

40 facts about Williams Syndrome

Brad Powell, Jo Van Herwegen & the CDLD team

To celebrate the 40th anniversary of the Williams Syndrome Foundation and to raise awareness of Williams syndrome, we have put together 40 research-evidenced facts about Williams syndrome.

Williams Syndrome is a rare genetic condition that is caused by a deletion of genetic material on the long arm of chromosome 7. It occurs sporadically in about 1 in 18,000 people. This fact sheet provides information on the medical aspects, brain development, cognitive and behavioural profiles, education, support and intervention and career outcomes of people with Williams syndrome, all of which are based on scientific research. These facts were randomly chosen from topics that we discussed during our lab meetings. This fact sheet can be used as a resource to pass on to family members, teachers and professionals.

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For more details about the CDLD lab: www.jovanherwegen.co.uk
Twitter: @CDLDlab

Medical Facts about Williams syndrome

1. Due to the rarity of Williams Syndrome, only one in 30 GPs will ever see an individual with Williams Syndrome, therefore, it might be useful to pass on these clinical guidelines: https://williams-syndrome.org.uk/wp-content/uploads/2018/07/williams_syndrome_guidelines_pdf.pdf
2. Children with Williams Syndrome often have sleep disturbances such as difficulty falling asleep, sleep anxiety, and waking during the night, all of which can negatively influence learning (Annaz, Hill, Ashworth, Holley, & Karmiloff-Smith, 2011; Ashworth, Hill, Karmiloff-Smith, Dimitriou, 2014).
3. Given that some individuals with Williams Syndrome have sleep issues, parents and carers should keep a sleep diary, using <http://kidsleepdr.com>, to discuss with the GP. Further information on sleep issues can be found on the WSF website <http://williams-syndrome.org.uk>.
4. There are some dental abnormalities associated with Williams Syndrome, therefore, children with Williams Syndrome should be enrolled in an individualised preventative oral healthcare programme from an early age. Routine follow up and regular dental examinations by a family dentist or local community dental services are essential. More information can be found here: https://williams-syndrome.org.uk/wp-content/uploads/2018/07/wsf_dental_guidelines_for_children.doc_pdf
5. A child with Williams Syndrome should have an annual cardiac examination until 4 years of age. Thereafter complete cardiac assessment, including echocardiography, at least every 5 years. See clinical guidelines for more information: https://williams-syndrome.org.uk/wp-content/uploads/2018/07/williams_syndrome_guidelines_pdf.pdf
6. Research indicates that as an individual with Williams Syndrome ages, there tends to be improvements in self-care, ability to complete household tasks and understanding of danger and there is no evidence of age related decline in social or adaptive functioning in adults with Williams Syndrome, at least up to the age of 50-55 years (Elison, Stinton & Howlin, 2010).
7. According to our files, the oldest person living with Williams Syndrome in the UK (that we know about) is currently 74 years old and is turning 75 this month!
8. Some individuals with Williams Syndrome may have hypercalcaemia, therefore sunblock should be used to limit vitamin D exposure, and vitamin D supplements should be avoided. See clinical guidelines for more information: https://williams-syndrome.org.uk/wp-content/uploads/2018/07/williams_syndrome_guidelines_pdf.pdf
9. Infants and children with Williams Syndrome may have difficulties eating, due to the occurrence of hypotonia, intestinal dysmotility (difficulties with the gut processing food) and sensory processing. Gradual exposure to certain foods can reduce anxieties around those foods. You can adapt your child's diet based on their development and skill, rather than age (Field, Garland & Williams, 2003). Visit this link for more information: https://www.stlouischildrens.org/sites/default/files/SLC18759_WS-Feeding_F.pdf
10. Individuals with Williams Syndrome can have vision problems, which can contribute to later impairments. However, these are often unnoticed in Education and Health Care Plans, which means it is important to ensure those preparing the reports are prompted to enquire about a child's visual status to provide suitable advice (Harvey, Ashworth, Palikara & Van Herwegen, 2020).

