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Personalized reading intervention for children with Down syndrome☆

Christopher J. Lemons[a,*], Seth A. King[b], Kimberly A. Davidson[f], Cynthia S. Puranik[c], Stephanie Al Otaiba[d], Deborah J. Fidler[e]

[a] Peabody College of Vanderbilt University, United States
[b] Tennessee Technological University, United States
[c] Georgia State University, United States
[d] Southern Methodist University, United States
[e] Colorado State University, United States
[f] University of North Georgia, United States

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ABSTRACT

The purpose of this replication study was to evaluate the potential efficacy and feasibility of an early reading intervention for children with Down syndrome. The intervention was developed in alignment with the Down syndrome behavioral phenotype. Six children between the ages of seven and ten years participated in a series of multiple-probe across lessons single-case design studies. Results indicate a functional relation between intervention and reading outcomes for four children. Results were mixed for one participant and no functional relation was demonstrated for another. The potential promise of pursuing aptitude-by-treatment interaction research for subgroups of learners with similar characteristics as an effort to personalize intervention is discussed.

1. Introduction

On January 30, 2015, President Obama launched his Precision Medicine Initiative with the aspiration of enhancing doctors' abilities to match treatments to patients. The President lauded precision—frequently referred to as personalized[1] (Katsnelson, 2013)—medicine as "one of the greatest opportunities for new medical breakthroughs that we have ever seen…(with the) promise of…delivering the right treatments, at the right time, every time to the right person (The White House, January 30, 2015)." Personalized medicine is aimed at understanding how individual differences (e.g., genes, environmental factors, diet) interact with treatments to effect outcomes. The term refers to the tailoring of treatments for individual patients through the ability to classify individuals into subpopulations that differ in risk-status or response to a specific treatment (National Research Council, 2011). An example of personalized medicine would be a doctor determining whether the drug Trastuzumab is likely to be effective in treating breast cancer based on findings from a diagnostic test—the drug is only effective in the 15% to 20% of cases in which tumors have an

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* Corresponding author at: Peabody College, Box 228, 110 Magnolia Circle, 418C OMC, Vanderbilt University, Nashville, TN 37203, United States.
E-mail address: chris.lemons@vanderbilt.edu (C.J. Lemons).

[1] Although we acknowledge the debate in the medical field regarding which term is more appropriate, we have opted to use the term *personalized* instead of *precision* throughout the manuscript to avoid confusion with Precision Teaching (Kubina & Yurich, 2012).

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overexpression of a specific receptor known as HER2 (Redekop & Mladsi, 2013).

Personalized medicine is premised on the assumption that reality is not homogeneous (de Leon, 2012). A critique of evidence-based medicine, which relies predominantly on randomized control trials (RCTs), is that "RCTs can tell us which treatments are effective but not necessarily which patients should receive them" (de Leon, 2012, p. 158). Accordingly, "one-size-fits-all" treatments deemed efficacious based on the average response of research participants in an RCT are rarely effective for all patients. This is due to both an assumption of statistical homogeneity and the differences between research participants and the complex nature of real-world patients. Exemplifying the point, in the United States, ten of the highest-grossing drugs fail to improve targeted conditions for between 3 and 24 people for every one person they do help (Schork, 2015). The aim of personalized medicine is to overcome some of the limitations of evidence-based medicine by helping doctors determine which intervention may be the best for an individual patient based on a broader set of data than has traditionally been considered. Treatments are then selected for individual patients based on characteristics shared with previously studied subgroups of individuals.

The field of education's counterpart to evidence-based medicine is the evidence-based practice (EBP) movement, a relatively recent focus on using rigorous, scientific studies to identify effective academic and behavioral interventions. The EBP movement has been principally advanced through the establishment and leadership of the Institute of Education Sciences (ESRA, 2002). Further, it has been more explicitly tied to practice through the latest reauthorizations of the Individuals with Disabilities Education Act (IDEA, 2004) and the Every Student Succeeds Act (ESSA, 2015). The core idea underlying the EBP movement is that practitioners should rely on evidence from experimental research to determine which practices they should implement to meet the needs of students under their charge. (For a more thorough review of EBPs, see Cook & Odom, 2013.)

