

Intellectual and Developmental Disabilities

Matching Level of Clinical Support to Patient Risk When Caring for Children with Behavioral Challenges

--Manuscript Draft--

Manuscript Number:	IDD-D-20-00110R2
Article Type:	Perspectives
Keywords:	adaptive care plan; family-centered care; behavior risk
Corresponding Author:	Melissa Liddle, PsyD, CCLS, CTRS Cincinnati Children's Hospital Medical Center Cincinnati, OH UNITED STATES
First Author:	Kerri Birkett, MS, CCLS, CIMI
Order of Authors:	Kerri Birkett, MS, CCLS, CIMI Melissa Liddle, PsyD, CCLS, CTRS Emily Jones, MS, MEd, CCLS Andrea Paulson, MD, MPH
Manuscript Region of Origin:	UNITED STATES
Abstract:	Adaptive care plans (ACPs) are an innovative method to providing care for children and adolescents with developmental disabilities who have challenging behaviors during healthcare encounters. ACPs take a family-centered approach to ensure that children with developmental disabilities are able to receive safe and appropriate healthcare by increasing communication and collaboration between caregivers and healthcare team members. Differing healthcare professionals are strategically involved in order to appropriately match the level of support to the patient's behavioral risk through a review of two case examples from the pediatric physical medicine and rehabilitation department. Specifically, case examples describe varying levels of accommodations and support provided to children with challenging behaviors, whose behaviors may have otherwise prevented them from receiving appropriate health interventions.

Matching Level of Clinical Support to Patient Risk When Caring for Children with Behavioral Challenges (IDD-D-20-00110R1)

Reviewers' comments:

1. On page 9, "Andy was identified to be at moderate risk... based on PRAP score of 12."

2. On page 10, "His ACP identified him t high risk based on his PRAP score of 18. "

Perhaps consider rephrasing to indicate "... risk based, in part, on his PRAP score."

Great suggestions. We have made the recommended changes to the manuscript on page 9 and 10.

On page 9, "Andy was identified to be at moderate risk for experiencing psychosocial distress for botulinum toxin injections in PRM based, in part, on his PRAP score (moderate range; score of 12)."

On page 10, "His ACP identified him to be at high risk, in part, due to his PRAP score of 18."

Matching Level of Clinical Support to Patient Risk When Caring for Children with Behavioral Challenges

Acknowledgements: Information described in the article has not been presented previously.

Thank you to the dedicated ACP child life specialists (Mary Faith Roell, Leslie Miller, Lauren Straub, and Maggie O'Grady) who make ACPs possible and provide supports to children with developmental disabilities and their families.

Key Words: adaptive care plan, family-centered care, behavior risk

Financial Disclosures: The authors have no financial relationships relevant to this article to disclose. The PRAP is licensed and sold by Cincinnati Children's Hospital Medical Center; the authors have no financial ties to the PRAP sales and distribution.

Conflict of Interest: All authors have indicated they have no potential conflicts of interest to disclose.

Contributor Statements: All authors conceptualized and drafted the initial manuscript and reviewed and revised the manuscript, as well as approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Running Head: MATCHING LEVEL OF CLINICAL SUPPORT

Abstract:

Adaptive care plans (ACPs) are an innovative method to providing care for children and adolescents with developmental disabilities who have challenging behaviors during healthcare encounters. ACPs take a family-centered approach to ensure that children with developmental disabilities are able to receive safe and appropriate healthcare by increasing communication and collaboration between caregivers and healthcare team members. Differing healthcare professionals are strategically involved in order to appropriately match the level of support to the patient's behavioral risk through a review of two case examples from the pediatric physical medicine and rehabilitation department. Specifically, case examples describe varying levels of accommodations and support provided to children with challenging behaviors, whose behaviors may have otherwise prevented them from receiving appropriate health interventions.

Keywords:

adaptive care plan

family-centered care

behavior risk

MATCHING LEVEL OF CLINICAL SUPPORT

Matching Level of Clinical Support to Patient Risk When Caring for Children with Behavioral Challenges