Facts about the brain of people with Williams syndrome

11. Brain imaging research has also identified atypical brain connections between the orbito-frontal cortex and the amygdala within individuals with Williams Syndrome. These two areas are responsible for inhibiting behaviours and evaluating threats. So, it seems that the brains of people with Williams Syndrome process social threat differently (Myer-Lindenberg et al., 2005).
12. In a study comparing racial stereotypes in children with Williams Syndrome to typically developing children, the children with Williams Syndrome did not display any racial stereotypes, whereas the typical developing children were more likely to describe people of their own race in a positive light. Given that Williams Syndrome is associated with reduced social fear, it suggests social fear processing is related to the emergence of racial stereotyping (Santos, Myer-Lindenberg & Derulle, 2010).
13. In the brain of individuals with Williams Syndrome, there is reduced volume in the Intraparietal Sulcus, compared to other areas of their brain. This region is responsible for reaching and directing eye-movements, which may explain some of difficulties people with Williams Syndrome may experience, such as assembling objects (Jackowski et al., 2009).

Facts about cognitive and behavioural development in Williams syndrome

14. Many People with Williams Syndrome have hyperacusis, which is increased sensitivity to certain sounds and frequencies. This can be challenging, however, research indicates that severity may decrease with age (Glod, Riby & Rodgers, 2019).
15. Research indicates that 91% of individuals with Williams Syndrome have sensory modulation difficulties, which is the ability to regulate arousal from our senses (John & Mervis, 2010). These difficulties can impact daily life, as they can contribute to an individual becoming overwhelmed or seeking more input. Our research is currently exploring whether general sensory difficulties remain the same or reduce with age.
16. Pre-schoolers with Williams Syndrome can follow other peoples 'gaze' (a sign of shared attention) but they may not necessarily understand the purpose of the shared attention, which means they may benefit from an explanation of why you are looking at the object (Vivanti et al., 2018).
17. Research indicates that individuals with Williams Syndrome have greater verbal abilities than non-verbal, which can lead to people over-estimating an individual with Williams Syndrome capabilities (Jarrold, Baddely & Hewes, 1998; Brock, 2008).
18. Individuals with Williams Syndrome have very good short-term memory and imitation abilities. This allows them to imitate words and even entire sentences, but without necessarily understanding the meaning behind it (Thomas et al., 2006).
19. People with Williams Syndrome are likely to have your best interests at heart. Across their lifespan, they typically have an intense drive for social interaction and a desire to form affectionate bonds with others (Ng, Järvinen, & Bellugi, 2014).

20. Individuals with Williams Syndrome can have weak central coherence, which means they see things differently to other people. For example, people with Williams Syndrome may be more likely to look at the finer details of objects and displays rather than the bigger picture (D'Souza et al., 2016).
21. Toddlers with Williams Syndrome can have impairments in pointing and triadic joint attention (looking at the same object together), which are early precursors to language. Given that individuals with Williams Syndrome have relatively good language skills in later childhood, it suggests language develops through an alternative pathway in Williams Syndrome (Laing et al., 2002).

Facts about Williams syndrome relevant to education

22. In one study, 71% of adults with Williams Syndrome had received college education, and one individual had studied at degree level (Howlin & Udin, 2006).
23. In the classroom, learning may be enhanced for people with Williams Syndrome by using active demonstration rather than learning by trial and error (Foti et al., 2018).
24. Individuals with Williams Syndrome are typically very good at counting, but sometimes they may not understand the meaning of what they are counting, therefore an explanation may be beneficial (Van Herwegen & Simms, 2020).
25. Children with Williams Syndrome can have difficulties with maths. Research suggests this is due to difficulties with 'sticky' eye-movements when they are infants, which makes it difficult to distinguish between different objects (Van Herwegen, Ranzato, Karmiloff-Smith & Simms, 2020). Therefore, pointing gestures and moving your finger slowly over the objects or displays as well as giving them more time to look at things at may help them learn better.

