February 13, 2025

From: Paul Terdal
To: House Committee on Behavioral Health and Healthcare
Re: Support for HB2023 – Medical Evidence Supporting ABA as Safe and Effective for Intellectual Disability and other Developmental Disabilities

Dear Chair Nosse and Members of the Committee,

During Tuesday's hearing on HB2023, there was some discussion about whether there was medical evidence supporting the effectiveness of Applied Behavior Analysis for treatment of behavioral symptoms associated with Intellectual Disability and other Developmental Disabilities. Specifically, Dr. Mike Franz of Regence testified that ABA was only evidence-based for autism and for self-injurious behavior.

In the dozen years since the Health Evidence Review Commission found that there was sufficient evidence to endorse ABA for autism and self-injurious behavior , there has been substantial additional research on use of ABA for other behavioral health conditions, including intellectual disability and developmental disabilities. I am attaching several journal articles and white papers summarizing some of this research:

- Dr. Eric V. Larsson, PhD, LP, BCBA-D, "How effective is ABA for the treatment of persons with intellectual disabilities?"
    - "There is extensive research in the field of Applied Behavior Analysis (ABA) that shows the effectiveness of focused treatment of the behavior disorders of children who suffer from intellectual disorders…."
- Dr. Eric V. Larsson, PhD, LP, BCBA-D, "Children with Intellectual disorders have a high rate of *preventable* accidental death and injury"
    - "Every day that goes by without effective treatment of children with intellectual disorders is a day of higher risk of death and injury for those children. It is critical that there be no delay in access to effective treatment, because these accidental deaths are all potentially preventable through effective Applied Behavior Analysis."
- Kurtz, P. F., Leoni, M., & Hagopian, L. P. (2020). Behavioral Approaches to Assessment and Early Intervention for Severe Problem Behavior in Intellectual and Developmental Disabilities. Pediatric clinics of North America, 67(3), 499–511. https://doi.org/10.1016/j.pcl.2020.02.005
    - "Both comprehensive and problem-focused ABA treatments have a strong base of empirical support."

Sincerely,

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Applied Behavior Analysis (ABA): How effective is ABA for the treatment of persons with intellectual disabilities?

Eric V. Larsson, PhD, LP, BCBA-D (2021)

There is extensive research in the field of Applied Behavior Analysis (ABA) that shows the effectiveness of focused treatment of the behavior disorders of children who suffer from intellectual disorders and who are between the ages of one to twenty-one. As a result ABA is the community standard of care for children, adolescents, and young adults who suffer from intellectual disorders.

> **In the research listed here, over 2,000 children and adolescents, who initiated treatment between the ages of one and twenty-one, were documented as receiving effective ABA treatment. Over one third of the participants were diagnosed with an intellectual disability.**

In addition, while many of the studies in this paper identify persons on the autism spectrum as participants, at least one third of the participants in these studies carried a diagnosis of intellectual disorders and received effective treatment. Several hundred studies also report on the clinically important impact of Applied Behavior Analysis (ABA) with children who are specifically *above* the age of seven. As a result, *especially as children reach older adolescence and adulthood*, ABA is clearly a widely established component of the community standard of care, and especially for those with intellectual disorders. Many of these studies also do include young adults; and many more specifically have studied the results of ABA with the adult population.

For a child starting treatment at any age, the average length of focused ABA treatment would be expected to be 3 years, and the range of medically necessary treatment durations has been shown to be from 18 months to 5 years of duration. Maximum cost effectiveness will be achieved when a competent authorization process involves evaluation of the individual child's response to treatment and prognosis every six months, as was typically done in the studies listed below. When applying such standards, the children would not automatically continue treatment indefinitely. Instead the intensity and duration would be tailored to each child's optimum effectiveness, by periodically evaluating each child's individual response to treatment, and thereby dramatically control costs by providing time-limited ABA for only so long as is medically necessary.

This review is broken into several sections:

I. Peer reviews and/or meta-analyses of ABA treatment of children and adolescents with intellectual disorders, between the ages of one and twenty-one.

II. References on the need for effective treatment of the behavioral health needs of persons intellectual Disorders.

III. The conclusions of independent review panels on evidence-based ABA practices between the ages of one and twenty-one.

IV. Additional 343 studies extend the evidence base for ABA treatment of children who suffer from intellectual disorders between the ages of one and twenty-one.

I. The following studies reported peer reviews and/or meta-analyses of ABA treatment of children and adolescents with intellectual disorders, between the ages of one and twenty-one.

Asmus, Ringdahl et al., in 2004, reported on 138 children aging from one to over twenty-one, who were evaluated and treated for aberrant behaviors such as aggression, self-injury, and destruction on a short-term inpatient unit:

"Aberrant behavior was reduced by 90% for the majority (66%) of the participants in an average time frame of 10 days. (page 300).
"Reduction of 20% or more was seen for all but 4 of the 138 participants." (page 300).

Asmus, J.M., Ringdahl, J.E., Sellers, J.A., Call, N.A., Andelman, M.S. & Wacker, D.P. (2004). Use of A Short-Term Inpatient Model To Evaluate Aberrant Behavior: Outcome Data Summaries From 1996 To 2001. Journal of Applied Behavior Analysis. 37, 283-304.

Brosnan and Healy, in 2011, reported on 18 studies of 31 children, aged three to 18, who received effective ABA treatment to reduce or eliminate severe aggressive behavior:

"All of the studies reported decreases in challenging behavior attributed to the intervention. Of the studies included, seven reported total or near elimination of aggression of at least one individual during intervention in at least one condition." (page 443).
"only four of the studies conducted follow-up assessments. However, each of these studies reported that treatment gains were maintained." (page 443).

Brosnan, J., & Healy, O. (2011). A review of behavioral interventions for the treatment of aggression in individuals with developmental disabilities. Research in Developmental Disabilities. 32, 437–446.

Campbell, in 2003, reported a meta-analysis of 117 published studies of behavioral interventions for the problem behaviors of 181 individuals with intellectual disorders, who ranged in age from two to 31 years of age. The problem behaviors included stereotypic behavior, self-injurious behavior, aggression and destruction:

"behavioral treatments were found to be significantly effective in reducing problem behavior. (page 133).
"Treatment was equally effective regardless of problem behavior and type of technique used. (page 133).
"The most salient clinical implication is that behavioral treatments are more effective when preceded by a functional assessment." (page 134).

Campbell, J.M. (2003). Efficacy of behavioral interventions for reducing problem behavior in persons with autism: a quantitative synthesis of single-subject research. Research in Developmental Disabilities. 24, 120-138.