Background

Children and adolescents with developmental disabilities (DD) often experience challenges in a healthcare setting, impacting the quality of care they receive. Importantly, children with DD experience a greater number of healthcare encounters compared to their typical developing, same-aged peers (Boulet et al., 2009; Chan et al., 2002; Liptak et al., 2006), as they also have a higher number of complicating medical conditions such as seizure disorders, pulmonary, and gastrointestinal conditions (e.g., Levy et al., 2010; Schieve et al., 2012). Despite having more encounters, health care experiences continue to be difficult. Parents indicate that children with DD experience challenging behaviors in a health care setting due to environmental or situational factors (e.g., long waits, bright lights, crowded waiting areas), communication barriers, children's fears, and in response to parents feeling overwhelmed during appointments (Bultas et al., 2016). Importantly, physicians reported that a child or adolescents' challenging behavior (e.g., hyperactivity, self-injurious behavior, sensory challenges) is the largest barrier to productive healthcare visits and often leads to difficulties with compliance (Bultas et al., 2016; Johnson and Rodriguez, 2013; Loo et al., 2009). Challenging behaviors may be in part why children with DD have a greater number of unmet health care needs compared to typically developing children (Centers for Disease Control and Prevention, 2010). This is particularly true for children with autism spectrum disorder (ASD; Kogan et al., 2008), due to their higher rates of problem behaviors, which is consistent with other research (e.g., Bultas 2012; Scarpinato et al., 2010).

Adaptive Care Plans

MATCHING LEVEL OF CLINICAL SUPPORT

Several interventions (e.g., praise and reward, distraction, picture or visual schedules, and coping kits) have been found to be successful in reducing challenging behaviors during health care encounters (Chebuhar et al., 2013; Drake et al., 2012; Johnson et al., 2014). One intervention developed prior to the health care encounter is a Quick Tip Card where parents write about their child's communication, sensory sensitivities, problematic behaviors, fears, and calming strategies and share this information with the health care team to curb difficulties (Bultas et al., 2016). Unlike aforementioned strategies and approaches, adaptive care plans (ACPs) as a collaborative endeavor between healthcare team members and caregivers of children with DD who have difficulty coping and cooperating in healthcare settings in order to provide proactive management of challenging behaviors during their encounters (Liddle et al., 2018). A child life specialist and the child's parent or caregiver collaborate to identify the child's past healthcare experiences, stressors and reactive behaviors, adaptability, communication preferences (e.g., primary language, visual images, etc.), sensory sensitivities, pain responses, and interests or motivators (see Liddle et al., 2018 for additional information and a sample ACP), which is developed into an ACP in the child's medical record. For patients who have existing behavior plans (i.e., developed in therapies or at school), this information can be incorporated into the ACP as applicable.

Essential to the ACP process are child life specialists, who are widely recognized as vital members of the interdisciplinary team who promote positive coping through psychological preparation, therapeutic play, and family-centered care (American Academy of Pediatrics, 2021). Child life specialists primarily work in medical settings, while others work in non-traditional settings such as dental offices, hospice organizations, or schools. Depending on the size of the organization, child life specialists may work with a broad range of patients, or they may work in

MATCHING LEVEL OF CLINICAL SUPPORT

a specialty area (e.g., inpatient critical care unit, outpatient surgical setting, emergency department) or with children who have a particular medical diagnosis. Child life specialists are well equipped to support the psychosocial needs of children with DD.

Developed in 2009, adaptive care plans are a relatively new intervention with limited research to date (e.g., Broder-Fingert et al., 2016; Balakas et al., 2015; Liddle & Sonnentag, 2020; Wittling et al., 2018). Despite this, adaptive care plans are increasingly effective to reduce anxiety and increase coping for children with ASD compared to children with other DDs in the outpatient setting (Liddle & Sonnentag, 2020). In a second study of children with ASD, when adaptive care plans (referred to as “autism-specific care plans”) were utilized prior to inpatient experiences, parents reported improved overall healthcare experiences, including increased attention and recognized efforts by the medical staff to support coping with the hospital experience (Broder-Fingert et al., 2016). Wittling and colleagues reported that after the implementation of ACP’s for children with ASD in a perioperative setting, healthcare professionals were more efficient in their time, had an increased comfort level, and greater knowledge of appropriate interventions to increase coping (2018). Additionally, Balakas and colleagues found that within the same setting, a majority of parents with children who had different types of DD were satisfied with the quality of care offered when adaptive care plans were utilized (2015). Therefore, ACPs have been proven to demonstrate positive outcomes from the perspective of parents and healthcare staff, as well as exhibit reductions in anxiety and increases in coping for children with ASD.

As ACPs have been increasingly integrated into our organization’s clinical practice, interdisciplinary healthcare members (e.g., physicians, nurses, patient care attendants, care managers, social workers) have provided higher numbers of ACP referrals. Based on our

MATCHING LEVEL OF CLINICAL SUPPORT

observations, patients meeting the criteria for ACPs are being referred at a higher rate and earlier in their care trajectory than previously. At this time, there are over 2,500 patients at our institution with ACPs requiring support during medical encounters; the number of plans continues to grow in accordance with the increasing population of children with identified developmental disabilities (Boyle et al., 2011). Additionally, implementing ACPs requires considerable resources in terms of each interdisciplinary team member's time and effort (e.g., acknowledgement and review of the plan in the medical record, preparing for environmental adaptations, creating accommodations during the visit; Liddle et al., 2018).

