

**Support for Dysgraphia:  
Understanding Impact, Identifying Resources,  
and Creating an Advocacy Community Around  
Learning Disabilities of Written Expression**

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**Outline**

- Unmet Needs
- What Is Dysgraphia? Why Use That Term?
- Education
- Community
- Awareness
- Unmet Needs - Revisited
- Future Directions & Take Aways

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**Unmet Needs**

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### A little bit of background on me...

- In 2019, entirely new to this community
- Scientist, speaker, advocate by professional background
- I experienced many of the same issues that I see every day in our community:
  - No understanding and awareness of written expression differences
  - No referrals for school-based testing
  - Difficulty advocating for 504/IEPs
  - Recognition of dysgraphia's effects on adults who were never diagnosed
- Where is the information? Where is the science?

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### It all started with a search

The screenshot shows the PubMed.gov search interface. The search term 'dyslexia' is entered in the search bar. Below the search bar, there are buttons for 'Save', 'Email', and 'Send to'. The results section shows '10,938 results' circled in red. Below this, it says '1/18/22' and '10,938 results for dyslexia'. The page number is 'Page 1 of 1,094'.

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### It all started with a search

The screenshot shows the PubMed.gov search interface. The search term 'dysgraphia' is entered in the search bar. Below the search bar, there are buttons for 'Save', 'Email', and 'Send to'. The results section shows '1,580 results' circled in red. Below this, it says '1/18/22' and '1,580 results for dysgraphia'. The page number is 'Page 1 of 158'.

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### It all started with a search

- 1/7 the amount of scientific literature as dyslexia
- Much of this was focused only on handwriting
- A significant amount focused on agraphia or loss of written expression skills, which is not what I was dealing with

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### Many immediately obvious needs

- No clear definition of "dysgraphia"
- Very little scientific/medical literature
  - "Cancer" -> 4.5M ; "Dysgraphia" -> 1500
- Little awareness in schools
- No centralized home for this community

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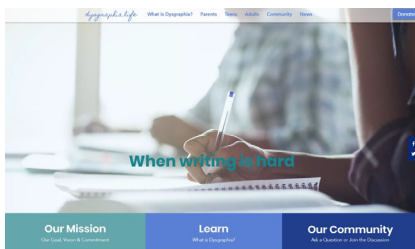
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### Dysgraphia Life®: [www.dysgraphia.life](http://www.dysgraphia.life)



Screenshot from first day the site was live: 10/29/19

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### Full transparency/COI – B Corp structure (for now, for sustainability)

- In the organization's articles of incorporation filed with the state of Virginia:
  - The purpose of the corporation is to create a general public benefit
  - The specific purpose is: Providing individuals with learning disabilities with information, education, beneficial products or services
- This structure allows us to fulfill the organizational mission/ purpose while sustaining the organization
  - Currently no income, entirely volunteer based, volunteers are mostly previous or current nonprofit employees

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### A note on language #WordsMatter

- Learning disorder vs disability vs difference
- Person first vs identity first language

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### What Is Dysgraphia?

And why do we use that term?

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### The typical presentation that we see

- Often manifests around age 7-8 but can be later
- Child starting to struggle in school
  - Homework is a battle
  - Avoidance of writing tasks
- Handwriting is unclear, difficult to read, not spaced correctly,
- Spelling is not sticking with them
- Lack of capitalization, punctuation, spacing
- These issues persist when copying
- "My child has all of these great thoughts when speaking, but can't seem to get them out on paper"

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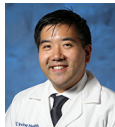
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### What is dysgraphia?

Review Article

Disorder of written expression and dysgraphia: definition, diagnosis, and management

Peter J. Chung<sup>1</sup>, Dilip R. Patel<sup>1</sup>, Iman Nizami<sup>2</sup>



Dr Chung, UC Irvine

"At its broadest definition, dysgraphia is a disorder of writing ability at any stage, including problems with letter formation/legibility, letter spacing, spelling, fine motor coordination, rate of writing, grammar, and composition."

Transl Pediatr. 2020 Feb;9(Suppl 1):S46-S54.  
doi: 10.21037/tp.2019.11.01.