Hagopian, Rooker, Jessel, & DeLeon, in 2013, reported a case-series analysis of functional analyses of the behavior of 176 individuals who were between the ages of three and 39 years old, and who had been admitted to an inpatient unit for severe problem behavior:

"a function was identified in 86.9% of the 176 cases and in 93.3% of the 161 cases for which the FA, if necessary, was modified up to 2 times. (page 95).
"These results indicate that multiple control was the most common finding, followed by social-positive reinforcement." (page 95).

Hagopian, L.P., Rooker, G.W., Jessel, J., & DeLeon, I.G. (2013). Initial Functional Analysis Outcomes and Modifications in Pursuit of Differentiation: A Summary of 176 Inpatient Cases. Journal of Applied Behavior Analysis, 46, 88-100.

Hagopian, Rooker, & Rolider. In 2011, reviewed the treatment of pica in 50 individuals from the ages of two to over twenty-one. Using APA criteria for empirically supported treatments, a total of 34 treatment studies were identified:

"these behavioral approaches are highly effective in reducing pica – as most studies identified reduced pica by more than 90% relative to baseline. (page 2118).
"there are more than a sufficient number of high-quality studies in the literature to characterize behavioral treatment as well established empirically supported treatments. (page 2118).
"Treatments combining reinforcement and response reduction procedures also exceed criteria to be designated as well established." (page 2118).

Hagopian, L.P., Rooker, G.W., & Rolider, N.U. (2011). Identifying empirically supported treatments for pica in individuals with intellectual disabilities. Research in Developmental Disabilities, 32, 2114–2120.

Hanley, Iwata, and McCord, in 2003, reported on 277 studies, which involved 536 children and adults (70% of the studies included persons between the ages of 1 and 18, and 37% also included persons older than 18), who received functional analyses of problem behaviors:

"96 percent were able to yield an analysis of the controlling variables of the problem behavior. (pages 166-167).
"The specific functional analysis of individual problem behaviors is crucial to the successful intervention with those behaviors. (pages 166-167).
"Large proportions of differentiated functional analyses showed behavioral maintenance through social-negative (34.2%) and social-positive reinforcement (35.4%). More specifically, 25.3% showed maintenance via attention and 10.1% via access to tangible items. Automatic reinforcement was implicated in 15.8% of cases." (pages 166-167).

Hanley, G., Iwata, B.A., & McCord, B.E. (2003). Functional analysis of problem behavior: A review. Journal of Applied Behavior Analysis, 36, 147-185.

Iwata and colleagues, in 1994, reported on the effective treatment of self-injurious behavior with 152 children, adolescents, and adults. In their sample, 39 were between the ages of 11 and 20, and 74 were twenty-one and older:

"The function of the self-injurious behavior could be identified in 95% of the persons, and in 100% of those cases an effective treatment could then be prescribed. (page 233).
"Across all categories of intervention, restraint fading was the most effective, but its 100% success rate is misleading because it was always implemented in conjunction with another procedure. (page 233).
"As single interventions, EXT (escape) had the highest success rate (93.5%); sensory integration and naltrexone had the lowest (0%). (page 233).
"Results of the present study, in which single-subject designs were used to examine the functional properties of SIB in 152 individuals, indicated that social reinforcement was a determinant of SIB in over two thirds of the sample, whereas nonsocial (automatic) consequences seemed to account for about one fourth of the cases." (page 234).

Iwata, B.A., Pace, G.M., et al. (1994). The functions of self-injurious behavior: An experimental-epidemiological analysis. Journal of Applied Behavior Analysis, 27, 215-240.

Jennett and Hagopian, in 2008, reported on 28 individuals aged seven to above twenty-one, who received a variety of forms of behavior therapy treatments for phobic avoidance. These were in 12 studies, which demonstrated treatment efficacy through the use of good experimental design:

"there is sufficient empirical support to characterize behavioral treatment as a well-established treatment for phobic avoidance displayed by individuals with intellectual disabilities. (page 158).
"All of the studies described that had good experimental designs and were shown to be efficacious included some form of live exposure to the feared stimulus plus reinforcement for appropriate behaviors (e.g., approach or absence of avoidance), suggesting that these are important components of treatment." (page 158).

Jennett, H.K. & Hagopian, L.P. (2010). Identifying Empirically Supported Treatments for Phobic Avoidance in Individuals With Intellectual Disabilities. Behavior Therapy, 39, 151-161.

Lang, et al. in 2010, reported on nine studies, which involved 110 children, aged nine to 23, who received a variety of forms of behavior therapy for anxiety:

"Within each reviewed study, at least one dependent variable suggested a reduction in anxiety following implementation of CBT." (page 60).
"CBT has been modified for individuals with ASD by adding intervention components typically associated with applied behaviour analysis (e.g. systematic prompting and differential reinforcement). Future research involving a component analysis could potentially elucidate the mechanisms by which CBT reduces anxiety in individuals with ASD, ultimately leading to more efficient or effective interventions." (page 53).

Lang, R., Regester, A., Lauderdale, S., Ashbaugh, K., & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: a systematic review. Developmental Neurorehabilitation, 13, 53–63.

Lang, et al. in 2009, reported on ten studies which involved 53 individuals from the ages of three to above twenty-one, who received a variety of ABA interventions for the treatment of dangerous elopement. However, in this one review, none of the reviewed treatments were found to qualify as "well established" evidence-based practice:

"elopement may often be maintained by operant contingencies and reduced by function-based interventions. (page 679).
"The studies with the most conclusive evidence ostensibly suggest a two-step process; practitioners should (a) assess elopement to identify its operant function, and (b) implement a function-based intervention" (page 679).

Lang, R., Rispoli, M., et al. (2009). Treatment of elopement in individuals with developmental disabilities: A systematic review. Research in Developmental Disabilities, 30, 670–681.

Reichow and Volkmar, in 2010, reported on 31 studies of 327 children, from the ages of six to over twenty-one, who benefited from ABA social skills training:

"Within the last 8 years, 66 studies with strong or acceptable methodological rigor have been conducted and published. These studies have been conducted using over 500 participants, and have evaluated interventions with different delivery agents, methods, target skills, and settings. (page 161).
"Collectively, the results of this synthesis show there is much supporting evidence for the treatment of social deficits" (page 161).

Reichow, B. & Volkmar, F.R. (2010). Social Skills Interventions for Individuals with Autism: Evaluation for Evidence-Based Practices within a Best Evidence Synthesis Framework. Journal of Autism and Developmental Disorders. 40, 149-166.