This article describes the varying role that interdisciplinary healthcare staff play when implementing the ACPs and addresses how healthcare professionals can provide the appropriate level of support to match the child's level of psychosocial risk. A demonstration of how healthcare physicians can provide appropriate interventions to match the amount of a child's psychosocial stress is exemplified through two case studies of children who received botulinum toxin injections at a large midwestern hospital's Division of Pediatric Rehabilitation Medicine (PRM).

Matching Support to a Child's Psychosocial Risk

Developing an ACP is a collaborative effort between child life specialists and family members (Liddle et al., 2018). In order to complete an ACP, a child life specialist receives formal training in both ACP development and the *Psychosocial Risk Assessment in Pediatrics* (PRAP) in order to evaluate the child's psychosocial risk or acuity following a medical procedure (Staab et al., 2014). This assessment evaluates the child's psychosocial abilities across eight domains: communication, special needs, temperament, anxiety and coping, past healthcare experiences, invasiveness of the procedure or encounter, the developmental impact of the

MATCHING LEVEL OF CLINICAL SUPPORT

healthcare experience, and the parents' or caregivers' level of stress (see Staab et al., 2014 for an interpretation of scores). Although historical PRAP scores can be used to determine level of risk, other factors such as the type or invasiveness of procedure, healthcare team members' knowledge of DD, ease of adaptations in that clinical area, and the ability of parents to remain calm and provide support are all necessary to consider when determining acuity for a particular procedure or healthcare encounter. After the ACP has been developed, the plan is available to all healthcare team members via the electronic health record (EHR). Based on each child's psychosocial risk level, different interdisciplinary team members (e.g., physician, nurse, medical assistant, social worker, care manager) have varying levels of involvement in the implementation of ACPs as to promote a safe and productive healthcare encounter. Using a report generating system within the institution's EHR, children with upcoming appointments who have ACPs are identified. Each healthcare area has a pre-identified "champion" (i.e., any member of the interdisciplinary healthcare team trained to promote ACPs within their clinical area) who is responsible for receiving and reviewing the ACP electronic report, then alerting the interdisciplinary health care team members that will be managing the child's case.

For children at a moderate level of risk, it is the medical team members (e.g., patient care attendant, registered nurse, and physician) who direct the recommended accommodations in the ACPs. For example, in response to a child who has a sensory sensitivity to touch or a child who is fearful of medical equipment, the nurse may not require vitals to be taken when it is not medically necessary. For a child who withdraws or feels uncomfortable in crowded environments, modifications may include avoiding the waiting room and limiting the number of medical personnel in the exam room at one time.

MATCHING LEVEL OF CLINICAL SUPPORT

When children are at an escalating level of risk, a child life specialist serves as the coordinator for the team when implementing the ACP by engaging in a pre-planning phone call with the child's caregiver to create an encounter-specific plan. Simultaneously, the child life specialist begins communicating this plan with the medical team through email and phone communication as well as coordinating with the child's care manager, if applicable. Feedback from both the healthcare team and the caregivers are used to develop a final plan, which is then disseminated to the healthcare staff prior to the visit. Based on each child's specific needs during the visit, the child life specialist may be providing interventions such as preparation using a visual schedule, engaging the patient in sensory play, or monitoring the patient for unsafe behaviors. The nurse may take selective vitals or complete the intake with the physician present to reduce overall appointment time. After the visit, a short debriefing session is held where all medical staff involved identify successes and continued challenges. The debriefing session serves as an educational opportunity for the interdisciplinary team, and information from the session is used to refine the patient's ACP in the EHR. Following the procedure, parents also participate in debriefing with the support team and planning occurs for the next visit. New information is used to plan for successful subsequent healthcare encounters.

For children who are at high psychosocial risk, the ACP child life coordinator engages in extensive pre-planning prior to the healthcare visit. Similar to the escalating risk level, the child life specialist begins with a conversation via telephone with the child's caregiver and direct communication with the medical team. Through the initial conversation, multiple accommodations are proposed that may help to promote a safe and successful healthcare encounter. In addition to lower-level support strategies, more involved accommodations are developed. For example, with a child who has difficulty transitioning into the medical center, the

MATCHING LEVEL OF CLINICAL SUPPORT

coordinator of the ACP would pre-register a patient prior to their arrival and meet the family at their car, walking them directly to an exam room. Additionally, for children who are extremely fearful of the medical environment or are highly aggressive, the physician may see the patient immediately upon arrival. Unique to this risk level, the coordinator of the ACP would facilitate additional support in conjunction with safety staff and other interdisciplinary team members.

