SCHOOL SUPPORT PLAN



A fillable plan designed to support caregivers and healthcare providers with communicating and advocating for a student's needs in the school environment

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Turner Syndrome: Support Plan

This document is designed to give educators an overview of how best to support girls and young women with Turner syndrome in the classroom. Please read the guidance below before completing the support plan template.

It is important to discuss the family's preference regarding disclosure of information to school staff and others involved in collaborating on the support plan. School staff should be informed whether the child is aware of their diagnosis and its features and whether this has been shared with friends and family. Personal preferences should be respected by all involved and these conversations should be revisited across time as the student develops and makes decisions about sharing information with other students in the school.

What is Turner syndrome (TS)?

TS is a genetic disorder characterized by the complete or partial loss of one of the two X chromosomes in girls. It affects approximately 1 in every 2,000 female births. Girls and women with TS often have a wide range of medical symptoms. Almost all individuals with TS are shorter than average and have non-functioning ovaries. Due to the complexity of the condition, girls with TS have regular health checks throughout their lives. Most individuals with TS have good language and reading skills. However, some have behavioral, social, or specific learning difficulties.

It is important to remember that the presentation of TS is highly variable and furthermore, that individuals with TS have numerous strengths. Verbal domains, including phonological processing and linguistic knowledge, tend to be areas of relative strength in individuals with TS. As with all students, educators are encouraged to take a strengths-based approach, use praise, and set realistic yet challenging goals for students with TS

Hearing



Many girls with TS have a hearing impairment. This may be caused by repeated 'glue ear' (middle ear infections with a buildup of fluid) or the hearing impairment may be more permanent or degenerative.

- Students with hearing loss or a hearing aid will benefit from a quiet workspace with little background noise when completing tasks that require higher levels of concentration or communicative demand.
- It is suggested that girls with TS are given preferential seating during instructional time.
- Students should be encouraged to make eye contact with the speaker.
- Teachers can use visual and non-verbal cues as well as hard-copy instructions to reinforce communication. Utilizing closed captioning on video, and a microphone in larger instructional spaces is also helpful.
- An exploration of appropriate assistive technologies to facilitate learning. Activities are also recommended to mitigate the impacts of hearing impairment and slow processing speed.

Processing Speed



Processing speed, including the ability to process verbal and visual information and react with quick motor speed, can be another area in which girls with TS show differences.

Having a slow processing speed has nothing to do with how smart a person is, and this is a common misconception.

Some individuals with TS may struggle to listen to information, make sense of that information, and begin responding in a brief time. If this is the case, these students may have difficulty keeping up in the classroom which, in turn, might make the student feel anxious. Additionally, students with slower processing speed may struggle to follow multi-step instructions. For example, if a teacher says “Time to start math. Put your books away, go back to your desks, get out your math book, turn to page 4 and start working on the questions,” a student that processes information at a slower speed will often have difficulty remembering all the steps.

- Allow more time to answer questions aloud.
- Allow extra time for written exams.
- Breaking up instructions into clear, discrete steps.
- Repeat instructions and check for understanding after a lesson. Ensure the student knows what they need to do to complete the task.

Spatial Awareness



Spatial awareness is the ability to understand where you are in relation to other objects or other people. More than 8 out of 10 girls with TS have difficulty understanding spatial relationships. This can make tasks like remembering how to get somewhere you have only been to once before, judging distances, reading maps, or playing throwing and catching games difficult.

Social Ability and Making Friends



Friendships play a key role in promoting wellbeing and good mental health. Although girls with TS tend to be very sociable, some girls can start to experience social difficulties during adolescence. Many teens and adults report finding it hard to read body language. Difficulties with spatial awareness can inadvertently lead to the invasion of others’ personal space.

Problems in creating social connections may be compounded by hearing impairments or processing speed differences, particularly not being able to keep with the speed of conversation or respond to questioning as quickly as their peers, which can be mistaken for being rude or disinterested.

- Support to overcome these difficulties can be offered by encouraging peer support or offering more structured friendship group interventions (e.g., social skills groups, friendship group, lunch bunch, buddy system, nurture group) both in school and community.

Hyperactivity, Attention, and Executive Functioning



Some individuals with TS can experience a phase in childhood that involves hyperactivity. This may include constant fidgeting and restlessness. Others may show no sign of these issues. Furthermore, students with TS might experience impairments in executive functioning including organization, prioritization, decision making, planning, and keeping track of time. Students with TS may also find it difficult to concentrate and sustain attention. Many youths with TS will benefit from routine, structure, and predictability in the school day.

- Using sensory and fidget toys may assist with focus time in class learning.
- Using a visual schedule or timetable in the classroom. This visual schedule should show the different components of the school day so that students know what they will be doing and when.

Gender Stereotypes



Stereotyping refers to the process of generalizing about individuals or groups based on certain characteristics, for example, gender. In the case of girls with TS in the educational setting, gender stereotypes can contribute to delayed detection of learning difficulties or neglect of emotional problems.