II. References on the need for effective treatment of the behavioral health needs of persons intellectual Disorders.

The following studies document the need for effective treatment of the behavior disorders that occur in the population of persons with intellectual disabilities.

Colombo, R. A., Munoz, A., Wallace, M., & Legaspi, D. (2024). Functional analysis and treatment of adult problem behavior: A review. Behavioral Interventions, 39(2), e1998. https://doi.org/10.1002/bin.1998

Hagopian, L. P., Kurtz, P. F., Bowman, L. G., O'Connor, J. T., & Cataldo, M. F. (2023). A Neurobehavioral Continuum of Care for Individuals with Intellectual and Developmental Disabilities with Severe Problem Behavior. Children's health care : journal of the Association for the Care of Children's Health, 52(1), 45–69. https://doi.org/10.1080/02739615.2021.1987237

Holburn S, Jacobson JW, Schwartz AA, et al. The Willowbrook Futures Project: A Longitudinal Analysis of Person-Centered Planning. American Journal on Mental Retardation. 2004 Jan;109(1):63-76. doi: https://dx.doi.org/10.1352/0895-8017(2004)109<63:TWFPAL>2.0.CO;2. PMID: 14651448.

İsvan N, Bonardi A, Hiersteiner D. Effects of person-centered planning and practices on the health and well-being of adults with intellectual and developmental disabilities: a multilevel analysis of linked administrative and survey data. J Intellect Disabil Res. 2023 Feb 20. doi: https://dx.doi.org/10.1111/jir.13015. PMID: 36808669.

Kennedy-Hendricks A, Bandara S, Daumit GL, et al. Behavioral health home impact on transitional care and readmissions among adults with serious mental illness. Health Serv Res. 2021 06;56(3):432-9. doi: https://dx.doi.org/10.1111/1475-6773.13594. PMID: 33118187.

Kurtz, P. F., Leoni, M., & Hagopian, L. P. (2020). Behavioral Approaches to Assessment and Early Intervention for Severe Problem Behavior in Intellectual and Developmental Disabilities. Pediatric clinics of North America, 67(3), 499–511. https://doi.org/10.1016/j.pcl.2020.02.005

Mandell, D.S., et al. (2009). Racial and ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99, 493-498.

Mandell, D.S., Listerud, J., Levy, S.E., & Pinto-Martin, J.A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1447-1453.

Mandell, D.S., Novak, M.M., & Zubritsky, C.D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*. 116, 1480-1486.

Ratti V, Hassiotis A, Crabtree J, et al. The effectiveness of person-centered planning for people with intellectual disabilities: A systematic review. Res Dev Disabil. 2016 Oct;57:63-84. doi: https://dx.doi.org/10.1016/j.ridd.2016.06.015. PMID: 27394053.

Shattuck, P.T., et. al. (2009). Timing of Identification Among Children With an Autism Spectrum Disorder: Findings From a Population-Based Surveillance Study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48, 474-483

Stancliffe RJ, Lakin KC, Taub S, et al. Satisfaction and sense of well being among Medicaid ICF/MR and HCBS recipients in six states. Intellect Dev Disabil. 2009 Apr;47(2):63-83. doi: https://dx.doi.org/10.1352/1934-9556-47.2.63. PMID: 19368486.

The National Core Indicators for Intellectual and Developmental Disabilities (NCI-IDD). Human Services Research Institute and National Association of States United for Aging and Disabilities; 2021. https://legacy.nationalcoreindicators.org/upload/aidd/NCI_IDD_Indicators_FINAL_21-22.pdf.

III. The conclusions of independent review panels on evidence-based ABA practices between the ages of one and twenty-one.

The US Department of Education commissioned a review of the evidence supporting focused intervention practices in 2014 for children aged birth to 22. The Autism Evidence-Based Practice Review Group of the **Frank Porter Graham Child Development Institute** set about to describe a process for the identification of evidence-based practices (EBPs) and also to delineate practices that have sufficient empirical support to be termed evidence-based. After reviewing 29,106 published articles, they found 1,090 that met their criteria, resulting in the identification of 27 evidence-based practices that consisted of focused interventions:

> "that are fundamental applied behavior analysis techniques (e.g., reinforcement, extinction, prompting), assessment and analytic techniques that are the basis for intervention (e.g., functional behavior assessment, task analysis), and combinations of primarily behavioral practices used in a routine and systematic way that fit together as a replicable procedure (e.g., functional communication training, pivotal response training)." (p. 19).

> "Fifteen of the EBPs have over 10 studies providing empirical support for the practice, and among those, the foundational applied behavior analysis techniques (e.g., prompting and reinforcement) have the most support. Antecedent-based interventions, differential reinforcement, and video modeling also have substantial support with over 25 studies supporting their efficacy. The number and variety of these replications speak to the relative strength of these EBPs." (p. 29)

> "The identification of focused intervention practices that have substantial evidence of efficacy provides the basis for designing comprehensive evidence-supported programs for children and youth with ASD… Developers of some comprehensive treatment models, such as the Lovaas Model and the Early Start Denver Model, have conducted randomized efficacy studies that provide empirical support for their program models, which would qualify them as evidence-based programs." (p. 32)

> Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., … Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder*. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group. Available at: autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf

In 2015, the **National Center for Autism** identified evidence-based practices for children up to the age of twenty-one. The Center found the following behavioral interventions that had their own unique established level of evidence: Behavioral Interventions, Cognitive Behavioral Intervention Package, Comprehensive Behavioral Treatment for Young Children, Language Training (Production), Modeling, Natural Teaching Strategies, Parent Training, Peer Training Package, Pivotal Response Training, Schedules, Scripting, Self-Management, Social Skills Package, and Story-based Intervention. Each of these interventions had to be supported by studies that met the criteria of the Scientific Merit Rating Scale (SMRS) and the Strength of Evidence Classification System, as follows:

> "The SMRS involves five critical dimensions of experimental rigor that can be applied to determine the extent to which interventions are effective. They are: {a} research design, {b} measurement of the dependent variable, {c} measurement of the independent variable or procedural fidelity, {d} participant ascertainment, and {e} generalization and maintenance." (p. 22)

"Sufficient evidence is available to confidently determine that an intervention produces favorable outcomes for individuals on the autism spectrum. That is, these interventions are established as effective." (p. 34)

National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Randolph, MA: Author.