At our institution, the Behavior Safety Team (BST) provides a patient safety service and specializes in helping children who are at extreme risk to themselves and others while in the healthcare environment due to a history of aggression or self-injury. As many children who have high risk also demonstrate aggressive behaviors, the BST's mental health facilitators become heavily involved to ensure a safe healthcare encounter. For example, the team may recommend that the child be paired with a mental health specialist (who is trained to manage aggressive or out-of-control behaviors), require all medical staff to wear personal protective equipment, or implement the safe use of brief, physical restraint, after all other options have been exhausted.

Through ACPs, support at every level can be provided by healthcare team members to ultimately help children cope with the medical environment. With each child experiencing more positive healthcare encounters, they will develop the confidence to more independently be able to navigate the typical protocol of healthcare encounters in the future.

Andy: At Moderate Risk in PRM

Andy, a 6-year-old male with diagnoses of cerebral palsy and severe developmental delay, presented to the PRM clinic for botulinum toxin injections to help manage his spasticity or tightening of his muscles. In collaboration with Andy's mother, a child life specialist developed Andy's ACP prior to his initial PRM visit. According to Andy's ACP, he is sensitive to loud and unexpected noises, bright lights, touch, and he feels overwhelmed around numerous people. He

MATCHING LEVEL OF CLINICAL SUPPORT

also has limited receptive and expressive communication skills that prevent him from understanding information that is presented verbally difficulties when he attempts to express his wants and needs. His ACP identified additional stressors for his procedure in PRM including waiting for his appointment and a fear of needles. Andy was identified to be at moderate risk for experiencing psychosocial distress for botulinum toxin injections in PRM based, in part, on his PRAP score (moderate range; score of 12).

When Andy arrived to PRM, the clinic medical assistant helped Andy and his mother by quickly escorting the family from the waiting room to an exam room with dim lighting, which decreased the amount of sensory stimulation. The “champion” also informed clinic staff about Andy’s specific needs from his ACP and suggested that the medical team reduce the number of persons that were present for the procedure to three (i.e., physician, nurse, and child life specialist). During the procedure, the child life specialist in the clinic engaged Andy in alternative focus during the procedure while Andy’s caregiver was responsible for emotional support and comfort in the form of soothing touch. The physician provided Andy within-the-moment sensory preparation that informed him when he would be experiencing different sensations (e.g., feeling cold wiping from the alcohol, touching to his leg, feeling poke from the needle etc.; Cohen, 2008). With these adaptations in place, Andy was able to cooperate with his injections, displaying minimal distress (e.g., crying, moaning), a typical response for a child receiving these injections.

Kyle: At High Risk in PRM

Kyle, a 19-year-old male with neurodevelopmental, psychological, and communication challenges (i.e., diagnoses of autism, moderate intellectual disability, intermittent explosive disorder, and significant communication limitations), who presented to the PRM clinic to help

MATCHING LEVEL OF CLINICAL SUPPORT

treat his limited mobility of his feet or acquired equinus deformity. He was no longer progressing with physical therapy and previously underwent a bilateral strayer procedure as well as plantar medial soft tissue release. He continued to have significant plantarflexion contractures, and both the physician and his mother felt that he would not tolerate a triple arthrodesis/complete cavus bony foot reconstruction or the post-op weight bearing restrictions. If Kyle's equinus deformity was not addressed, he would experience worsening gait with decreased endurance and increased pain. Therefore, it was recommended that he was treated with botulinum toxin injections combined with orthotic devices to try and manage his ankle position.

According to his pre-established ACP, Kyle had severe sensory sensitivities to both touch and unfamiliar textures. He would not tolerate the sticky texture or coldness of topical numbing agents and would attempt to escape from these situations. His ACP identified him to be at high risk, in part, due to his PRAP score of 18. In addition to medical experiences, information in his ACP indicated that his long drive to the medical center causes him to experience distress. Kyle's other stressors included the transition from his mother's car to the clinic, waiting prior to the appointment, waiting in the exam room for his PRM procedure, laying down on the table, and fear of needles. When experiencing these stressful demands, Kyle would engage in aggressive behavior toward himself and others. In discussing these concerns with Kyle's mother, general anesthesia was offered. Kyle's mother expressed concern that general anesthesia would be more stressful and invasive for Kyle and preferred to have his botulinum toxin completed in clinic rather than using general anesthesia.

