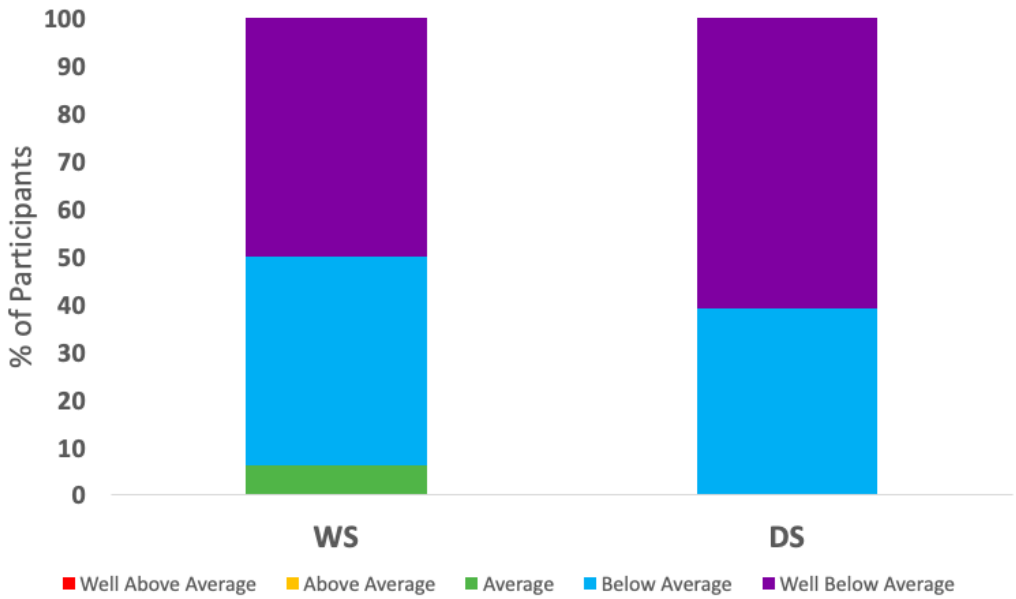
Dear participants and families,

Thank you all so much for participating in our research project, and for being so warm and welcoming to me during the sessions. The aim of this research was to learn more about the motor abilities, anxiety and daily living skills of people with Williams Syndrome (WS) and people with Down Syndrome (DS). To do this, we asked a group of individuals with WS and a group of individuals with DS to take part in some motor tasks (such as balancing, playing with a ball, drawing, etc.), and some activities of daily living (such as tying shoe laces, using cutlery, tiding up, etc.). We also asked parents to complete some questionnaires about their son or daughters daily living skills and their anxiety. We would like to share with you the results of this project, and we hope that you find this interesting and helpful.

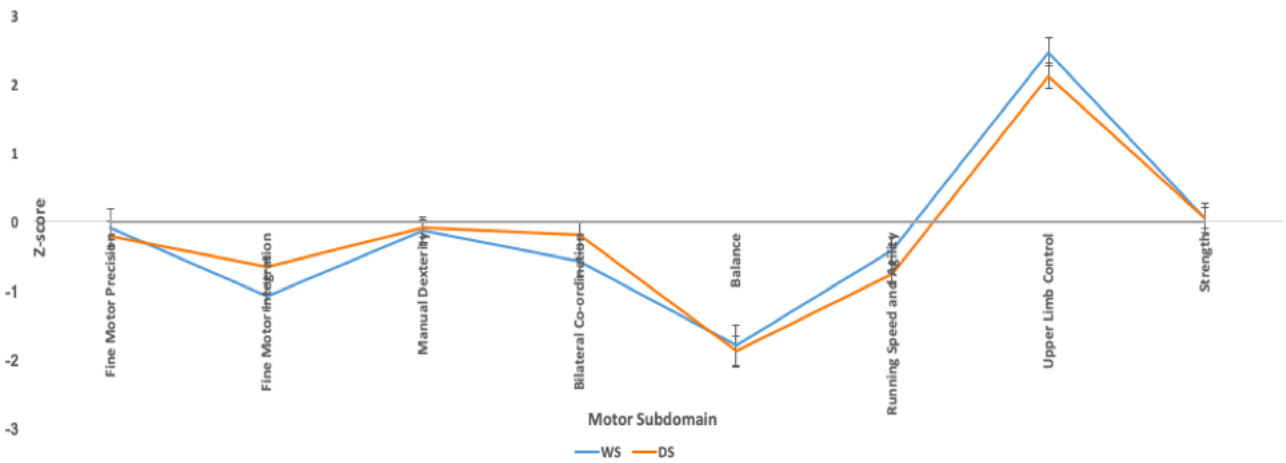
Motor abilities

Motor ability was assessed using the Bruininks-Oseretsky Test of Motor Proficiency, Second Edition short form (BOT2-SF; Bruininks & Bruininks, 2005). This motor test assesses both fine motor (e.g. drawing) and gross motor (e.g. walking, balancing, etc.) ability. Results indicated that most members of the WS group and all member of the DS group were performing in the 'below average' (3rd-16th percentile) or 'well below average' (<2nd percentile) zone of the BOT2-SF. However, it is possible for participants with WS to score in the 'average' zone (17th-18th percentile). This can be seen in the bar graph below. This demonstrates motor difficulties in both children and adults with WS and DS.