One stereotype is that girls are naturally better at certain subjects, such as language arts and humanities, while being less competent in science and mathematics. Considering that girls with TS have a higher risk of experiencing mathematical learning difficulties, the existence of this stereotype might impede early detection and efforts to promptly address these difficulties.

Another stereotype is that girls are more emotional, sensitive, or shy than boys. Research has shown that girls with TS experience increased anxiety. If this trait is interpreted as less of a concern because of gender stereotypes, then the opportunities for support or treatment may be missed.

Body-Image



Adolescent girls are particularly vulnerable to gender stereotypes and expectations around their body image. Short stature is common in TS. Without growth hormone therapy, the average adult height for women with TS is 4ft, 8in (142cm). Short stature puts the person at risk for "juvenilization" (i.e., the tendency to treat the person according to their height age rather than their chronological age) by both peers and adults. This can contribute to delayed social maturity.

Maximizing adult height in those with TS through growth hormone therapy may involve delaying initiation of pubertal onset through hormone replacement therapy. Progressing through puberty significantly later than peers can contribute to feelings of being different from peers and lead young girls to feel self-conscious.

- Opportunities to educate youth in schools about the prevalence of variations in physical development and reproductive function would help to normalize self-perceptions of being out-of-step with one's peers.

Sexual Health Education



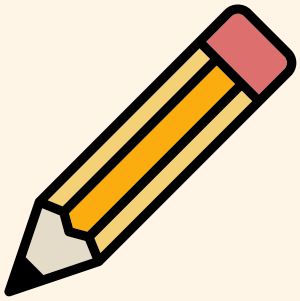
It is essential that school-based staff and teachers delivering sexual health education are aware of and sensitive to variability in the biological processes of human sex development and the psychological effects this can have on individuals with TS. For example, the public tend not to know enough about genetic variation and may wrongly assume that all girls/women have a 46,XX karyotype and all boys/men have a 46,XY karyotype.

As mentioned above, most assume that everyone goes through puberty without medical intervention, yet some children require hormone replacement for puberty to begin and be sustained. Additionally, not all individuals will be fertile or able to carry a pregnancy to term.

Timely consultation with the family can inform more inclusive sexual health education. In addition, the socio-emotional wellbeing of TS girls needs to be monitored when participating in these instructional units.

Additional 1:1 time with healthcare professionals or school-based personnel to address specific questions or concerns would be beneficial.

- During sexual health education it is essential that generalizations are not made such as, 'All girls have periods etc.' Just adding the word 'most' provides a much more sensitive approach



School Support Plan

This documentis to be completed by the student's specialist provider(s) and their caregivers to enable clear communication and help advocate for necessary supports in the school environment.

Personal Details

Student Name: **Date of Birth:**

General information	
School:	
Teacher	**Grade:**
Teacher:	
Parent/Guardian:	
Parent/Guardian:	

Healthcare information	
Primary Care Provider:	
Specialty Healthcare Provider: **(e.g., endocrinologist)**	
Clinical Psychologist:	
School Psychologist:	

Psychosocial Goals & Concerns

#1	Concern:
	Goal:
	Action:
#2	Concern:
	Goal:
	Action:
#3	Concern:
	Goal:
	Action:

Psychosocial Goals & Concerns (cont'd)

#4	Concern:
	Goal:
	Action:

Other Programs/Services: (e.g., ***therapy, social skills groups at hospital)***	
Potential Barriers: (***e.g., changes/issues to watch and plan for)***	
Team Goals: (***e.g., follow-up, test results, plan developed)***	

Health Goals & Concerns

#1	Concern:
	Goal:
	Action:

#2	Concern:
	Goal:
	Action:

Current Health Issues:	
Relevant Health History	

References & Resources

The information in this document was created relying on the following references:

Gravholt, C. H., Andersen, N. H., Christin-Maitre, S., Davis, S. M., Duijnhouwer, A., Gawlik, A., Maciel-Guerra, A. T., Gutmark-Little, I., Fleischer, K., Hong, D., Klein, K. O., Prakash, S. K., Shankar, R. K., Sandberg, D. E., Sas, T. C. J., Skakkebaek, A., Stochholm, K., van der Velden, J. A., International Turner Syndrome Consensus Group, & Backeljauw, P. F. (2024). Clinical practice guidelines for the care of girls and women with Turner syndrome. *Eur J Endocrinol*, *190*(6), G53-G151. https://doi.org/10.1093/ejendo/lvae050

School Nursing and Health - Health Conditions & Care Plans. Colorado Department of Education. Retrieved September 25, 2004

Turner Syndrome Support Society. *How to help your child survive and succeed at school.* Harlow Printing Limited. Retrieved September 25, 2004.

Links to additional resources:

United States of America	United Kingdom

• Turner Syndrome Society of the United States
• Turner Syndrome Foundation
  ○ Learning-specific resources
  ○ School Accommodations
	• Turner Syndrome Support Society
	
	International:
	• Turner Syndrome International

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