Kyle's safety concerns warranted a phone call with his caregiver in order to identify any additional stressors and to discuss specific components of the medical visit that could have the potential to escalate his behaviors. His mother reported that Kyle's psychiatrist prescribed an oral

MATCHING LEVEL OF CLINICAL SUPPORT

anxiolytic for him to take in order to reduce his anxiety prior to his PRM procedure. She also described in more detail his challenges during his previous healthcare encounters and expressed a lack of confidence that Kyle could be successful during his procedure. After conversing with his mother, the coordinator spoke with the medical team about potential recommendations and accommodations. The physician listened as the ACP coordinator informed her of Kyle's stressors and his past aggressive responses. The physician weighed this information with the necessary nature of the procedure when determining how to best adapt the healthcare procedure in order to have a productive, but also safe visit. Due to his aggressive behavior, the physician recommended a brief, physical restraint, that involved only a few staff members. Due to Kyle's severe sensory sensitivities, at the request of his family, the team agreed to forgo the standard pain management procedures of topical numbing agent and vapocoolant spray, due to his adverse behavioral sensory-based reactions. The team knew that he was also prescribed an anxiolytic to help with his anxiety. When all accommodations were presented to Kyle's mother, she expressed feeling relief that the team understood Kyle's individual needs and felt supported. She also indicated feeling greater confidence in the medical team.

The coordinator of the ACP advocated that many other modifications be made to individualize Kyle's care. Due to Kyle's history of aggressive behaviors, BST collaborators recommended that all staff wear protective equipment, including Kevlar gloves and sleeves, which were used to protect against the risk of grabbing, scratching, and pinching. Due to a history of hair pulling, staff with long hair were directed to pull it away from their face (e.g., in a ponytail).

Immediately prior to Kyle's visit, the ACP coordinator and clinic staff huddled to review the plan of care for Kyle and reaffirm assigned roles. When the family arrived to the medical

MATCHING LEVEL OF CLINICAL SUPPORT

center, the ACP coordinator met Kyle and his caregivers in the pre-designated parking area and used a wheelchair to escort him to the clinic. Because Kyle struggled with waiting prior to the appointment, the team agreed that Kyle should bypass the waiting area, and go directly to an exam room, where the medical team waited for him. Immediately upon the family's arrival, the medical team greeted the patient. Kyle was invited to lay down on the exam table and informed through verbal and visual cues about the procedure. Each staff member had a pre-identified position around the exam bed in order to provide a brief physical restraint only during injections (consent obtained prior to the encounter). After the procedure concluded, Kyle appeared calm and was able to follow directions. When Kyle requested to leave the exam room, he and a family member walked in the hallways while the primary caregiver spoke to the medical team. Once the visit concluded, Kyle returned to the wheelchair and the ACP coordinator escorted the family back to their car. His mother reported that he not only coped well with the procedure but was pleased that everyone remained safe throughout his visit to the clinic. After the family left the clinic, the interdisciplinary team met to discuss the execution of Kyle's plan and outcome.

Discussion

As the above case examples illustrate, when healthcare professionals collaborate with families, proactively plan accommodations, continuously communicate and collaborate, and clearly define their roles, patients are more likely to have a safe and productive visit and parents and caregivers may feel greater satisfaction with their child's healthcare experience. Without the support from all medical care team members, our patients may not have been able to receive their necessary procedures in the PRM clinic.

Future Directions

MATCHING LEVEL OF CLINICAL SUPPORT

At this time, it is essential to continue to quantify the outcomes of ACPs. Although there have been a few studies that analyze the effectiveness of ACPs (Broder-Fingert et al., 2016; Balakas et al., 2015; Liddle & Sonnentag, 2020; Wittling et al., 2018), these studies have been conducted solely with children with ASD and/or in isolated clinical areas. Further research is needed using ACPs on a wider scale, both in inpatient and additional specialty care settings, as well as with developmental conditions besides ASD. Furthermore, better assessment tools are needed to determine clinically significant change as a result of ACP implementation.

