Adults with PWS need lifelong support in daily activities, study finds

Functional skills 'remain largely consistent' once patients reach adulthood

Written by Andrea Lobo | January 22, 2026

Adults with Prader-Willi syndrome (PWS) need substantial support with daily activities, including personal care, social interactions, and problem solving, according to a study from Japan.

The results suggest “that once adulthood is reached, daily living skills and adaptive functioning remain largely consistent over time,” the researchers wrote. “Early intervention in childhood, followed by continued support into adulthood, may be crucial for maintaining independence and enhancing quality of life in individuals with PWS.”

Previous studies have shown that children gain functional independence as they grow older.

The researchers found that most participants in the adult study could manage certain tasks — including chair and toilet transfers, walking, and memory tasks — independently. However, they needed help with others.

The study, “Functional Independence in Adults With Prader–Willi Syndrome: First Report Using the FIM Instrument,” was published in the *American Journal of Medical Genetics*.

Retrospective analysis looks for age, genetic effects on function

PWS is caused by the loss of function of genes in a region of chromosome 15 known as the PWS locus. This occurs when the genes inherited from the father are not active, as they should be, while the corresponding genes inherited from the mother are switched off as usual. This leads to PWS symptoms including poor muscle tone and feeding difficulties in infancy, followed by excessive hunger and progressive obesity during childhood and adulthood, as well as developmental delays and behavioral problems.

The researchers conducted a retrospective analysis to explore the effects of age and genetics on functional outcomes in 54 adults with PWS followed at Dokkyo Medical University Saitama Medical Center. Most participants (68.5%) were young adults (ages 18-29), with a mean age of 23, while 31.5% were 30 and older, with a mean age for that group of 33.7.

In both groups, the most common genotype was deletion (about 70%), in which PWS locus genes on the paternal chromosome 15 are missing or deleted. About 30% had maternal uniparental disomy, or when the child inherits two inactive copies of chromosome 15 from the mother and none from the father.

The older group had a higher body mass index (BMI), a measure of body fat based on weight and height, than younger adults (36.5 vs. 26.9), reflecting the known tendency toward progressive weight gain in people with PWS.

There was no significant association between age and total, motor, or cognitive Functional Independence Measure scores. Motor items include self-care (such as eating and dressing), bladder and bowel control, locomotion, and transfers (bed/chair/wheelchair and toilet), while cognitive items include communication, social interactions, problem-solving, and memory.

The study found no significant differences in functional independence between the two main genetic subtypes.

“Neither chronological age nor genetic subtype had measurable effects on overall, motor, or cognitive functional independence,” the researchers wrote.

The highest rates of independence, corresponding to higher FIM scores, were observed for chair and toilet transfers (88.9%), followed by tub transfers (85.2%), walking (83.3%), and memory (81.5%). There were also high independence rates for climbing stairs, toileting, bladder and bowel control, and dressing.

On the other hand, adults with PWS required considerable support in areas such as grooming (35.2%), social interactions (29.6%), bathing (25.9%), and problem solving (25.9%). The researchers identified these as “key targets for intervention.”

Overall, the older participants exhibited a tendency toward lower FIM scores than younger adults, particularly in domains of grooming, comprehension, and expression, although the differences were not statistically significant.

There were also no significant differences between participants with IQ scores below 50 (considered intellectual disability) and those with IQ scores of 50 or higher. However, those with higher scores showed slightly higher mean scores.

“These findings underscore the need for structured long-term care planning and integrated support systems for adults with PWS, including access to specialized rehabilitation, community-based services, and coordinated multidisciplinary care across the lifespan,” the researchers wrote.

About the Author

Andrea Lobo Andrea Lobo is a Science writer at BioNews. She holds a Biology degree and a PhD in Cell Biology/Neurosciences from the University of Coimbra-Portugal, where she studied stroke biology. She was a postdoctoral and senior researcher at the Institute for Research and Innovation in Health in Porto, in drug addiction, studying neuronal plasticity induced by amphetamines. As a research scientist for 19 years, Andrea participated in academic projects in multiple research fields, from stroke, gene regulation, cancer, and rare diseases. She authored multiple research papers in peer-reviewed journals. She shifted towards a career in science writing and communication in 2022.

ORIGINAL ARTICLE

Functional Independence in Adults With Prader–Willi Syndrome: First Report Using the FIM Instrument

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ABSTRACT

A significant positive correlation between age and functional independence has been reported in pediatric patients with Prader–Willi Syndrome (PWS) using the Functional Independence Measure (FIM) for Children (WeeFIM). However, no previous study has evaluated the use of the FIM in adults with PWS. This study aimed to assess functional independence in adults with PWS using the FIM and to explore the effects of age and genetic subtype on functional outcomes. We conducted a retrospective, single-center study of 54 genetically confirmed patients with PWS of Japanese descent. No significant correlations were observed between age and FIM scores. Similarly, no significant differences were found between age groups or genetic subtypes in total, motor, or cognitive FIM domains. Radar chart analysis illustrated slightly lower FIM scores in older adults, although these differences were not statistically significant. These findings highlight the importance of individualized support plans tailored to age and specific functional needs. Early intervention in childhood, followed by continued support into adulthood, may be crucial for maintaining independence and enhancing quality of life in individuals with PWS.

Conflicts of Interest

The authors declare no conflicts of interest.