spectrum Disorder.

van der Miesen AIR¹, Hurley H², Bal AM², de Vries ALC³.

+ Author information

Abstract

Several studies have suggested an overrepresentation of (symptoms of) autism spectrum disorder (ASD) among individuals with gender dysphoria. Three studies have taken the inverse approach in children with ASD and showed increased parent report of the wish to be of the opposite gender in this group. This study compared the self-reported wish to be of the opposite gender (one item of the Youth Self-Report [YSR] and the Adult Self-Report [ASR]) of 573 adolescents (469 assigned boys and 104 assigned girls) and 807 adults (616 assigned males and 191 assigned females) with ASD to 1016 adolescents and 846 adults from the general population. Emotional and behavioral problems were measured by the DSM-oriented scales of the YSR and ASR. In addition, the Children's Social Behavior Questionnaire and the Adult Social Behavior Questionnaire were used to measure specific subdomains of the ASD spectrum to test whether specific subdomains of ASD were particularly involved. Significantly more adolescents (6.5%) and adults (11.4%) with ASD endorsed this item as compared to the general population (3-5%). In adolescents, assigned girls endorsed this item more than assigned boys. No significant gender differences were found in the adults with ASD. In addition, on all DSM-oriented scales of both the YSR and ASR, adolescents and adults with ASD who endorsed the gender item had significantly higher scores compared to those without. There were no significant associations between endorsement of the gender item and any specific subdomain of ASD, providing no evidence for a specific role of one of the ASD subdomains and endorsement of the wish to be the opposite gender.

"They Thought It Was an Obsession": Trajectories and Perspectives of Autistic Transgender and Gender-Diverse Adolescents.

Strand JF^{1,2,3,4}, Powers MD^{5,6,7}, Knauss M^{5,7,8}, Sibarium E^{5,9}, Leibowitz SF¹⁰, Kenworthy L^{5,6}, Sadikova E^{5,6,7}, Wvss S¹¹, Willing L^{6,7}, Canlan R¹², Pervez

N¹² One-third of the participants said other people had questioned their gender diversity because they are autistic. For example, they said people had told them that their gender diversity is an obsession rather than a 'real' experience, or that the experience is a feature of autism itself. They found these assumptions distressing.

Ab
De: <https://www.spectrumnews.org/opinion/viewpoint/need-respect-sexual-orientation-gender-diversity-autism/>

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themes and experiences in this population, results should inform clinical research approaches and priorities.

views

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RESOURCES

- American Academy of Child and Adolescent Psychiatry:
[https://www.aacap.org/AACAP/Families and Youth/Resource Centers/Youth In Transition Resource Center/Youth In Transition Resource Center Home.aspx](https://www.aacap.org/AACAP/Families_and_Youth/Resource_Centers/Youth_In_Transition_Resource_Center/Youth_In_Transition_Resource_Center_Home.aspx)
- American Academy of Pediatrics: [https://www.aap.org/en-us/Documents/medicalhome transition resources.pdf](https://www.aap.org/en-us/Documents/medicalhome_transition_resources.pdf)
- American College of Physicians: <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>
- Autism Speaks Puberty and Adolescence Toolkit:
<https://www.autismspeaks.org/sites/default/files/2018-08/Puberty%20and%20Adolescence%20Resource.pdf>
- Autism Speaks Transition Toolkit: <https://www.autismspeaks.org/tool-kit/transition-tool-kit>
- Autism Speaks Transition Toolkit – Utah:
<https://www.autismspeaks.org/sites/default/files/2018-10/utah-ttk.pdf>
- Got Transition: <https://www.gottransition.org/>
- Menstruation Management and Disabilities: [autismbeacon.com/images/uploads/supporting-women-carer. Pdf](https://autismbeacon.com/images/uploads/supporting-women-carer.Pdf) and [http://www.teachingsexualhealth. ca/](http://www.teachingsexualhealth.ca/)
- NATIONAL AUTISM INDICATORS REPORT: DEVELOPMENTAL DISABILITY SERVICES AND OUTCOMES IN ADULTHOOD: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Services-and-Outcomes-in-Adulthood/>

RESOURCES CONT.

- NATIONAL AUTISM INDICATORS REPORT: HIGH SCHOOL STUDENT ON THE AUTISM SPECTRUM: [National Autism Indicators Report: high School Students on the Autism Spectrum](https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-High-School-Students-on-the-Autism-Spectrum/) <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-High-School-Students-on-the-Autism-Spectrum/>
- NATIONAL AUTISM INDICATORS REPORT: TRANSITION INTO YOUNG ADULTHOOD: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/>
- Supporting the Healthcare Transition from Adolescence to Adulthood in the Medical Home: <https://pediatrics.aappublications.org/content/142/5/e20182587>
- Utah Parent Center: <https://utahparentcenter.org/wp-content/uploads/2016/07/Higher-Education-Options.pdf>



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