There are two key areas in which we hope to expand the reach of ACPs. The first is through enhanced health care team member education. Per Ong et al. (2017), many health care providers do not receive adequate training on working with children with developmental disabilities and do not feel prepared to handle challenging behaviors safely. This sentiment has been echoed by staff at our institution, who have been eager for information and resources related to working with this patient population during ACP trainings. There is limited formal education on this topic; therefore, additional ACP education would increase health care team members' confidence and competence in caring for patients with developmental disabilities and challenging behaviors. The second area of expansion is through implementation of ACPs in adult health care settings. Successful transition to adult care is a challenge for many patients with developmental disabilities for a variety of reasons, including inadequate supports in the adult health care setting (Brown et al., 2019; Dressler et al., 2018; Heron et al., 2019; Zablotzky et al., 2020). For patients who are no longer receiving healthcare in a pediatric setting and are unable to comply with traditional healthcare protocols, they would likely benefit from the similar support and proactive planning to receive appropriate healthcare.

Conclusion

MATCHING LEVEL OF CLINICAL SUPPORT

ACPs individualize the care provided to children with developmental disabilities who struggle to cope in order to promote safe and productive healthcare encounters. As these plans are utilized throughout the medical center, many multidisciplinary staff members become involved with implementing the recommendations and accommodations in their clinical areas. ACP coordinators, or child life specialists, have realized that psychosocial risk determines the types of accommodations provided, as well as how and when differing healthcare team members become involved. Furthermore, for ACPs to be implemented properly, continuous collaboration with multidisciplinary healthcare professionals is necessary. As the two PRM case examples demonstrate, matching the child's psychosocial risk level with healthcare team supports provides the right level of intervention and can lead to positive outcomes for both children and families.

MATCHING LEVEL OF CLINICAL SUPPORT

References

- American Academy of Pediatrics. (2021). Policy statement: Child life services. *Pediatrics*, *147*(1), doi:<https://doi.org/10.1542/peds.2020-040261>
- Balakas, K., Gallaher, C., & Tilley, C. (2015). Optimizing perioperative care for children and adolescents with challenging behaviors. *The American Journal of Maternal/Child Nursing*, *40*(3), 153-159. doi:10.1097/NMC.0000000000000124
- Boulet, S. L., Boyle, C. A., & Schieve, L. A. (2009). Health care use and health and functional impact of developmental disabilities among US children, 1997-2005. *Archives of Pediatrics and Adolescent Medicine*, *163*(1), 19-26. doi:10.1001/archpediatrics.2008.506
- Boyle, C. A., Boulet, S., Schieve, L.A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., ...Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*, *127*(6), 1034-1042. doi:10.1542/peds.2010-2989
- Broder-Fingert, S., Shui, A., Ferrone, C., Iannuzzi, D., Cheng, E., Giauque, A.,...Kuhlthau, K. (2016). A pilot study of autism-specific care plans during hospital admission. *Pediatrics*, *137*, S196-S204. doi:10.1542/peds.2015-2851R
- Brown, M., Macarthur, J., Higgins, A., & Chouliara, Z. (2019). Transition from child to adult health care for young people with intellectual disabilities: A systematic review. *Journal of Advanced Nursing*, *75*, 2418-2434. doi:10.1111/jan.13985\
- Bultas, M. (2012). The health care experiences of preschool children with autism. *Journal of Pediatric Nursing*, *27*, 460-470. <https://doi.org/10.1016/j.pedn.2011.05.005>
- Bultas, M., McMillin, S. E., & Zand, D. H. (2016). Reducing barriers to care in the office-based health care setting for children with autism. *Journal of Pediatric Health Care*, *30*(1), 5-14. doi:10.1016/j.pedhc.2015.08.007

MATCHING LEVEL OF CLINICAL SUPPORT

- Centers for Disease Control and Prevention. (2010). *National Survey of Children with Special Healthcare Needs*. Retrieved from <http://childhealthdata.org/browse/survey/results?q=1624&r=1>
- Chan, E., Zhan, C., & Homer, C. J. (2002). Health care use and costs for children with attention-deficit/hyperactivity disorder: National estimates from the Medical Expenditure Panel Survey. *Archives of Pediatrics and Adolescent Medicine*, *156*, 504-511.
doi:10.1001/archpedi.156.5.504
- Chebuhar, A., McCarthy, A. M., Bosch, J., & Baker, S. (2013). *Journal of Pediatric Nursing*, *28*, 125-134. doi:10.1016/j.pedn.2012.05.004
- Cohen, L. L. (2008). Behavioral approaches to anxiety and pain management for pediatric venous access. *Pediatrics*, *122*, S134-S139. doi: 10.1542/peds.2008-1055f
- Drake, J., Johnson, N., Stoneck, A. V., Martinez, D. M., & Massey, M. (2012). Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital. *Pediatric Nursing*, *38*, 215-221.
<https://pdfs.semanticscholar.org/d2d3/715ece0743e97b9c5ef3b119faafdc80b532.pdf>
- Dressler, P., Nguyen, T., Moody, E., Friedman, S., & Pickler, L. (2018). Use of transition resources by primary care providers for youth with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *56*(1), 56-68. doi:10.1352/1934-9556-56.1.56
- Heron, L., Agarwal, R., Greenup, J., Maddux, M., Attong, N., & Burke, S. (2019). Disparities in healthcare transition support received by adolescents with special healthcare needs. *Journal of Applied Research in Intellectual Disabilities*, *33*, 180-192.
doi:10.1111/jar.12658