Facts about Williams syndrome related to support and Intervention

26. Many individuals with Williams Syndrome have a passion for music, and therefore music can be used as a motivator, reward or a method to increase attention (Thankur, Martens, Smith, Roth, 2018). For example, you could make up a song with your child's name in to get their attention, to help with tidying up or to help with remembering how to tie their shoelaces.
27. Reduced strength (hypotonia) and visual integration skills can make tasks like writing and learning to tie shoelaces difficult. Using Velcro shoes can increase your child's independence, and a computer or tablet can be used to replace pen and paper-work <https://williams-syndrome.org/teacher/information-for-teachers>

28. Following a routine and keeping the sensory environment predictable may be beneficial to reducing anxiety in individuals with Williams Syndrome, given that uncertainty in everyday interactions has been linked to anxiety (Glod, Riby, Rodgers, 2019).
29. Like autism, individuals with Williams Syndrome may have difficulties understanding other people's intentions, therefore social stories may be useful to supporting the development of social awareness (Morel et al, 2018).
30. Mindfulness is growing popularity for treating fears, phobias and anxiety, and research suggests it can be beneficial for people with Williams Syndrome (Miodrag, Lykens & Lense, 2013).
31. Music therapy has also been shown to improve children with Williams Syndrome mathematical abilities (Reis, Schader, Milne, & Stephens, 2003).
32. Children with Williams Syndrome who engage in music lessons (i.e. piano, singing, drums, violin, guitar, etc) can have enhanced verbal memory, for example recalling and recognising spoken information (Dunning, Martens & Jungers, 2015).
33. Individuals with Williams Syndrome tend to approach strangers more than others. Teaching stranger safety skills using instructions, role-play and feedback has been found to be an effective way to increase stranger safety behavior amongst individuals with Williams Syndrome (Fisher, 2013).
34. Individuals with Williams Syndrome can have difficulties finding their way around. However, they have good verbal memory abilities and thus identifying unique landmarks within the environment can help them (Farran et al., 2016).
35. There is a lack of research investigating the effectiveness of therapies for individuals with Williams Syndrome. However, a case study suggests modified Habit Reversal Therapy may be beneficial for reducing body focussed repetitive behaviours. The modifications consisted of using straightforward behavioural strategies, such as simple relaxation techniques, simple instructions, broadening the role of parents and teachers, and practicing skills in game-like formats, amongst others (Conelea & Klein-Tasman, 2013).
36. Many interventions that have been developed for autism may also be of benefit for people with WS, due to the socio-cognitive similarities between the two conditions (Vivanti et al, 2018). However, further research in this area is needed.
37. Young children with Williams Syndrome often struggle with early reading ability because of their overall language delay, limited vocabulary and difficulties with phonological awareness. Encouraging reading using both phonics, sight word reading and visual approaches to introduce and reinforce the meaning of new words in a variety of different contexts could benefit children with Williams Syndrome. However, this is yet to be researched (Mervis, 2009).

Careers

38. At the age of 26, Jenny Lynn Unrein a woman with Williams Syndrome has a successful business selling painting, greeting cards, and jewellery all over the world
<https://www.jennyludesigns.com/about>
<https://themighty.com/2015/05/shes-26-lives-with-williams-syndrome-and-has-her-own-successful-business/>
39. Acting is one career that plays to the strengths of people with Williams Syndrome. For example, Gabrielle Marion-Rivard, the Canadian born actress and singer, was awarded the Canadian Screen Award for Best Actress in 2014! To view the trailer for the film, follow this link:
https://www.youtube.com/watch?v=aO_aUGM5L9E
40. Another famous performer is Ben Monkaba, who is renowned for his musical, 'clown' and public speaking abilities! To find out more about Ben, check out his website <https://benmonkabamusic.com/about-me> and to listen to him play the drums, follow this link:
<https://www.youtube.com/watch?v=fUS19HQfpSs>

We hope you found our fact sheet interesting and valuable, and if you have any questions, please do not hesitate to get in touch with the CDLD Lab! www.jovanherwegen.co.uk

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