

## **SUPPORTING ADOLESCENTS AND ADULTS WITH WILLIAMS SYNDROME TAKE STEPS TOWARDS INDEPENDENCE**

*These guidelines were informed and reviewed by a group of parents/caregivers of adults with WS who attended a focus group on independence, held at the UK Williams Syndrome Foundation convention in 2022.*

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### **Why is independence important?**

We all crave independence as we grow up, particularly during adolescence and into young adulthood. Having opportunities to be independent is important for individuals with WS as it provides exposure to new situations, from which new skills are learnt for the future. It also helps to build confidence, self-esteem and a sense of achievement.

### **What does it mean to be independent?**

What independence looks like will differ from person to person, depending on individual factors and different contexts. Independence does not have to mean independent from support. It's about taking steps towards a gradual increase in autonomy.

### **What challenges do adolescents and adults with WS face in gaining independence?**

Providing people with WS with the opportunities they need to develop independence comes with various challenges. Below are some challenges experienced by parents and caregivers of adolescents and adults with WS.

- Access to public transport
- Ability to navigate from A to B
- Access to social care
- Access to community activities
- Urban vs. rural living
- Caregiver concerns over vulnerability
- Ensuring safety and managing risks
- Internet independence
- Family expectations vs. adult abilities
- Support from others
- Managing hyperacusis and sensory difficulties (the wind, dogs barking)
- Managing anxiety and social phobia

Understandably, parents and caregivers of those with WS may feel anxious about their son/daughter's independence. Concerns about safety and vulnerability can be a huge challenge in supporting individuals with WS to take steps towards independence. We know from research that parents often manage concerns by restricting opportunities for socialisation and high levels of supervision.

These worries may limit the opportunity that the individual with WS has to practice independent navigation, learn from social situations and build self-esteem.

### **Setting small goals**

Identify a realistic goal – the goal may relate to building skills and confidence for later life, but it is important that the goal links to the individual's motivations and desires. A goal might be a trip to the cinema with a friend, walking to the local postbox to post a letter, or to join a club to meet people.

One parent suggested completing a task in a relatively safe environment like a supermarket. The goal could be to find items, load the conveyor belt, trolley etiquette, queue, pay and pack their chosen items e.g. to make a chosen recipe.

In working towards a goal, it can be helpful to break it down into gradual **learning opportunities**.

### **Tips suggested by caregivers for building independence**

- ❖ Ensure the individual with WS decides which activity/goal they want to focus on.
- ❖ Take small steps and manage risk.
- ❖ Set up situations where the individual increases independence within their capabilities.
- ❖ Try things out in controlled, safe environments.
- ❖ Plan – if things go wrong what is the course of action?
- ❖ Monitor and teach safety skills (especially online).

### **Navigating independently**

When learning a new route, it is essential for the individual with WS to practice many times. When practising, ask the adult to actively lead you from point A to point B, correcting their errors as you walk along.

Encourage the individual to point out and verbalise useful landmarks. For example, “There is a post-box at this corner”. Teach about which landmarks are most useful and why. Individuals with WS show a strong reliance on landmarks and it’s important that they know how to select useful ones.

Most people with WS find it difficult to understand the layout of an area. This makes taking short cuts or alternative routes extremely challenging. Make sure the individual has strategies to use if they should become lost, or if their usual route is unavailable (e.g. know how to phone someone). Knowing what to do in these situations can help the individual to stay calm and reduce anxiety.

Be aware that the return route should be learned as well, as the visual environment is different when travelling back!

A supermarket is a good place to start navigating. The individual could practice finding items using a fixed route. Ask them to verbalise key landmarks (bakery, freezer section). They could try locating where the entrance / exit / checkouts are from different points in the supermarket. This is extremely challenging but can be used to adapt a learned route.

For more guidance on navigation and related research, see [here](#)

Example goal: ***to travel independently by foot to the local club***

Learning opportunities towards this goal:

- Practice the full route multiple times with a parent (discuss the journey together)
- Practice the route with a trusted, familiar person (but not a direct family member). Adult is supported to lead.
- Adult is supervised for most of the journey, but completes the last step independently and is met at the end destination
- Adult is supervised for the first step of the journey and is met at the end destination
- Adult independently walks the route, in communication via text with family member, and is met at the end destination

*After each step have a conversation about what worked well/not so well, how the adult felt about it, to learn from the experience. Lots of planning involved e.g., what to do if there are roadworks; ensuring phone is charged (back up phone?), know who to ask for help if needed.*

## Social independence

Many individuals with WS enjoy meeting new people and thrive on social interaction. Socialising helps to develop conversational skills, creates a sense of connection with others, helps to develop friendships and positively impacts mental health and wellbeing. However, opportunities for socialisation may not be as frequent in adulthood and research tells us that adults with WS can experience loneliness. We also know from research asking adults with WS to reflect on their friendships, that activities in the community provide meaningful opportunities for individuals to develop and maintain friendships.

It is important to acknowledge that where an interaction does not go so well, it can knock the confidence of the individual and their family members. Individuals with WS may need support in understanding why an interaction did not go well – talk this through and reflect on what they would do next time.

Social interactions may need to be controlled to varying levels based on concerns of vulnerability. Alternatives to parent supervision include organised groups, trusted friends of the family, buddy and befriending schemes.

### Creating opportunities for adults to socialise outside of the family may include:

- Part of organised work/activity
- Clubs/community groups
- Meeting up with friends
- Online (but very clear guidance needed)
- Respite clubs
- Enjoyable employment
- Internships via colleges
- Specific tasks e.g., going to the shop to buy specific items, going to the hairdresser

Currently there is little research evidence on strategies to foster healthy social relationships and reduce social vulnerability. However, we know from research that individuals with WS can find it challenging to make judgements of trust, so may benefit from training on stranger danger awareness, evaluating others' intentions and identifying deceit. Teaching on safe online interactions is important given individuals will often be keeping in touch with friends via social media.

### Support with the issues mentioned above:

- People with a learning disability in the UK are entitled to a free bus pass and free travel for a carer [Subsidised travel for people with a learning disability | Mencap](#)
- Schemes: travel buddies and travel training [Local transport initiatives for people with a learning disability | Mencap](#)
- Finding the right PA for your child.
- Some parents recommend adapted SmiLE therapy as a good way of practising social and communication skills in a safe environments.
- Hazard Alley safety centre (if you are local to Milton Keynes) <https://www.safetycentre.co.uk>
- [Williams Syndrome Foundation - www.williams-syndrome.org.uk](http://www.williams-syndrome.org.uk)  
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