

OASIS · AT A GLANCE

Incontinence in Autistic Adults: Management, Dignity, and Getting Help

One of the most common daily realities of caregiving for a Level 2 or 3 adult, and one of the least discussed anywhere. Five different causes exist, and they don't all call for the same response.

BY JIM PALASTY · 10 MIN READ · FIVE CAUSES, AND THEY ALL NEED A DIFFERENT ANSWER

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DISTINCT CAUSES OF INCONTINENCE IN AUTISTIC ADULTS

Never fully achieving continence, regression during transitions, medical causes like UTIs or constipation, sensory factors, and behavioral factors. Each one points toward a different response.

How it works

THREE STEPS

STEP 1

The topic barely gets discussed

Incontinence is one of the most common daily caregiving realities and one of the least written about anywhere.



STEP 2

Cause matters more than the symptom

The right response to incontinence depends entirely on which of several very different causes is actually driving it.



STEP 3

Dignity and cost both deserve attention

Practical management strategies and the real financial burden of supplies both belong in this conversation.

Matching cause to response

Never achieved continence	Ongoing management approach, not a corrective one
Regression after a transition	Investigate the stressor; may resolve with stability
Medical cause (UTI, constipation)	Requires medical evaluation and treatment first
Sensory factors	Occupational therapy evaluation may help
Behavioral factors	Functional assessment, similar to other behavior patterns

THE UTI THAT HAD BEEN THERE FOR MONTHS

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Sherry's son had a sudden increase in incontinence episodes that she assumed was a permanent regression, until a caregiver support group member asked a simple question: had anyone checked for a UTI. He had one, likely for months, undetected because he couldn't verbally describe the discomfort. Treatment resolved the new incontinence pattern within two weeks, a physical cause the whole time, never actually a regression at all.

MONTHS OF ASSUMED REGRESSION
TURNED OUT TO BE AN INFECTION
NOBODY HAD THOUGHT TO TEST FOR.

What matters, at a glance

Never fully achieving continence

Some adults never developed full continence, requiring an ongoing management approach rather than a corrective one.

Regression during transitions

Stress, change, or loss of services can trigger a genuine regression in previously achieved continence.

Medical causes get missed often

UTIs and constipation are common, treatable causes of incontinence that frequently go undiagnosed in adults who can't report symptoms clearly.

Sensory and behavioral factors

Some incontinence relates to sensory processing or behavioral patterns rather than a purely physical cause, and needs a different kind of support.

Supplies are expensive and often uncovered

Adult incontinence products carry real, ongoing cost, and Medicaid coverage varies significantly and often falls short.

Community access is a real barrier

Reliable incontinence management directly affects whether outings, day programs, and community activities are actually feasible.

BRING THESE · CHECK AS YOU GO

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| ☐ A medical evaluation ruling out UTI, constipation, or other physical causes | ☐ Notes on any recent transitions, stressors, or service changes |
| ☐ Contact information for an occupational therapist, if sensory factors are suspected | ☐ Research into your state's Medicaid coverage for incontinence supplies |
| ☐ A consistent bathroom routine or visual schedule, if helpful | |

YOUR MOVE

When incontinence changes or begins, here is how to approach it

- 1 Rule out a UTI, constipation, or other medical cause first.
- 2 Note whether the change coincided with a specific stressor or transition.
- 3 Consider whether sensory factors might be involved; request an OT evaluation if so.
- 4 Build a consistent, predictable bathroom routine and visual schedule.
- 5 Research Medicaid and other coverage options for incontinence supplies.
- 6 Address community access barriers directly rather than avoiding outings.

This is one of the most common challenges caregivers face and one of the quietest. You are not failing at something everyone else has figured out.

INCONTINENCE MANAGEMENT RESOURCES

The National Association for Continence (nafc.org) offers management resources and product guidance applicable to adults with disabilities.

Check your state Medicaid program directly for incontinence supply coverage, since benefits and reimbursement levels vary significantly by state.

Informational only. Not legal or medical advice. Verify current program rules before acting.

ABOUT THE AUTHOR



Jim Palasty

Jim Palasty is the founder of OASIS for Autism and a single father of an adult autistic daughter in Michigan.