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***Q&A Summary:***
***Autism Spectrum Disorder (ASD) Part V:***
***Dual Diagnosis of Down Syndrome and ASD***
October 2, 2018

**Presenter:** Julie A. Grieco, PsyD

1. What screening tools are available to screen children with Down syndrome (DS) for autism spectrum disorder (ASD)?
    a. DiGuiseppi C, Hepburn S, Davis JM, et al. Screening for autism spectrum disorders in children with Down syndrome. *J Dev Behav Pediatr*. 2010;31:181-191.

2. Is there a specific assessment tool/screening for DS-ASD or just the bundle of assessments you listed?
    a. There is not one specific tool that is unique to this population, but instead several tools are often used as part of a neuropsychologic evaluation in the context of clinical expertise to confirm or exclude a diagnosis.

3. Can you recommend how to get child tested for ASD if s/he has already been diagnosed with DS?
    a. If there are concerns about ASD, it is important to refer to a neuropsychologist who specializes in evaluating children with neurodevelopmental disorders, preferably one who has experience evaluating patients with DS and ASD.

4. Which condition is usually diagnosed first?
    a. DS is diagnosed first, most often at birth or prenatally.

5. What tools and programs are available for adults to improve social behavior and communication and by what type of specialist? Is cognitive behavioral therapy (CBT) applicable?
    a. CBT is applicable for patients who have a mental age over 6 years.
    b. Social behavior and communication should be addressed through use of applied behavioral analysis (ABA) strategies, direct social skill instruction/groups and in vivo modeling. Adults in group homes and/or day programs should have these components integrated into their programming.

6. What resources (websites, books, support groups, etc.) are available for parents who have children with dual diagnoses (ASD/DS)?
    a. http://www.ds-asd-connection.org/
    b. https://www.ndss.org/resources/dual-diagnosis-syndrome-autism/
    c. *Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals*, by Margaret Froehlke, RN and Robin Zaborek

7. What are good community resources for young adults with ASD/DS that help with the transition to adulthood? Or how do families find these types of resources?
    a. Many DS programs, including the program here at Massachusetts General Hospital, spend several years preparing and facilitating a smooth transition between pediatric and adult care. The process of transitioning should start in adolescence, and gradual transitions to new providers who have experience

working with patients with dual diagnoses are needed. Families can meet and interview providers independently; however, in my experience, if families are able to obtain referrals from a larger program, it can be very helpful in reducing stress for the patient and their family.

b. Also, please remember to register for our final 2018 ASD webcast, Part VI, when we discuss the transition to adult care. It will be held on November 6, from 1–2 p.m. EDT. You can register at: https://www.optumhealtheducation.com/autism-part-VI-2018-reg

8. What is Down syndrome disintegrative disorder? What are the characteristics?
    a. Jacobs J, Schwartz A, McDougle CJ, Skotko BG. Rapid clinical deterioration in an individual with Down syndrome. *Am J Med Genet A*. 2016;170:1899-1902.
    b. Worley G, Crissman BG, Cadogan E, et al. Down Syndrome Disintegrative Disorder: New-Onset Autistic Regression, Dementia, and Insomnia in Older Children and Adolescents With Down Syndrome. *J Child Neurol*. 2015;30:1147-1152.

9. Why celiac? Do they have a higher rate of the celiac clumping due to long periods of time in the bathroom? Or due to behavior?
    a. Pavlovic M, Berenji K, Bukurov M. Screening of celiac disease in Down syndrome - Old and new dilemmas. *World J Clin Cases*. 2017;5:264-269.
    b. Carnicer J, Farre C, Varea V, Vilar P, Moreno J, Artigas J. Prevalence of coeliac disease in Down's syndrome. *Eur J Gastroenterol Hepatol*. 2001;13:263-267.

10. What are the prospects for ABA therapy coverage for those with a diagnosis of DS but no ASD diagnosis, and do you feel it is an effective therapy for those with DS without the dual diagnoses?
    a. Coverage would depend on the child's insurance policies.

