

Development of Dyslexia Informational Paper: A Process Approach

Audience: Parents, students, teachers, pre-service teachers, and administrators.

Participants: Primary focus on role and function in educating students to read.

- individuals with dyslexia
- parents of children with dyslexia,
- regular education and reading teachers
- evaluators (school and independent),
- interventionists (within the school and external to the school),
- special education teachers/coordinators,
- expertise in 504 and IDEA compliance,
- trainers and coaches in reading and dyslexia,
- assistive technology and accessible materials,
- principals/assistant principals.

Key Facilitation Components (Actively manage present to invent future)

- Target audience **generated FAQ's before group was called together.**
- Group decision **to address questions not otherwise documented** or extensively covered elsewhere (we would include links and resources).
- **Introductions:** who I am, hat I wear, what I most want to accomplish, I would be disappointed if..., I can't live with...(became working agreements and non-negotiables to monitor and manage)
- Stakeholders and target audience drafted **case examples** with intention of including in paper to make this real. This purpose changed as it established shared understanding as to "why" to support the **motivation, trust, and shared experience** needed to focus the work.
- **Established non-negotiables** for the outcome and work (pop-corned out after folks had done introductions and listed the roles they take on relative to the work). **Our non-negotiable** was that we would disband the group if any member or organization pulled away or discredited the work after it was done.
- Toggled with six approaches to addressing adaptive challenges (1997, Heifetz and Laurie)
 - **Getting on balcony**—focus on outcome and unified goal. Supporting stakeholders to see the big picture and be realistic about the contribution of the product to the systemic change needed. Took time to educate stakeholders on rationales, systems, and process of law and policy making.
 - **Identifying the challenge**—naming challenges of doing what kids need and getting out of assumptions. Use of parking lots and sticky notes to name challenges and put them in the "circle of concern model."
 - **Regulating distress**-- pacing, sequencing, use of 3rd point activities (extensive use of museum walk), rephrasing, small group work, breaks, using group members to help regulate tensions.
 - **Maintaining disciplined attention**-- Continuously revisited questions to see what we were and were not addressing. Selected experts who could negotiate agreement in good faith of student outcomes and could educate group on differing perspectives. As we drafted responses,

maintained question as header. Used reflection frame: “Is this answering the question? Is the answer clear and concise?”

- **Giving the work back to the people**—individuals selected questions to answer and thereby worked as a team to write answers to questions. In pairing up to draft the public specter of wordsmithing was taken away. Draft sessions were broken up with opportunities to review drafts in a museum walk. All members had opportunities at this time to use sticky notes to compliment, question, add, revise, or make recommendations. If we got stuck, we’d let it sit or send it to expert for additional thinking. The **group norm** was to focus on brainstorming preferred language and making positive suggestions. Members were redirected away from criticizing and walking away. They were encouraged to give an alternative or commit to bringing alternative back to group at a later moment. Edits were sometimes assigned to individuals to fix later in working drafts to be exchanged via email.
- **Protecting all voices**—we gave multiple opportunities to be heard and address each other with questions. We used a language frame to address the tendency to react emotionally to experiences that were not personally experienced. Use of paraphrasing, rephrasing or redirecting to clarify key idea so the *how* didn’t get in way of *what* was being communicated. Stakeholder’s shared collaboration and commitment included shared regulation to keep the work moving. One member recognized she was unable to regulate and stepped back from the writing and became a reviewer. It was important to maintain her connection.
- **3 phase review cycle:** 1) writers read and clarified. Made sure non-negotiables were met 2) Experts who wanted to be involved but couldn’t contribute to the writing reviewed using a structured review guide. 3) Parents and general education teachers at a conference session reviewed sections to see what we got right and what needed improvement.
- **Everyone had to agree to support, post paper, and host joint presentation at the end.**

