## Approaching Encopresis with Sensitivity

There is significant correlation between childhood fecal incontinence (encopresis) and complex presentations and family circumstances. The correlations include (but are not limited to) anxiety/depression, decreased attendance, and poorer school performance for children. Additionally, children with encopresis are statistically more likely to come from family environments which are less emotionally expressive and less organized, and where parents have fewer socio-economic resources and less educational attainment. The American Academy of Pediatrics also warns that "more abuse occurs during toilet training than during any other developmental step".

This challenging combination of factors means that providers must be extremely sensitive in the management of fecal incontinence in children and youth, particularly when trauma or abuse are suspected or known. Below are some recommendations for where to start with addressing fecal incontinence with vulnerable or abused children and youth.

### **Priorities**

Supporting the dignity and social, emotional, and physical safety of the child comes first.

- Always allow a person who is incontinent to have a barrier garment (disposable brief, pull-up or diaper), and support them to find discrete ways to transport and dispose of them.
- Decrease financial stress on families by helping them to access Medicaid funded continence supplies
- Develop an in-school plan, both for unexpected accidents, and routine hygiene
- Offer the child a private and secure restroom to change
- Collaborate with home and medical to create a laxative schedule that will allow the child to have their bowel movement in the safest, lowest stress time and place.
- Deemphasize the topic of incontinence, and avoid comments about willpower/effort ("why don't you just try?"). Children experiencing fecal incontinence often have shame and secrecy, and first need to be accepted as they already are.

### Team

Encopresis is a complex disorder, best managed by an interdisciplinary team.

- Community Health Team: Coordinates services among many services and providers for vulnerable children and families
- Parent/Guardian: Encopresis causes stress for parents, so integrate parent concerns, needs, and beliefs (inc. reactions, discipline approaches, and hopes)
- **School Nurse:** Confirm that the school nurse knows that there is a child in the program with encopresis, and work to develop an Individualized Health Plan, particularly if there is no IEP, 504, or other individualized plan.
- **School Counselor:** Mitigate/address bullying ostracization risks.
- School OT/PT/SLP: Plan accommodations and programming to match child needs.
- **Pediatrician/Gastroenterologist:** Modify medication regimens and sitting schedules. May also have a care coordinator to help with communication and resources.
- **Outpatient/Community Mental Health:** Spend dedicated time with children, parents, and families to support or resolve stressors contributing to incontinence.

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### Education

Most parents and caregivers do not willfully refuse or neglect their child's medical care, but may struggle to understand or execute a program from a doctor or mental health professional.

- **Health:** Educate the parent as to why the incontinence is not the child's fault, and may not be within their control (including accidents, refusing to sit, etc.)
- Medication: Explain the relationship between constipation, withholding, and incontinence. Parents better adhere to medication and toileting plans when they understand that they are crucial for development of continence.
- **Sitting Schedules:** Offer supports such as reinforcer schedules, visual supports, and positioning supports.
- Cycles of Stress: Offer education on how the child responds to stress, or why they may
  not feel free or ready to practice toileting. Parents may also need education on their own
  stress response, and how that impacts their management/support of their child.
- Language & Communication Offer scripts for parents to respond to accidents. Instead of "Well, I told you to go use the toilet, but now you're filthy!", try "It feels hard to try and use the toilet right now".

### **Resources and References**

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