11. I have a client with dual diagnoses who also appears to have agoraphobia, but with minimal verbal skills, it is difficult to confirm. Is there a treatment that could help with this dislike of entering certain places?
    a. ABA therapy will likely be the most effective way; however, considering potential sensory sensitivities, ruling out underlying medical issues that are making the patient uncomfortable to leave the home, and eventually considering the role of psychopharmacology, may be helpful.

12. In reviewing treatment plans from various board-certified behavior analysts (BCBAs), they can vary quite a bit in regard to the amount of parent training/involvement in ABA treatment. What do you think is the minimum standard and the recommended amount of parent training/involvement? Per week, for example?
    a. The recommended amount would be as much as possible. However, a general guideline is usually at least 10 hours per week.

13. What percentage of treatments are covered by private and state health insurance?
    a. Coverage depends on the child's insurance policies.

14. How do you evaluate how many hours of ABA therapy are needed for an older, school-age child who has already had 2 years of 20–25 hrs/wk and is in an exceptional student education (ESE) classroom?

    a. There is no standard amount recommended; at that point I would refer for a neuropsychologic evaluation to assess progress and inform specific recommendations that are unique to the child. Patients in this group can present in many different ways, and their progress can vary so widely. It is best to get a tailored assessment to inform recommendations to support development.

15. While occupational therapy is a covered benefit for most people dual diagnoses of ASD and DS, why isn't ABA a covered therapy if ABA therapy benefits the individual?
    a. ABA therapy is often covered for patients with an ASD diagnosis. The type of insurance and/or geographic location may influence the extent of coverage. Here is a link for more information: http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx

16. Who should a child be referred to, if DS and ASD are suspected?
    a. A neuropsychologist who has experience in evaluating children with both conditions is recommended. Many hospitals that have DS programs will have staff available who can provide this type of service.

17. Are there any educational services or tutoring to assist children with ASD-DS that insurance will pay for? Academics are a huge difficulty.
    a. Medical insurance does not cover academic evaluation or intervention, so unfortunately, no.

18. Can a 5-year old still have high probability of improvement if therapy has just started?
    a. Absolutely. Developmental gains are expected with interventions. While the rate of progress may differ from typically developing individuals, a child should always be making progress. Change in their programming is indicated if there is no progress or if regression is observed.

19. Do you have any suggestions for kids who are in kids' church services; in these situations, they are around other kids and volunteers are not really sure how to handle the child? Do you have suggestions for toys or re-grouping?
    a. Modeling interactions, explicitly teaching other children how to interact with the child and incorporating preferred activities are recommended. If the child uses an augmentative communication device, teaching others how to use it and prompting the child to use it are recommended.

20. What factors do you consider when determining whether a patient with ASD-DS would do better in an out-of-home placement (eg, group) instead of remaining at home?
    a. The main factor is usually the level of dependence/need for supervision and the amount of resources available to provide that support. Patients who have significant behavioral dysregulation and/or very complex medical needs are also more likely to require an out-of-home placement.

21. Inclusion is so important for kids with DS, but with dual diagnoses, ABA seems more important. Where does inclusion fit in?
    a. Inclusion is a wonderful component of many patients' educational progress; however, the amount of inclusion needs to be determined by the individual and what environment will facilitate his/her developmental progress. It is recommended that a neuropsychologic evaluation be conducted to help guide

the family and educators in selecting the best balance to help facilitate developmental gains for the patient.

22. What is the incidence of obsessive-compulsive behavior in this population?
    a. Obsessive thoughts (perseveration) and repetitive behaviors are common features of ASD. Patients with ASD do not receive an additional diagnosis of obsessive-compulsive disorder given that symptoms are best understood as a component of ASD.

If you have questions regarding this document or the content herein, please contact: moreinfo@optumhealtheducation.com.