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### Feifer Assessment of Writing: 3 subtypes of dysgraphia

- Graphomotor Dysgraphia
  - Motor skills
- Dyslexic Dysgraphia
  - Spelling – phonologic and/or orthographic
- Executive Dysgraphia
  - Working memory & executive function



Steven Feifer, D. Ed., NCSP, ABSNP

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### Community Snapshot: Needs Assessment Survey

- Open for ~6 weeks (December 7, 2021 – January 21, 2022)
- Purpose: Help identify greatest needs, will be used to plan and prioritize new initiatives, resources, and research studies.
- Open to all members of the community
  - 95 respondents from 35 different states
  - 78% identified as parents
- Not representative – only promoted on social media, website, & in monthly e-newsletter

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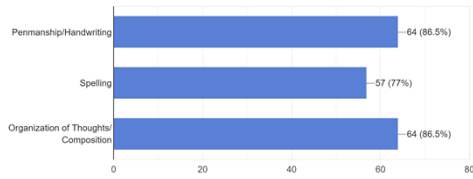
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### Poll results: Areas of difficulty

What areas does your child find difficult? (Please choose all that apply)  
74 responses



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### Diagnosing “dysgraphia”

- World Health Organization
  - ICD-10: F81.81 Specific learning disorder, with impairment in written expression
  - ICD-11: 6A03.1 Developmental learning disorder with impairment in written expression
- American Psychological Association
  - DSM-5 315.2 Specific learning disorder of with impairment of written expression
    - Specifiers that include deficits in spelling accuracy, grammar and punctuation accuracy, clarity or organization of written expression

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### So why do we use this term? People get it.

Dysgraphia and Dyslexia - What's the difference?



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### Assessments

- There is not one standard test or set of tests used to diagnose dysgraphia.
- Testing for dysgraphia/SLD of written expression is typically done as part of a comprehensive neuropsychological evaluation by a psychologist or in a school-based setting.
- There are also occupational therapy assessments for motor skills and sensory issues. Many people start with OT/handwriting.
- Roughly 2/3 of our poll respondents reported private testing – this is NOT an option for everyone

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### Education

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### Website content

- Goal: to be a resource for people struggling with written expression and their loved ones
- Sections for parents, teens, adults
- Evidence-based content
- Constantly expanding
- Resource links
- Blogs! [Contact us– [info@dysgraphia.life](mailto:info@dysgraphia.life) ]

“...coming across your page today was a huge relief and resource find for me! To know that there is some one willing to put all this info together is amazing.”

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### Orton-Gillingham approach & structured literacy

For Acquiring Written Language & Spelling Skills

- Structured & Systematic (has a method with well defined organization)
- Sequential (from easiest to hardest based on the research)
- Cumulative (increases learning by slowly adding content)
- Simultaneously multi-sensory (delivers information by sight, sound, touch, and movement at the same time)
- Based in language principles (phonological, orthographical and morphological)
- Scientifically peer-reviewed

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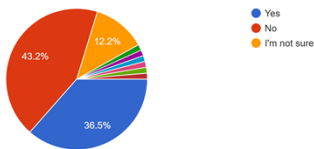
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### But this approach is still not the norm

Has your child ever been taught reading or writing using a 'structured literacy' or 'Orton-Gillingham' approach?  
74 responses



Very small sample size, but only 12.5% of adults said Yes

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### Elementary school accommodations

- Extra time for test taking and/or assignments
- Scribe for certain tests or assignments
- Allow oral presentation of work when appropriate (this could include video responses to questions instead of written responses)
- Use of specialized spacing paper for handwritten work
- Use of fidget toys/hand strengthening toys
- Early utilization of computer/keyboarding
- Assistive technology – word prediction software (such as Co-Writer), talk-to-text programs
- No penalties for spelling or grammar mistakes on certain assignments, when appropriate
- Allow marking responses on the test booklet for any standardized tests with “fill in the bubble” formats
- Use of graphic organizers to organize compositions, in older grades
- No copying from the board (notes or assignment information provided or student allowed to take a photo)

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### High school/college accommodations

- Extra time for test taking
- Audio recordings of lectures
- Note-taker/scribe
- Allow oral presentation of work when appropriate (this could include video responses to questions instead of written responses)
- Assistive technology such as talk-to-text, spell/grammar check, and Grammarly

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### Top school accommodations in our poll

More than 50% of those with school-based accommodations had:

- Extra time for assignments and tests
- Talk-to-text/voice typing
- Notetaker/scribe/copies of notes
- No or reduced copying
- Graphic organizers

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### Dysgraphia webinar series

How do we continue to enhance education? Bring experts directly to the community to teach and answer questions.