Goals of Informational Paper

Stated	Behind the Scenes	Action as result:
<p>Why not just call it dyslexia? Why are there so many terms to describe a student with a reading problem?</p>	<ul style="list-style-type: none"> • No way to get consensus that replicates beyond folks in the room. • Honor multiple perspectives, establish empathy, and support problem-solving. • Listening carefully to non-negotiables and paying close attention to use of language. • Consensus, “I may not love it, but I can live with it and defend it.” • Educate on nuances of how DSM and IDEA were created and have different goals. 	<ul style="list-style-type: none"> • Added call-out boxes with specific stakeholder voices and stories. • Listed, defined and clarified multiple terms or phrases so that everyone can understand variety of language used to describe same thing. Parents were adamant that we include terms professionals use in meetings, “don’t dumb down the language.” • Included rationale for why DSM and School law have different terms and criteria
<p>What does dyslexia or a struggling reader look like?</p>	<ul style="list-style-type: none"> • Some stakeholders wanted the label. Some said the label doesn’t help match instruction. • Described characteristics specifically enough to stop the “waiting to mature” attitude. 	<ul style="list-style-type: none"> • Put information into a table that starts on page 3. (Inspired by Shaywitz) • Characteristics—Terms you may hear from adults about your child—actions you can take • Included actions connected to the descriptors so readers could take action—some are redundant and that was ok
<p>How can I prepare myself to request services and supports for a child who is struggling with reading?</p>	<ul style="list-style-type: none"> • What can parents do and say to help focus attention on what student needs, not what is “typically done/available.” • Build parents and general education teacher skills to advocate effectively. • Manage the emotions of feeling blamed and vilified by one group. 	<ul style="list-style-type: none"> • Included directions that were consistent with successful parent experience and problem-solving done in effective school teams. • Joint presentations after the paper included examples of how to do it.

Stated	Behind the Scenes	Action as result:
<p>What services and supports are available through the school and community, and how can we get access to those services?</p> <p>What can I do when services are not offered within the school?</p> <p><i>Lots of non-negotiables in this section.</i></p>	<ul style="list-style-type: none"> • Not all students with a label will qualify for services. There are legal mandates to discuss; This was biggest controversy and required most listening and education • There are trust issues over data and who has collected it. This is a behavior that has to stop, but how.— collective hill to die on. • Described limits of legal obligations. Double checked with internal and external legal sources • Discussed holistic approach—to balance out what each contributes and highlight coordination opportunities. 	<ul style="list-style-type: none"> • Created pie chart that lists holistic approach supports • Created decision tree with narrative (yes this is too long and too complex in narrative form, but best we could do). • 2E case study and section—names that this is real and legitimizes concerns to be addressed. Written by 2E parent, researcher, advocate but owned by everyone.
<p>How do I know that what is being offered will work?</p> <p>What should instruction look like ?</p> <p><i>Lots of non-negotiables in this section.</i></p>	<ul style="list-style-type: none"> • Managed emotions around the fact that what is needed sometimes exceeds organizational and human capacity despite what the law promises. Who owns the responsibility and who pays are tough issues. Managed use of talking points to stay focused on product and what would help. • Advocates needed some way to describe and talk about effective instruction that doesn't name a program. • Educated advocates that schools legally retain right to select instructional materials and. Fidelity checks didn't yet exist as mainstream discussion curriculum • Named lack of competency and cross-disciplinary agreement creates barrier to getting right services. • Managed fear that naming a specific type of reading problem will leave other issues unaddressed. Managed disbelief that reading failure is most attributable to decoding and not other literacy-related skills. • Unconsciously thought about the “ladders of inference” and prepared to bring folks back to data and “look for’s.” 	<ul style="list-style-type: none"> • Listened to non-negotiables and crafted positive language for each of most contentious sections. • Defined what's working and critical features of instruction. • Pulled heavily on experts for each domain to stay true to professional and research experience, then put through compliance lens, verified that response was acceptable to all. • Critical instruction list defined, teachable, and repeatable skills from research. We had plans to use this for training, coaching, and a checklist, for parents to use in observations. • List will include language skills, decoding skills, and comprehension skills (non-negotiable that we address holistic needs). • Buyer beware section—drafted by advocates with advocate voice.