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Beyond One-Size-Fits-All: A Tailored Approach to Perioperative Pain in Youth with Developmental Disabilities

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Undergoing surgery is uniquely challenging for youth with developmental disabilities, a variety of conditions that cause varying degrees of physical, intellectual, language, and/or behavioral needs (e.g., intellectual disability, Down syndrome, autism spectrum disorder; Balakas et al., 2015). Sensory challenges like alarms, needle sticks, bright lights, strong smells, and disrupted routines are inherent in a fast-paced hospital environment (Selvey et al., 2019; Winterberg et al., 2022), triggering distress, disruptive behaviors, aggression, self-injury, and nonadherence with care (Winterberg et al., 2022; Selvey et al., 2019). Beyond safety concerns and unmet healthcare needs (Winterberg et al., 2022), perioperative distress may also increase vulnerability to postoperative pain (Valkenburg et al., 2012).

Though under-researched, youth with developmental disabilities likely face higher postoperative pain risk when compared to typically-developing peers, largely attributed to greater medical complexity, atypical pain expression, challenges with developmentally-appropriate pain assessment, and variation in providers' medication administration (Valkenburg et al., 2012; Bevan et al., 2023; Winterberg et al., 2022).

Despite progress in postoperative pain assessment and treatment (Densmore et al., 2010; Brimeyer et al., 2024), targeted research in youth with developmental disabilities is lacking, as this population is largely excluded from studies investigating best practices (Winterberg et al., 2022).

Consequently, healthcare providers report lower confidence in caring for youth with developmental disabilities undergoing surgery (Selvey et al., 2019). The wide variability in need, development, triggers, and coping makes a universal approach to perioperative pain care in this population challenging. Nonetheless, reducing perioperative distress may be a key modifiable factor in improving postoperative pain outcomes (Bevan et al., 2023). Understanding patients' unique needs and finding practical ways to adapt surgical care using individualized, biopsychosocial, and interdisciplinary planning can promote safer, more equitable healthcare for patients with diverse needs (Selvey et al., 2019). This commentary outlines preliminary evidence-based recommendations for adapting surgical care to minimize pain risk in youth with developmental disabilities. These strategies should be further tailored to each patient's individual needs and clinical circumstances.

- 1) **Family-centered care.** Requires proactive communication between the healthcare team and the family. Before surgery, educate families about what to expect, invite questions, and gather patient preferences to minimize uncertainty. Communicate directly and concretely with the patient using their preferred communication method whenever possible (e.g., "new, clean bandages" instead of "dressing change"; Calkins et al., 2020; Nchinda et al., 2026; Winterberg et al., 2022; Bevan et al., 2023). Clinicians should ask

caregivers how their child best understands and communicates medical information.

- 2) **Coordinated communication.** Designate a “spokesperson” (a longer-term provider like a nurse, psychologist, or Child Life Specialist (CLS) to provide consistent messaging between the healthcare team and family. Prioritize care coordination through rounds or secure messaging to avoid providing families with conflicting guidance (Calkins et al., 2020; Selvey et al., 2019; Balakas et al., 2015; Winterberg et al., 2022; Bevan et al., 2023).
- 3) **Preoperative pharmacological planning with a pharmacist.** Consultation is beneficial when premedication or sedation is needed, particularly given the medical complexities of this population. Pharmacists offer expertise in medication delivery to reduce patient burden, offering strategies to mix or mask medicines (Selvey et al., 2019). Involving parents optimizes medication delivery and adherence, while pediatric psychologists can recommend non-pharmacological strategies and identify when premedication may be warranted (Calkins et al., 2020; Selvey et al., 2019; Veeravalli et al., 2025; Winterberg et al., 2022; Bevan et al., 2023).
- 4) **Conduct individualized preoperative assessment.** Seek preoperative input from parents, therapists, teachers, and specialists to understand a patient’s abilities and needs. Obtain a thorough history of past surgical/medical experiences, sensory sensitivities, triggers, effective coping strategies, preferred means of communication, items or strategies that soothe the patient, pain expression, degree of disability, behavior, ability to transition, and strengths. Results should inform a *personal patient care plan* that is clearly documented in the patient’s chart and visible at bedside. High-risk patients can be flagged to direct staff to the personalized care plan (Selvey et al., 2019; Veeravalli et al., 2025; Winterberg et al., 2022). See Balakas et al., 2015; Bevan

et al., 2023, or Nchinda et al., 2026, for examples of structured preoperative interviews.