In 2017, the **Ontario Association for Behavior Analysis** conducted a review of the research evidence and best practices for the treatment of autism spectrum disorder. This panel also separated their review into various age groups and identified evidence-based practices in both the age ranges of 6 to 14 and 15 to 22. The main recommendations and findings of this task force were:

"Only those interventions that meet the standards of evidence-based practice should be supported. Commentary: As noted in previous reports, the vast majority of evidence-based interventions consist of applied behaviour analysis (ABA) or incorporate established behaviour analytic procedures. These interventions are often described as either focused ABA interventions or comprehensive ABA interventions." (p. 93)

"The interventions that we have accepted as evidence based are shown in Tables 6 and 7 and are: comprehensive behavioral treatment for young children (EIBI) and the following focused ABA interventions: cognitive behavioural intervention, differential reinforcement (DRA, DRI, DRO), discrete trial teaching, extinction, functional behaviour assessment, language training, modeling, naturalistic teaching, parent training, peer-mediated intervention, Pivotal Response Treatment® (PRT), visual schedules, scripting, self-management, social skills training, story-based intervention, prompting, reinforcement, response redirection, structured play groups, task analysis, time delay, video modeling, exercise, functional communication training, Picture Exchange Communication System® (PECS), and technology-based intervention." (p. 94)

Ontario Association for Behaviour Analysis. (2017). *Evidence-Based Practices for Individuals with Autism Spectrum Disorder: Recommendations for Caregivers, Practitioners, and Policy Makers*. Toronto, ON: Author.

V. These additional 343 studies extend the evidence base for ABA treatment of children who suffer from intellectual disorders between the ages of one and twenty-one.

Ahrens, E. N., Lerman, D. C., Kodak, T., Worsdell, A. S., & Keegan, C. (2011). Further evaluation of response interruption and redirection as treatment for stereotypy. *Journal of Applied Behavior Analysis*, *44*(1), 95-108. doi: 10.1901/jaba.2011.44-95

Allen, K. D., Wallace, D. P., Greene, D. J., Bowen, S. L., & Burke, R. V. (2010). Community-based vocational instruction using videotaped modeling for young adults with autism spectrum disorders performing in air-inflated mascots. *Focus on Autism and Other Developmental Disabilities*, *25*(3), 186-192. doi: 10.1177/1088357610377318

Anderson, J., & Le, D. D. (2011). Abatement of intractable vocal stereotypy using an overcorrection procedure. *Behavioral Interventions*, *26*(2), 134-146. doi: 10.1002/bin.326

Athens, E. S., Vollmer, T. R., Sloman, K. N., & Pipkin, C. S. P. (2008). An analysis of vocal stereotypy and therapist fading. *Journal of Applied Behavior Analysis*, *41*(2), 291-297. doi: 10.1901/jaba.2008.41-291

Baer, D. M. & Guess, D. (1971). Receptive training of adjectival inflections in mental retardates. *Journal of Applied Behavior Analysis*, 4, 129-139.

Baer, D. M. & Guess, D. (1973). Teaching productive noun suffixes to severely retarded children. *American Journal of Mental Deficiency*, 77, 498-505.

Baer, D. M., Peterson, R. F., & Sherman, J. A. (1967). The development of imitation by reinforcing behavioral similarity to a model. *Journal of the Experimental Analysis of Behavior*, 10, 405-416.

Barbetta, P. M., Heron, T. E., & Heward, W. L., (1993). Effects of active student response during error correction on the acquisition, maintenance, and generalization of sight words by students with developmental disabilities. *Journal of Applied Behavior Analysis, 26,* 111-120.

Barbetta, P. M., Heward, W. L., & Bradley, D. M. (1993). Relative effects of whole-word and phonetic-prompt error correction on the acquisition and maintenance of sight words by students with developmental disabilities. *Journal of Applied Behavior Analysis. 26,* 99-111.

Belchic, J. K., & Harris, S. L. (1994). The use of multiple peer exemplars to enhance the generalization of play skills to the siblings of children with autism. *Child and Family Behavior Therapy, 16,*1-25.

Bellini, S., & Akullian, J. (2007). A Meta-Analysis of Video Modeling and Video Self-Modeling Interventions for Children and Adolescents with Autism spectrum disorders. *Exceptional Children*, 73, 261-284.

Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 28, 153-162.

Bernard-Opitz, V., Sriram, N., & Nakhoda-Sapuan, S. (2001). Enhancing social problem solving in children with autism and normal children through computer-assisted instruction. *Journal of Autism & Developmental Disorders*, 31, 377-384.

Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2001). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities*. 22, 425-447.

Billingsly, F. F., & Neel, R. S. (1985). Competing behaviors and their effects on skill generalization and maintenance. *Analysis and Intervention in Developmental Disabilities, 5*, 357-372.

Blew, P. A., Schwartz, I. S., & Luce, S. C. (1985). Teaching functional community skills to autistic children using nonhandicapped peer tutors. *Journal of Applied Behavior Analysis. 18,* 337-342.

Bouxsein, K. J., Tiger, J. H., & Fisher, W. W. (2008). A comparison of general and specific instructions to promote task engagement and completion by a young man with Asperger syndrome. *Journal of Applied Behavior Analysis*, *41*(1), 113-116. doi: 10.1901/jaba.2008.41-113

Brown, F., Holvoet, J., Guess, D., & Mulligan, M. (1980). Individualized curriculum sequencing model (III): Small group instruction. *Journal of the Association for the Severely Handicapped*, 5, 352-367.

Brown, J. L., Krantz, P. J., McClannahan, L. E., & Poulson, C. L. (2008). Using script fading to promote natural environment stimulus control of verbal interactions among youths with autism. *Research in Autism Spectrum Disorders*, 2(3), 480-497. doi: 10.1016/j.rasd.2007.08.006

Brown, K. A., Wacker, D. P., Derby, K. M., Peck, S. M., Richman, D. M., Sasso, G. M., ... Harding, J. W. (2000). Evaluating the effects of functional communication training in the presence and absence of establishing operations. *Journal of Applied Behavior Analysis, 33*(1), 53-71. doi: 10.1901/jaba.2000.33-53

Brown, K. M., Willis, B. S., Reid, D. H. (1981). Differential effects of supervisor verbal feedback plus approval on institutional staff performance. *Journal of Organizational Behavior Management, 3,* 57-68.

Brown, L., & Pearce, E. (1970). Increasing the production rate of trainable retarded students in a public school simulated workshop. *Education and Training of the Mentally Retarded*, 5, 15-22.

Brown, L., Van Deventer, P., Perlmutter, L., Jones, S., & Sontag, E. (1972). Effects of consequences on production rates of trainable retarded and severely emotionally disturbed students in a public school workshop. *Education and Training of the Mentally Retarded*, 7, 74-81.