- Free, live webinars
- Target audience: parents
- Experts in dysgraphia/SLD in written expression or related topics
- ~45 minute presentation and questions on general situations (not student specific)

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### Dysgraphia webinar series

- October 20, 2021 with George McCloskey, PhD  
Executive Functions & Writing



- June 23, 2021 with Cheri Dotterer, MS, OTR/L  
Dysgraphia? What Is It Anyway?



- March 3, 2021 with Steven Feifer, D. Ed., NCSP, ABSNP  
The Neuropsychology of Written Language Disorders:  
Developing Evidence-Based Interventions



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### Learnings from webinar series

- Feedback is extremely positive and appreciative
- The expert speakers believe that this kind of forum is needed
- Parents are not the only ones attending -> many teachers and other professionals are joining to learn about dysgraphia and strategies to help

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**Next webinar: February 16<sup>th</sup>, 2022**

February 16th, 2022 7:30PM ET

Understanding Your Child's Dysgraphia:  
A Cognitive Science Perspective



Dr. Brenda Rapp      Dr. Michael McCloskey

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**Community**

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**What does our community look like?**

- Dysgraphia is common!
  - Dohla & Heim, 2016: prevalence for developmental writing disorders is about 7–15% among school-aged children
  - Chung et al: Between 10% and 30% of children experience difficulty in writing, although the exact prevalence depends on the definition
- Some studies show more common in boys (Katusic et al. 2009)
- Can be (but not always) accompanied by other learning disabilities – ADD/ADHD, dyslexia
- Typical presentation: parent is searching because the child is struggling with writing in school

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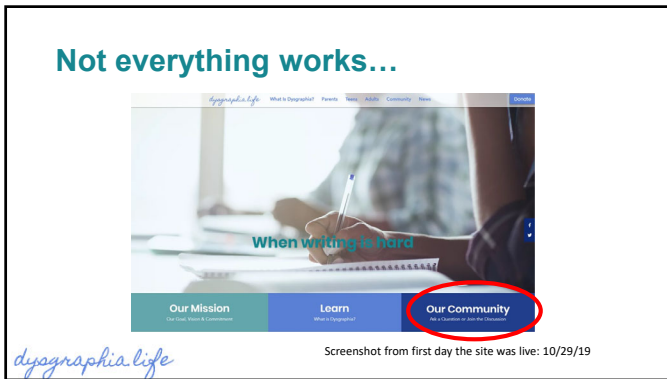
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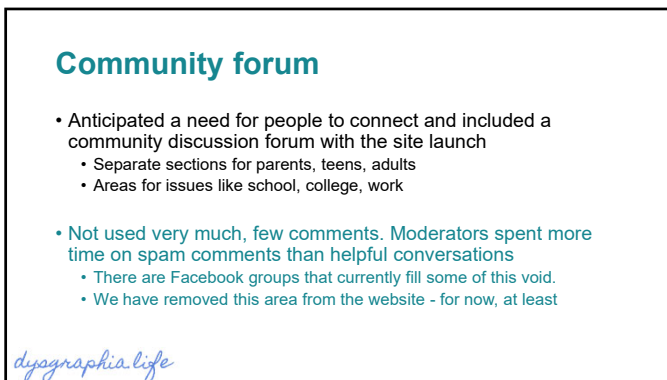
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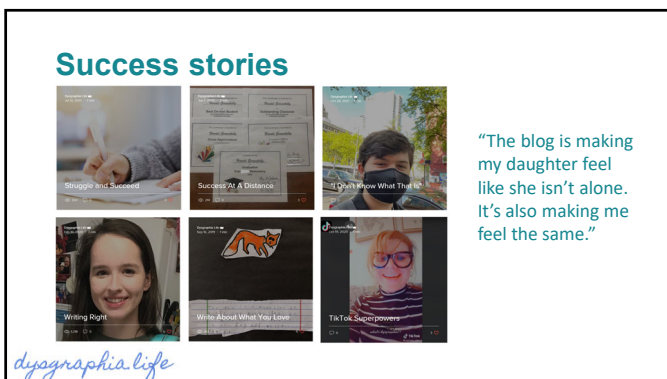
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### Our most common email question

Hi,

I am the parent of a child who is XXX years old and we are in XX, XX. I am looking someone to diagnose/tutor/provide OT/help my child who is having writing difficulties. Could you suggest someone?