Just as in the medical field, educational interventions that are deemed EBPs are not presumed to work for every student. As noted by Cook and Odom (2013), the implementation of an EBP increases the probability that a majority of students will demonstrate improved outcomes; however, for any individual student, this improvement is not guaranteed. In fact, as many as 2%–7% of the general population fail to respond to EBPs delivered as secondary prevention (D. Fuchs & Fuchs, 2015), with documented rates of nonresponse for students with disabilities as high as 25% to 50% (Fuchs, Fuchs, & Compton, 2012; O'Connor & Fuchs, 2013). This poor rate of response for students with disabilities is reflected in national data that indicate that 67% of fourth graders with disabilities and 63% of eighth graders with disabilities lacked basic reading skills (U.S. Department of Education, 2015). The current level of insufficient response to educational interventions puts many students with disabilities on a path toward poor post-secondary outcomes. Despite improvements over the past three decades, recent data suggest that when compared to same age, non-disabled peers, individuals with disabilities are less likely to enroll in postsecondary school, paid less per hour, and less likely to live independently (Sanford et al., 2011).

In an attempt to ameliorate poor student outcomes, many schools provide instruction though a sequence of progressively intensive tiers designed to meet the needs of students with persistent academic and behavioral needs. These models are most commonly referred to as Response to Intervention (RTI; Fuchs et al., 2012) or Multi-Tiered Systems of Support (Burns, Jimerson, VanDerHeyden, & Deno, 2016). Although there are minor variations in implementation, in general, the first tier is primary prevention (e.g., Tier 1) designed to address the needs of all students. Students who demonstrate inadequate response to primary prevention receive additional, more intensive secondary prevention that is most often delivered through a standardized protocol (e.g., Tier 2). Again, progress is monitored. If students continue to demonstrate insufficient response, they are designated to receive intervention services at the most intensive level of tertiary prevention (e.g., Tier 3). In many RTI and MTSS models tertiary prevention is synonymous with special education services.

Most RTI and MTSS models recommend that tertiary prevention services be individualized to meet students' needs; however, neither model provides sufficient procedural details to guide the tailoring of tertiary intervention. Data-based individualization (DBI; National Center on Intensive Intervention, 2013) is one approach that provides educators with a framework for individualizing interventions for students who are nonresponsive to EBPs provided through primary and secondary prevention. The DBI framework guides interventionists to intensify and adapt standard protocol instructional platforms for nonresponsive students based on progress monitoring data. The framework provides guidance for the types of adaptations (e.g., quantitative, qualitative) that may be warranted; however, the process is not prescriptive, and thus relies a great deal on the expertise of the interventionists in applying the framework appropriately to successfully meet the needs of individual students. Curriculum-based assessment (CBA; Hosp, Hosp, & Howell, 2007) and curriculum-based evaluation for instructional design (CBE-ID; Burns, Parker, & Tucker, 2014) provide somewhat different guidance to individualize interventions. However, like DBI, they require highly competent practitioners with deep content area expertise (i.e., reading, mathematics, behavioral intervention) who can integrate the use of data and complex decision-making.

Although the logic of multi-tiered intervention systems appears to hold promise, the question of whether RTI or MTSS models will substantially improve outcomes for students—especially those with disabilities—remains to be seen. There is some evidence that providing primary and secondary prevention meets the needs of a greater number of students (Coyne, Oldham, Leonard, Burns, & Gage, 2016; Vaughn et al., 2009). Conversely, there is also evidence that implementing tiered systems of intervention often falls short of intended outcomes (Balu et al., 2015). The fact that schools have not seen drastic improvements of student outcomes associated with tiered intervention systems coupled with the concerns about the burdensomeness of and technical skill required to deliver individualized intervention is disconcerting. However, the personalized medicine movement may offer guidance.

1.1. Personalized educational interventions via aptitude-by-treatment interaction research

The educational equivalent of personalized medicine would be to assign nonresponsive students to specific interventions based on