Buckley, S. D., & Newchok, D. K. (2005). An evaluation of simultaneous presentation and differential reinforcement with response cost to reduce packing. *Journal of Applied Behavior Analysis*, *38*(3), 405-409. doi: 10.1901/jaba.2005.71-04

Buggey, T., Toombs, K., Gardener, P., Cervetti, M. (2000). Training responding behaviors in students with autism: Using videotaped self-modeling. *Journal of Positive Behavior Interventions, 1,* 205-214.

Burgess, R. L., Burgess, J. M., & Esveldt, K. C. (1970). An analysis of generalized imitation. *Journal of Applied Behavior Analysis*, 3, 39-46.

Call, N. A., Pabico, R. S., Findley, A. J., & Valentino, A. L. (2011). Differential reinforcement with and without blocking as treatment for elopement. *Journal of Applied Behavior Analysis*, *44*(4), 903-907. doi: 10.1901/jaba.2011.44-903

Camarata, S. (1993). The application of naturalistic conversation training to speech production in children with speech disabilities. *Journal of Applied Behavior Analysis, 26*. 173-182.

Cannella-Malone, H. I., Fleming, C., Chung, Y. C., Wheeler, G. M., Basbagill, A. R., & Singh, A. H. (2011). Teaching daily living skills to seven individuals with severe intellectual disabilities: A comparison of video prompting to video modeling. *Journal of Positive Behavior Interventions*, *13*(3), 144-153. doi: 10.1177/1098300710366593

Carr, E. G., Newsome, C. D., & Binkoff, J. A. (1980). Escape as a factor in the aggressive behavior of two retarded children. *Journal of Applied Behavior Analysis, 13,* 101-117.

Casey, L. O. (1978). Development of communicative behavior in autistic children: a parent program using manual signs. *Journal of autism & childhood schizophrenia*. 8, 45-59.

Celiberti, D. A., & Harris, S. L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy,* 24(4). 573-599.

Charlop, M. H. (1983). The effects of echolalia on acquisition and generalization of receptive labeling in autistic children. *Journal of Applied Behavior Analysis. 16,* 111-127.

Charlop, M. H., & Milstein, J. P. (1989). Teaching autistic children conversational speech using video modeling. *Journal of Applied Behavior Analysis. 22,* 275-286.

Charlop, M. H., & Trasowech, J. E., (1991). Increasing autistic children's daily spontaneous speech. *Journal of Applied Behavior Analysis. 24,* 747-762.

Charlop, M. H., & Walsh, M. E. (1986). Increasing autistic children's spontaneous verbalizations of affection: An assessment of time delay and peer modelling procedures. *Journal of Applied Behavior Analysis, 19,* 307-314.

Charlop, M. H., Kurtz, P. F., & Casey, F. G. (1990). Using aberrant behaviors as reinforcers for autistic children. *Journal of Applied Behavior Analysis. 23,* 163-182.

Charlop, M. H., Kurtz, P. F., & Milstein, J. P. (1992). Too much reinforcement, too little behavior: Assessing task interspersal procedures in conjunction with different reinforcement schedules with autistic children. *Journal of Applied Behavior Analysis, 25,* 795-808.

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Children with Intellectual disorders have a high rate of *preventable* accidental death and injury

(2019) Eric V. Larsson, PhD LP BCBA-D

Every day that goes by without effective treatment of children with intellectual disorders is a day of higher risk of death and injury for those children. It is critical that there be no delay in access to effective treatment, because these accidental deaths are all potentially preventable through effective Applied Behavior Analysis (Lang, Rispoli, Machalicek, et al., 2009).

The risk of death is particularly high for children with intellectual disorders who are younger than 15 years (Guan and Li, 2017a; 2017b). In those studies, three specific causes of death – drowning, suffocation, and asphyxiation – accounted for 79% of the total deaths in children who suffer from intellectual disorders.

One especially high risk cause of these accidental deaths is from wandering away to dangerous locations. It is commonly found that children with intellectual disorders are at higher risk of wandering than are children with other special needs. One study found that the rate at which children with an ASD attempt to elope from a safe environment is nearly four times higher than that of their unaffected siblings (McIlwain and Fournier, 2012). Further studies document the high rates of death and severe injury in the harmful and potentially life-threatening situations that the children wander to. The deaths occur in traffic accidents, drowning, other sources of asphyxiation, falls from dangerous climbing, and eating poisonous substances (Bilder, et al. 2013; Kalb, et al. 2012; Kalb, et al. 2016； Lunsky, et al. 2017; Rice, et al. 2016; Shavelle, et al. 2001).

Also of great concern, individuals with intellectual disorders have a heightened risk for being victims of abuse (Sullivan and Knutson, 2000) given their limited ability to recognize, report, and exit dangerous situations. These behavioral deficits negatively impact the safety, health, and well-being of adults with intellectual disorders.

Individuals with intellectual disorders may also be nearly twice as likely to die by age 43 when compared with the general population (Mouridsen et al., 2008). In that study, an increased risk of accidental deaths due to drowning and suffocation was reported, while co-occurring epilepsy accounted for one third of the deaths. These findings have been replicated in a second study (Gillberg et al., 2010).

Adults with intellectual disorders also are at an increased risk of developing life-threatening medical disorders such as diabetes, coronary heart disease, and cancer (Tyler et al., 2011). Behavioral medicine approaches can be used to prevent mortality in some cases (Hawkins, et al. 2015).

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Behavioral Approaches to Assessment and Early Intervention for Severe Problem Behavior in Intellectual and Developmental Disabilities

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Severe problem behavior; Intellectual disability; Applied behavior analysis; Behavioral assessment and treatment; Early intervention

PHENOMENOLOGY OF PROBLEM BEHAVIOR

Description and Prevalence

Children with intellectual and developmental disabilities (IDDs) are at increased risk for problem behavior.[1] A subset of these individuals develop severe problem behavior, which can pose serious and immediate risk for injury, loss of function, disfigurement, and even death.[2] Self-injurious behavior (SIB) includes behaviors such as head-banging, head hitting, self-biting, and self-scratching. These can cause localized swelling, bruising, and bleeding; loss of tissue from tongue, lips, ears, and nose; blindness from retinal detachment; and permanent disfigurement.[3] Aggressive and disruptive behaviors can reach comparable levels of severity and result in severe injuries to family members and staff.[4] Pica (the ingestion of nonedible items) and elopement (leaving a supervised area without caregiver knowledge) can result in injury or death.[5]