Thanks,  
XXX

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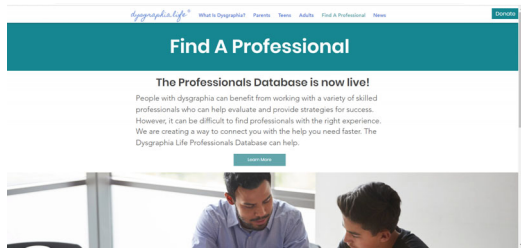
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### Professionals database



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### Awareness & Advocacy

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### General goal: raising awareness of dysgraphia across many sectors

- **General Public** – increase understanding of the existence of dysgraphia / SLD in written expression
- **People with writing difficulties & loved ones** – awareness that this is common, you are not alone, and there is help
- **Educators** – understanding of dysgraphia, how to support writing in the classroom, best ways to help
- **Policymakers** – dysgraphia should be included with support for other learning disabilities

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### October: Learning Disabilities Awareness Month



Reached over 30,000 people on Facebook alone with a tiny budget

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### Advocacy

Advocacy is an activity by an individual or group that aims to influence decisions within political, economic, and social institutions.

- Currently, supporting self-advocacy & advocacy on behalf of one's children
- Future direction: grassroots & political advocacy to influence education policies

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**Unmet Needs - Revisited**

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**Needs in the Dysgraphia Community**

- Awareness, awareness, awareness
- Education of teachers how to help students
- Connecting the community
- More research: neurobiology, genetics, effectiveness of interventions and accommodations, long-term outcomes

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**Future Directions**

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### Areas of growth for Dysgraphia Life

- Awareness
  - More public awareness of dysgraphia & difficulties in written expression
  - Eventual advocacy at a state and national level
- Education
  - Continually expand website content
  - Continue to provide free webinars & find new methods to educate people with writing difficulties & their loved ones
  - Considering expansion to professionals, particularly teachers
- Community
  - Expand Professionals Database ([Please join today!](#))
  - Continue to highlight successes

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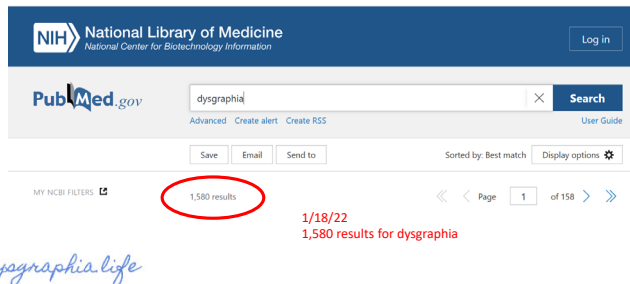
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### It all started with research studies...



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### Dysgraphia Registry

- Creating a Dysgraphia Registry in 2022
  - Create an activated community around dysgraphia research
  - Will survey people longitudinally to understand "natural history" of dysgraphia
  - Help understand outcomes & quality of life concerns
  - Opportunities for researchers to connect with the community for additional biological studies (imaging, genetics)
  - Catalyze more opportunities for dysgraphia research

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### How can you help?

- Everyone: spread the word about dysgraphia
- Professionals
  - Join the Professionals Database
  - Collaborate on a blog or webinar
  - Remind clients that they are not alone and there ARE strategies to help
- Community
  - Include dysgraphia in broader LD-related efforts (policy & awareness)
  - Share success stories
  - Participate in surveys & research (Dysgraphia Registry - late 2022)

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### Take Aways

- There are major gaps related to dysgraphia/specific learning disability of written expression
  - Research
  - Awareness – both in school and general public
- Definition of dysgraphia need to be clarified
  - Consensus to alleviate confusion
  - Better definition will lead to better assessments & strategies
- There are ways to help people with writing difficulties
- Education, awareness, and advocacy will be key
  - It will take a coordinated community effort to address these areas

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### Thank you!

- Dysgraphia Life Community
- Everyone who answered the Needs Assessment Survey
- Everyone who shared success stories
  
- Amy Copeland, MPH
  
- All of our webinar speakers and professionals who wrote news blog articles

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Contact us at [info@dysgraphia.life](mailto:info@dysgraphia.life)

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