MATCHING LEVEL OF CLINICAL SUPPORT

- Johnson, N. L., Bekhet, A., Robinson, K., & Rodriguez, D. (2014). Attributed meanings and strategies to prevent challenging behaviors of hospitalized children with autism: Two perspectives. *Journal of Pediatric Health Care, 28*, 386-393.
doi:10.1016/j.pedhc.2013.10.001
- Johnson, N. L., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing, 39*(3), 131-141.
https://epublications.marquette.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1282&context=nursing_fac
- Kogan, M., Strickland, B., Blumberg, S., Singh, G., Perrin, J., & van Dyck, P. (2008). A national profile of the health care experience and family impact of autism spectrum disorder among children in the United States. *Pediatrics, 122*, e1149-e1158.
doi:10.1542/peds.2008-1057
- Levy, S., Giarelli, E., Lee, L., Schieve, L., Kirby, R., Cunniff, C., ...Rice, C. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics, 31*, 267-275. doi:10.1097/DBP.0b013e3181d5d03b
- Liddle, M., Birkett, K., Bonjour, A., & Risma, K. (2018). A collaborative approach to improving health care for children with developmental disabilities. *Pediatrics, 142*(6), 1-6.
doi:10.1542/peds.2018-1136
- Liddle, M., & Sonnentag, T.L. (2020). Effectiveness of adaptive care plans for children with developmental disabilities during outpatient clinic appointments. *Journal of Autism and Developmental Disorders, 1-11*. <https://doi.org/10.1007/s10803-020-04764-1>

MATCHING LEVEL OF CLINICAL SUPPORT

- Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from US national samples. *Journal of Autism and Developmental Disorders, 36*, 871-879. doi:10.1007/s10803-006-0119-9
- Loo, C., Graham, R., & Hughes, C. (2009). Behaviour guidance in dental treatment of patients with autism spectrum disorder. *International Journal of Pediatric Dentistry, 19*, 390-398. doi:10.1111/j.1365-263X.2009.01011.x.
- Ong, N., McCleod, E., Nicholls, L., Fairbairn, N., Tomsic, B., & Eapen, V. (2017). Attitudes of healthcare staff in the treatment of children and adolescents with intellectual disability: A brief report. *Journal of Intellectual and Developmental Disability, 42*(3), 295-300. doi:10.3109/13668250.2016.1236368
- Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing, 15*, 244-254. doi:10.1111/j.1744-6155.2010.00244.x
- Schieve, L. A., Gonzalez, V., Boulet, S. L., Visser, S. N., Rice, C. E., Braun, K. N., & Boyle, C. A. (2012). Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006–2010. *Research in Developmental Disabilities, 33*, 467- 476. doi:10.1016/j.ridd.2011.10.008
- Staab, J. H., Klayman, G., & Lin, L. (2014). Assessing pediatric patient's risk of distress during health-care encounters: The psychometric properties of the Psychosocial Risk Assessment in Pediatrics. *Journal of Child Health Care, 18*(4), 378-387. <https://doi.org/10.1177/1367493513496671>