Estimates vary widely, but approximately 50% of individuals with IDD experience some form of problem behavior, with a smaller proportion (5%–10%) exhibiting very severe problem behavior with extreme consequences for families and caregivers.[6–8] These

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problems appear to be more common among individuals with IDD who also have autism spectrum disorder (ASD).[4,9] Other known risk factors for problem behavior include greater deficits in intellectual functioning and communication, and the presence of sensory impairments.[1,10] Recently identified risk markers include repetitive and restricted behavior and interests, overactivity/impulsivity,[11,12] and prenatal factors (level of maternal education, maternal smoking, and electronic fetal monitoring during labor) associated with SIB in children with ASD.[13,14]

In this population, problem behavior is a heterogeneous phenomenon. Onset of problem behavior may occur in early childhood or adolescence, or adulthood in some cases. Individuals may present with one type of problem behavior or may engage in multiple forms. These behaviors can occur from dozens to hundreds of times daily or episodically. Problem behaviors sometimes co-occur with irritability or in the context of an outburst where there also are expressions of anger, frustration, and other negative emotional states.[15] Because these behaviors can vary greatly in their complexity and intensity, so does their impact on children and families. When problem behaviors occur regularly, and with high intensity, they might produce injuries to self or others, restrict participation in activities appropriate for the individual's developmental level, and necessitate a higher level of care (constant supervision, multiple people required to manage problem behavior when an episode occurs, and so forth) and increased emergency room visits.[16] As a result of these many challenges, it is more likely that medication is overprescribed for this population with poor efficacy and high risk of negative side effects.[17,18] When these behaviors are severe and persistent, they can lead to mistreatment, including inappropriate restraint and seclusion,[19] expulsion from school, placement in restrictive settings, and occurrence of physical and emotional trauma to family members.[20–22] Family members often report feeling isolated, and financial resources are strained as a result of additional expenses.

Establishment of Problem Behavior

Problem behavior in this population is thought to be the product of the interaction between deficits stemming from IDD and experiences that reinforce and strengthen these behaviors.[23,24] Deficits in communication and adaptive skills and limited ability to regulate emotions may increase the frequency and intensity of frustrative experiences, setting the stage for episodes of irritability and problem behavior. Because problem behavior often is dangerous or socially unacceptable, caregivers understandably work to calm children via redirection, consolation, or interruption.[25] For example, if a child engages in SIB when presented with instructional demands, the caregiver may give the child a break in an attempt to calm the child and avoid injury or disruption of the environment. Although well-intended, these reactions sometimes may reinforce the problem through basic learning processes and thus increase its future occurrence. Caregivers sometimes also actively work to avoid situations that might cause distress by altering their routines—but if this process of accommodation continues and expands to other situations, then altered routines to avoid challenging situations may become highly disruptive to the point they are unsustainable.[26] Thus, although efforts to make problem behavior cease or to avoid situations that occasion it may provide some immediate relief to the caregiver, such interactions can lead to the establishment and maintenance of maladaptive caregiver-child interaction patterns.[25,27–29]

These interaction patterns can impair functioning further as the avoidance of potentially challenging situations expands over time and across settings and becomes a source of chronic stress for parents.

BEHAVIORAL ASSESSMENT AND TREATMENT OF PROBLEM BEHAVIOR

For any given case, the historical events that led to establishment of problem behavior may be difficult if not impossible to identify. Functional behavioral assessment is acknowledged to be the best approach to precisely identify events in the environment that presently occasion problem behavior (antecedents) and the reinforcers that strengthen and maintain those behaviors (consequences). Once identified, knowledge of these controlling events can inform the development of individualized behavioral interventions that are directly tied to the variables that maintain the behavior. Such knowledge also can contribute to identifying what other elements of the clinical presentation should be targeted with pharmacologic interventions, including emotion dysregulation, irritability, hyperactivity, and so forth.[30,31]

Applied Behavior Analysis

Applied behavior analysis (ABA) is a discipline that utilizes principles of learning and behavioral science for the purpose of addressing problems of social significance.[32] ABA-based treatment for addressing the needs of persons with IDD has 2 broad domains of application: (1) educational treatment delivered in the context of a comprehensive intervention and (2) problem-focused treatment, aimed at addressing specific problems. Comprehensive ABA intervention is broad in its scope, aimed at establishing educational and adaptive skills to have an impact on global measures of functioning when applied over an extended period (301 service hours per week, over a span of years is not uncommon). When implemented early, comprehensive treatment often is referred to using the term, *early intensive behavioral intervention*.[33–35] Problem-focused ABA interventions are more relevant to the current discussion on problem behavior, because these are aimed at addressing more specific problems—most typically, problem behavior, such as SIB, aggression toward others, pica, disruptive behavior, and elopement. Problem-focused interventions are more targeted and, therefore, more time-limited. The goal of these interventions is reducing problem behavior while also establishing and strengthening adaptive behaviors. Some individuals may require both types of ABA treatment. Despite their differences, both comprehensive and problem-focused ABA interventions are based on the same empirically validated learning principles, which involve the objective measurement of behavior using direct observation of behavior, carefully controlling environmental variables for the purpose of pinpointing specific determinants of the severe problem behavior to inform treatment development, and isolating operative components of behavioral interventions.

Empirical Support for Applied Behavior Analysis

Both comprehensive and problem-focused ABA treatments have a strong base of empirical support. Group designs (including randomized controlled trials) have been used to evaluate comprehensive ABA treatment,[34] and single-case experimental designs have been extensively used to document problem-focused ABA interventions (assessment and

treatment of problem behavior). Several meta-analyses have examined ABA problem-focused interventions for decreasing rates of various types of problem behavior (eg, see Hayaert and colleagues[36] and Harvey and colleagues[37]). Structured evaluative reviews also have demonstrated that ABA-based approaches are efficacious for aggression,[38] SIB,[39] elopement,[40] and, more broadly, severe problem behavior.[41,42] Problem-focused ABA treatment of problem behavior also has been supported by the Autism Evidence-Based Practice Review Group[43] and the National Standards Project.[44]

Functional Behavioral Assessment

As applied to the assessment and treatment of problem behavior, problem-focused ABA relies heavily on functional behavior assessment. Functional behavior assessment involves a range of techniques aimed at identifying the variables that occasion and maintain problem behavior. Rating scales, interviews, and observations of problem behavior in uncontrolled naturalistic settings and controlled formal assessments can be performed. Generally, less-intensive assessment procedures should be used initially (ie, interviews and rating scales), reserving more time and resource-intensive assessments if less-intensive procedures fail to produce clear assessment findings or lead to the development of an effective intervention. Research on methods that rely on the reporting of others shows they have limited validity relative to methods involving direct observation of behavior. A formal controlled functional analysis, in which conditions are systematically manipulated, is the most valid and scientifically rigorous method of assessment because it directly examines how problem behavior changes as environmental antecedents and consequences are systematically altered.[45] For example, if a child's problem behavior is hypothesized to be maintained by attention from a caregiver, the test condition would involve arranging a situation in which the caregiver provides a form of attention (e.g., telling child to stop, consoling him/her) whenever the problem behavior occurs. In the control condition in this case, the caregiver interacts with the child, without providing attention for problem behavior.