We also wanted to look at the motor profile to see whether individuals were better/worse at some motor tasks than others. We found that for the majority of motor skills, both individuals with WS and individuals with DS performed at the level of a 4- to 5-year-old child. They did show relatively stronger

performance, however on the Upper Limb Control task (where they had to drop and catch and dribble a tennis ball) on which they performed at the level of a typically developing 6- to 7-year-old child. Performance on the Balance task (where they had to walk in a straight line and balance on a thin beam) was the weakest, where performance was below the level of a typically developing 4- to 5-year-old child. The motor profile is shown in the graph below. The data was adjusted so that the zero line represents the performance of a TD4-5-year-old. So, performance at the zero line represents a similar level of performance to a TD4-5-year-old, performance above the line represents better performance than a TD4-5-year-old, and performance below the line represents performance below a TD4-5-year-old. This research could be used to inform professionals who are undertaking motor interventions with individuals with WS or DS about relative strengths and difficulties. It also provides information to new parents of children with WS or DS about the specific areas of motor ability that their son or daughter may struggle with.



Anxiety

Anxiety was investigated using the Spence Children's Anxiety scale (SCAS, Spence et al., 2003), which is completed by parents/carers. It was found that 80% of the individuals with WS and 44% of the individuals with DS scored above the 'clinically anxious' cut-off on the SCAS. This was expected in the WS group, as it has been previously found that individuals with WS have high anxiety in comparison to the general population (Baxter et al., 2013; Somers, Goldner, Waraich & Hsu, 2006) and to other populations with neurodevelopmental disorders (Dykens et al., 2005; Pegorara, Steiner, Celeri, Banzato & Dalgalarrondo, 2014). However, while individuals with DS experienced significantly less anxiety than the WS group, the rate of anxiety was still higher than expected in the DS group based on previous research (e.g. Graham et al., 2005; Haveman et al., 1994; Einfeld et al., 1999). This suggests that anxiety may be a significant problem for both individuals with WS and individuals with DS. The table below shows the percentage of individual in each group who scored in the clinically anxious range for each area of anxiety assessed by the SCAS. This again shows that individuals with WS are scoring in the clinically anxious range more than the DS group on all areas of anxiety. Individuals with WS are most likely to experience general anxiety and individuals with DS are most likely to experience panic symptoms.

Area of anxiety	WS (n=20)	DS (n=18)
Obsessive Compulsive Disorder	80%	50%
Social anxiety	50%	39%
Panic/agoraphobia	75%	55%
Separation anxiety	55%	22%
Physical injury fears	75%	39%
General anxiety	85%	33%

We also wanted to see whether there would be a relationship between anxiety and motor ability, as we hypothesised that the high anxiety that individuals with WS often experience could be limiting their performance on motor tasks. For example, we suspected that the poor performance on the balance task was contributed to by fear of falling off the beam. However, we did not find a correlation between motor ability and anxiety in either group. This suggests that, while individuals may struggle with their motor ability and have high anxiety, these two are unrelated and not impacting each other.

Daily living

Finally, we assessed daily living ability in individuals with WS and individuals with DS. We did this in two ways: firstly, by designing a practical daily living assessment (P-DLT), specifically to be used with individuals with WS and individuals with DS, and also by asking parents to fill out an online questionnaire about their son/daughters daily living skills. We found that there was no difference between the WS and DS group on their performance on the P-DLT. Individuals in both groups found the tying shoelaces task most difficult and the pouring water from a jug task easiest. Individuals also struggled with doing up buttons on a shirt, and appeared to have difficulty in planning when asked to complete a washing up and tidying up tasks (e.g. participants would put clean items back with dirty items, miss out items when putting them away, etc.). It may be helpful for individuals from both groups to use visual help sheets to plan tasks with lot of steps, as it was observed that individuals tended to do better on the tidying up task when they made good use of the help sheet provided.

We were also interested in whether there was a relationship between motor ability and daily living skills in individuals with WS or individuals with DS. We found that motor ability was associated with the P-DLT, our novel practical daily living task. Thus, a focus on the motor and planning demands of everyday tasks (e.g. breaking the task into ordered steps, practicing the motor elements) could have a significant impact on independence and daily life of individuals with WS and individuals with DS.

Tips for families

- Be aware that the motor difficulties are not straightforward, and if the individual is prone to anxiety then they might be less likely to want to engage. If they are likely to be doing something that they are anxious about due to motor skills then practice these tasks with them beforehand to improve confidence.
- People with WS and DS need a safe and supportive place to practice motor skills. They need to be able to enjoy physical activity to practice motor skills. Encourage people with WS/DS to engage in sports and exercise/walk a bit further/try new things.

- Find motor activities that the individual enjoys taking part in. This could be something like joining a sports club, going dancing or doing art activities. Not only will doing these activities potentially improve motor skills, but they will also build confidence in the individual's own abilities.
- It may be helpful for individuals to use visual help sheets to plan tasks with lot of steps, as it was observed that individuals tended to do better on the tidying up task when they made good use of the help sheet provided.

Many thanks again to all the families who took part in this research, and to all who showed support and interest in this project. Thank you as well to the Williams Syndrome Foundation, UK for helping to fund this project and for all their help with recruitment. Thank you as well to the Down Syndrome Association who advertised this project and to all the groups on social media who shared the project details.

Sincerely,

Leighanne Mayall, Emily Farran and all of us at the UCL Institute of Education.