MATCHING LEVEL OF CLINICAL SUPPORT

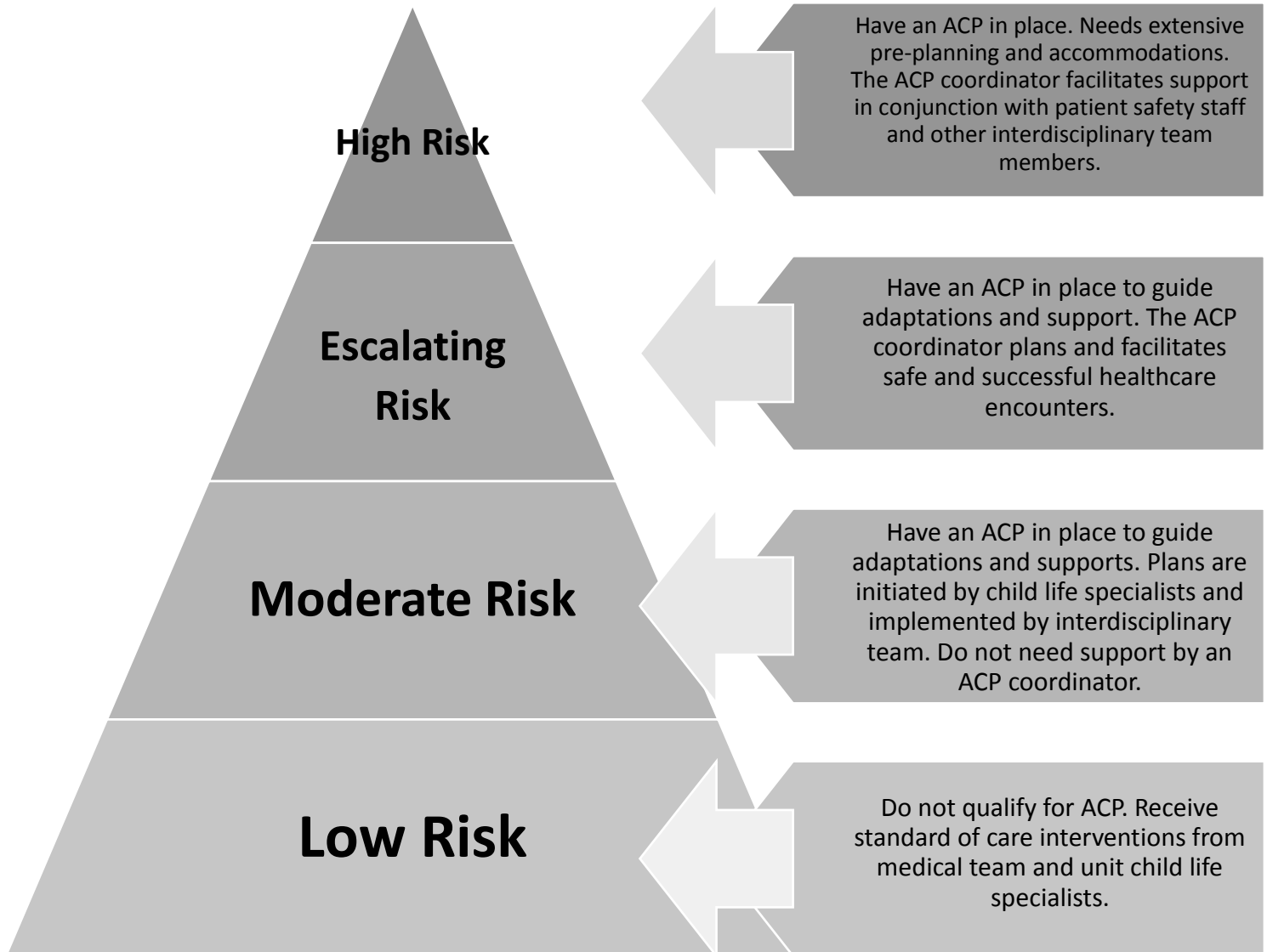
Wittling, K., Dufur, J. P., McClain, A., & Gettis, M. (2018). Behavioral coping plans: One inter-professional team's approach to patient centered care. *Journal of Pediatric Nursing, 41*,

135-139. <https://doi.org/10.1016/j.pedn.2018.05.004>

Zablotsky, B., Rast, J., Bramlett, M., & Shattuck, P. (2020). Health care transition planning among youth with ASD and other mental, behavioral, and developmental disorders.

Maternal and Child Health Journal, 24, 796-804. doi:10.1007/s10995-019-02858-6

Figure 1: Aligning Patient Acuity to Level of Support



March 24, 2021

Susan Havercamp
Associate Editor
Intellectual and Developmental Disabilities

Dear Dr. Havercamp,

Thank you for the opportunity to submit a second revision of our manuscript, “Matching Level of Clinical Support to Patient Risk When Caring for Children with Behavioral Challenges” (IDD-D-20-00110R1) for consideration of publication in *Intellectual and Developmental Disabilities*. We were delighted to read your positive feedback of the article and that you also believe this will be beneficial to the IDD community. We made the recommended changes to the article. Thank you for the thorough review and high-quality input.

In the annotation included with this resubmission, we name each concern listed by the reviewers, followed by our description of specific changes, within the revised manuscript.

We look forward to hearing from you. Thank you again for considering this revised contribution.

Sincerely,

Melissa Liddle, PsyD., CCLS, CTRS
Psychology Fellow
Cincinnati Children’s Hospital Medical Center
3333 Burnet Ave.
Cincinnati, OH 45229
(513) 404-4931 | melissa.liddle@cchmc.org