- 5) **Preoperative desensitization to the hospital environment.** Use medical play or pre-surgery visits to build positive associations with the hospital and facilitate familiarity and rapport with staff (though it must be individualized, as preoperative exposure to the hospital may exacerbate/elicit anxiety). Social stories offer an alternative to familiarize the patient with what to expect. Allow comfort items (e.g., familiar bedding) and encourage distraction (Winterberg et al., 2022; Selvey et al., 2019; Veeravalli et al., 2025; Balakas et al., 2015; Nchinda et al., 2026).
- 6) **Streamline admission procedures.** Complete paperwork in advance, facilitate modified hospital arrivals (e.g., have staff escort the patient from the car to clinic, allow access to priority parking, valet, or an alternate entrance into surgery clinic), allow multiple caregivers to accompany the patient for extra support, and/or schedule surgery as the first case of the day to reduce wait time. Maintain consistent staff throughout the perioperative process and arrange pre-surgery staff introductions when possible. A CLS can escort the patient and family throughout their surgical care. Using care clustering, or performing multiple procedures under one administration of anesthesia, reduces patient burden (Bevan et al., 2023; Selvey et al., 2019; Veeravalli et al., 2025; Balakas et al., 2015; Nchinda et al., 2026; Winterberg et al., 2022).
- 7) **Adapt preoperative/perioperative procedures,** where appropriate. Allow the patient to wear their own clothing versus a hospital gown, accept flexible placement for ID bracelets, obtain admission weight at home, defer or spot-check vitals versus continuous monitoring, and/or ensure the patient’s comfort items are available in the room. Allow caregiver(s) to be present during

both anesthesia induction and recovery prior to the patient waking. When indicated, utilize validated pain assessment tools — such as the Visual Analog Scale (VAS; Benini et al., 2004) for patients capable of self-reporting or the revised-FLACC observational scale (Malviya et al., 2006) for those unable to self-report — to ensure accurate and reliable evaluation of postoperative pain. Provide a visual schedule outlining steps in the perioperative process (Bevan et al., 2023; Selvey et al., 2019; Veeravalli et al., 2025; Balakas et al., 2015; Nchinda et al., 2026; Winterberg et al., 2022).

8) **Adapt the surgical environment to be consistent, predictable, and low-stimulus.**

This may require considerable creativity and flexibility from the healthcare team to adjust procedures to meet nuanced patient needs. Key strategies may include: dimming lights, reducing disruptions by using “quiet zone” signage, offering a quieter, alternate waiting room, limiting staff allowed in the room, removing or disguising triggering medical equipment, choosing a room away from exits to minimize elopement risk, consolidating care into as few rooms as possible, and/or allowing the patient to walk the halls if desired (Bevan et al., 2023; Selvey et al., 2019; Veeravalli et al., 2025; Balakas et al., 2015; Nchinda et al., 2026; Winterberg et al., 2022).

9) **Maximize non-pharmacological pain management.** Use techniques such as diaphragmatic breathing, vibration, relaxation, and distraction/alternate focus. When possible, use wound closure materials like Dermabond or SteriStrips instead of sutures or staples to avoid stressful postoperative removal (Selvey et al., 2019; Winterberg et al., 2022).

10) **Minimize postoperative distress.** Have caregivers lead dressing changes, vitals, and bathing when appropriate. Prioritize prompt discharge by providing discharge instructions before the child wakes from anesthesia and discharge directly from the PACU (Post-Anesthesia Care Unit) if applicable to minimize transitions. Decrease postoperative distress by preemptively giving IV hydration in the operating room (to minimize the need for postoperative fluid intake) and removing IVs while still under anesthesia. Consolidate follow-up visits to minimize clinic trips (Selvey et al., 2019; Nchinda et al., 2026; Bevan et al., 2023).

11) **Encourage adherence.** Use distraction, comfort items, and rewards/incentive or token economies when appropriate. Demonstrating procedures using “Tell Show Do” and using additional strategies like behavioral shaping, contingencies (e.g., if/then, first/then), offering pre-task choice or “choice where possible,” and prompt hierarchies (e.g., modeling, completing least-to-most demand tasks) can be beneficial (Veeravalli et al., 2025; Selvey et al., 2019; Winterberg et al., 2022).

Youth with developmental disabilities face unique and diverse perioperative challenges. Drawing on emerging research, this commentary offers an initial framework for more equitable surgical care, but more research is needed.

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