Classification of problem behavior is based on its function, which includes 2 broad classes, both of which include subclasses: (1) socially maintained (occasioned and reinforced through the interactions of others) and (2) automatically maintained (occurs independent of social contingencies). SIB is socially maintained in two-thirds to three-fourths of cases and automatically maintained in one-fourth of cases.[46–48] Aggression most often is socially maintained, whereas pica most often is automatically maintained.[49] Within the broad class of socially maintained problem behavior, the subclasses include problem behavior maintained by (1) attention from adults or peers, (2) escape from or avoiding unpleasant circumstances (eg, demands placed on them by a parent or teacher), and (3) acquiring or gaining access to preferred items, activities, and so forth. In contrast, automatically maintained problem behavior persists independent of interactions with others and presumably via some unknown biological process. That is, the act of engaging in the problem behavior directly produces consequences independent of social interaction that are presumed to be reinforcing in some way.

Function-Based Treatment

Function-based treatment represents best practices in ABA.[46] With knowledge of the controlling variables of problem behavior, precisely targeted interventions can be devised. Broadly speaking, this approach involves 2 primary components designed to (1) strengthen appropriate alternative behaviors (using reinforcement) concurrently with (2) the withholding of reinforcement that maintains the targeted problem behavior (operant extinction). One of the most commonly researched treatments of problem behavior maintained by social consequences is referred to as *functional communication training* (FCT). FCT involves training a child to emit an appropriate communicative response to access reinforcement in lieu of problem behavior. Described in more than 200 studies, FCT is an empirically supported treatment[50] that also has been shown to be highly effective using meta-analysis[51] and in 3 consecutive-controlled case series studies.[52–54] Noncontingent reinforcement (NCR) is another widely researched function-based treatment that has been demonstrated to be empirically supported treatment using the APA criteria[55] and via meta-analysis.[56] NCR involves the response-independent delivery of reinforcers responsible for maintaining problem behavior at fixed or variable times during treatment, thus attenuating motivation for problem behavior. A range of other ABA problem-focused interventions have been shown to be efficacious (see Hagopian and colleagues[49] for a review).

EARLY INTERVENTION AND PREVENTION

The benefits of early intervention are well documented for children with ASD[57,58] and children with IDD.[59–61] For example, outcome studies on intensive programs for children with ASD that focus on skill acquisition and reduction of behavioral excesses have reported significant improvements, including gains on estimates of intellectual functioning, success in regular education classrooms, and functioning similarly to non-ASD samples.[34,57,58] Similarly, elimination or prevention of problem behavior in young children with IDD permits access to early intervention and preschool programs from which they otherwise might be excluded because these programs are not equipped to deal with severe problem behavior. Such programs have components (teaching cooperation, early language skills, and so forth) that would be particularly beneficial to young, at-risk children. Thus, early intervention for problem behavior is highly cost-effective, relative to costs of intensive treatment, and can produce measurable improvement in long-term outcomes for children with IDD.

As discussed previously, research findings from the field of ABA have shown that patterns of caregiver responding and child communication deficits contribute greatly to the maintenance of severe problem behavior exhibited by individuals with IDD.[48] These findings have been replicated with young children who exhibit SIB and other problem behaviors.[62,63] Outcomes of functional analyses conducted with children as young as 1 year to 6 years indicated that in most cases, problem behavior is maintained by social consequences—consistent with research on older children and adults.[48,64] Treatment using FCT and other function-based interventions (eg, NCR) produced notable reductions in problem behavior and increases in communication and other appropriate behaviors. In addition to the impressive clinical outcome, parents found the behavioral assessment and

treatment procedures very acceptable.[65] Thus, best practice procedures, when applied at an early age, can effectively treat severe problem behavior.

In contrast to the extensive research literature on treatment of severe problem behavior, preventing the development of problem behavior has received little attention. Initial studies have applied FCT as a preventive approach with children at risk for development of problem behavior, with promising results. Young children taught communication phrases that were substitutable for common social functions of problem behavior (ie, to obtain adult attention or preferred activities or to escape task demands) showed decreases in minor problem behavior; frequency and severity of problem behavior increased in control group children, demonstrating a preventive effect for FCT.

Recent studies have examined prevention of problem behavior using single-case experimental designs (rather than group designs) because this approach permits precision in within-subject measurement, replication, and control, which has great utility in the initial stages of experimental evaluation of prevention approaches.[66] Sensitivity tests based on functional analysis methods have been developed to screen for the emergence of problem behavior in single cases. Communication training is conducted in the specific contexts where problem behavior is likely to occur, and then a prevention effect of FCT is demonstrated. A laboratory model to study the prevention of development of problem behavior also has been piloted,[67] which integrates basic and applied behavioral research. In sum, these studies suggest that FCT may be a feasible approach to preventing the development of more severe forms of problem behavior.

PEDIATRIC CARE: SURVEILLANCE, PREVENTION, AND EARLY INTERVENTION

Surveillance

In light of the increased risks for children with IDD to display severe problem behavior, ongoing surveillance on the part of pediatricians for the early emergence of this problem is necessary. The presence of genetic conditions that may be associated with problem behavior, the diagnosis of ASD, intellectual and sensory impairments, and deficits in adaptive skills are known risk factors for problem behavior and, therefore, must be assessed to determine the relative risk. Many recommendations on pediatric management of ASD[68–70] also are applicable to the broader population of children with IDD. Awareness of the family's social supports, resources, and the caregivers' capacity to physically manage problem behavior can inform efforts to seek supports available through insurance or social service organizations. Evaluation of caregiver stress and psychiatric issues also is necessary to guide caregivers to access services necessary to address their needs (Box 1).

As discussed previously, problem behavior in IDD stems from the interaction of deficits associated with IDD and the environment. Problem behavior can be difficult to tolerate because it is potentially harmful to the child or others. Consequently, there often is a sense of urgency on the part of caregivers to interrupt problem behavior or even prevent it from occurring. Although sometimes necessary and even helpful, attempts to calm, console, and

appease the child also can reinforce and, therefore, maintain the behavior in the long term. Caregivers inadvertently reinforcing problem behavior from time to time may not result in long-term problems, but persistent maladaptive patterns of interaction can be established through reinforcement processes that can increase the occurrence and severity of problem behavior over time. Therefore, the pediatrician has a critical role in educating caregivers about the potential risks related to the emergence of problem behavior to prevent these patterns of interaction from being established and to initiate early intervention efforts rapidly once it appears they are emerging. Surveillance by routinely inquiring about problem behavior at regular visits is essential to identifying emerging problem behavior and caregiver-child interaction patterns that may inadvertently strengthen problem behavior. Caregiver report of problem behavior may be the primary source of information, because some children may be inhibited in the examination room. Children's behavior, however, and a caregiver's reactions to problem behavior in the waiting area and in response to physical examination can be informative. As has been reported in other pediatric populations, including children dealing with chronic medical problems, caregiver responses that are overly indulgent or overly harsh are associated with negative outcomes.

Likewise, it also is important to identify what efforts caregivers undertake to avoid situations that occasion problem behavior. Accommodation involves efforts aimed at avoiding situations that could lead to problem behavior, including engaging in routines or activities that are disruptive to family functioning and appeasing a child when it appears problem behavior begins to occur. Although not all accommodations are unreasonable, some can be highly disruptive to functioning to the point they are not sustainable and maintain maladaptive interaction patterns where the child is in charge. Therefore, the level of risk should be based on consideration of injuries incurred, close calls, and the potential for injury based on consideration of how often the behavior occurs, its likely sequelae, and the level of effort necessary to prevent its occurrence.

Early Intervention

Referring caregivers to locally available early intervention services for children with IDD is essential, because these can provide families access to myriad services to promote development and positive caregiver-child interactions. Evidence supporting the efficacy of early intervention for children with ASD is robust. When the presence of problem behavior is evident, assessment of physical risks of problem behavior is important for determining what level of intervention is indicated. Any observation of injuries to a child or caregiver should be discussed. As discussed previously, problem behavior can include aggression, property destruction, SIB, elopement, pica, and other behaviors that pose risk to self and others. Within these different types, there is tremendous variation in both the form of the behavior and risks it may pose. Risk can be determined by the presence of injuries, the nature of the behavior itself, and the inherent risks it poses. Aggression can produce serious injury, anxiety, and post-traumatic stress to caregivers[38]; SIB can result in infection, loss of tissue, permanent disfigurement, and loss of function[39]; pica can necessitate surgery and result in poisoning, asphyxiation, and even death[71]; and elopement can result in injury or death.[5] Caregiver reports of close calls where severe injury was narrowly avoided by caregiver vigilance can indicate level of risk. Likewise, risk also can be ascertained based on

a review of what efforts currently are in place to supervise the child and to prevent injury: the more intensive the efforts needed, the greater the risk because such efforts are difficult to sustain over long periods of time (see Box 1).

Secondary Intervention

Once problem behavior is determined to be present and warranting intervention, a variety of options often exist. Some school systems provide intensive behavioral services, and some states mandate funding for services for children diagnosed with ASD. Because many states have recognized that ABA is the most empirically supported approach for problem behavior, licensure and funding for behavior analysts have increased the availability of services. If resources available through educational and public early intervention services are insufficient to meet the needs, referral for specialized behavioral services or the use of medication should be considered.[72] Ideally, medication would be applied after a functional behavioral assessment has been conducted to identify environmental antecedents and child-caregiver interactions that may be reinforcing the problem behavior. Aripiprazole and risperidone have Food and Drug Administration approval for treatment of irritability in ASD and have been deemed appropriate to use if problem behavior poses risks to safety or could lead to more restrictive placement or if other interventions have been attempted and failed to produce sufficient improvement. Other medications have limited support for ASD[72] and SIB.[73–77] Pediatricians must determine whether they possess sufficient experience and knowledge to initiate medication management or if referral to another medical professional is appropriate (see Box 1).

Although the combined use of medication and basic behavioral intervention requires further study and is not routinely practiced, this approach has been advocated by many. The general premise is that medication and behavioral interventions can work synergistically. Medications may decrease emotional reactivity, irritability, impulsivity, and other sources of dysregulation, whereas behavioral interventions target adaptive skills and alter maladaptive patterns of interactions (see Hagopian and colleagues[30]). In addition, improved regulation produced by medication may increase a child's ability to benefit from behavioral interventions. Finally, if behavioral and pharmacologic interventions are combined, behavioral data being collected to evaluate the behavioral intervention could be used to help evaluate the effects of medications. Whether medication is applied alone or concurrently with behavioral interventions, measuring outcomes in a systematic manner (eg, the Aberrant Behavior Checklist) helps assess outcomes and adverse effects.

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Box 1

Prevention and early intervention for problem behavior

- Primary prevention
  - Referral for early intervention services for IDDs
    - Departments of health and education
  - Assessment
    - Child's functioning
    - Caregiver capacity and resources
  - Education of caregivers
    - Education of caregivers on increased risk of problem behavior
    - Education of caregivers on resources
  - Ongoing surveillance for emergence of problem behavior
    - Injuries
    - Caregiver report
    - Observations during clinic visits
- Early intervention
  - Assessment of problem behavior and caregiver capacity
    - Risks of problem behavior
    - Caregiver capacity and skills
  - Education of caregivers on caregiver-child interaction patterns
  - Referral to specialists
- Secondary intervention
  - Referral to and collaboration with behavior specialists
  - Relevant factors to consider related to initiating medication management
    - Consider response to behavioral intervention
    - Consider risks of problem behavior
    - Consider comorbid medical and psychiatric conditions
    - Consider level of experience and knowledge
    - Consider referral to another physician with specialized expertise
  - If medication management is initiated
    - Monitor outcomes using objective measures
    - Monitor for potential adverse effects
    - Monitor regularly, adjusting dosage or medicine based on response

KEY POINTS

- Problem behavior occurs in 50% of children with intellectual and developmental disabilities; in 10% of cases, problem behavior is considered severe.
- Risk factors for problem behavior include presence of more severe intellectual disability, a diagnosis of autism, sensory impairments, and deficits in communication.
- Functional analysis and function-based treatments based on the principles of applied behavior analysis are considered best practices.
- Pediatricians play a crucial role in early identification of problem behavior, referral to early intervention services, and parent education.