How To Guide
Starting a Grassroots Movement for Dyslexia in Your State

Do you feel that dyslexia gets little attention in the public education system? Do you have the desire to unite families and professionals in your state to bring attention to the struggles faced by students with dyslexia? Do you have the need to speak out about the roadblocks faced when trying to access services and supports? Do you want to see policy change?

By now you must know that families and students across the country face identical challenges yet feel their voices go unheard. A grassroots movement for dyslexia can allow everyday parents and citizens the chance to be proactive on this issue. It gives them a format in which to promote change!

Grassroots organizing can be challenging but when parents are motivated to institute change, a small movement can quickly become a large-scale statewide initiative!

In a very short period of time, Decoding Dyslexia - NJ, established in 2011, has had a great impact in their state and beyond. This “How To Guide” has been developed to help parents and professionals in other states start similar parent-led movements. They believe that dyslexia needs to be addressed on the national stage with each state uniting families to speak up and speak out about the struggles and roadblocks faced.

Decoding Dyslexia – NJ is a grassroots movement driven by NJ families concerned with the limited access to educational interventions for dyslexia and other language-based learning disabilities within our public schools. We aim to raise dyslexia awareness, empower families to support their children and inform policy-makers on best practices to identify, remediate and support students with dyslexia in NJ public schools.

To start a Decoding Dyslexia group in your state, contact DD-NJ directly at info@decodingdyslexianj.org

Use this How To Guide to get a grassroots movement for dyslexia started in your state. Be confident in the fact that a group of parents can be very powerful. Policy-makers connect in a very real way to the stories and suggestions of their constituents. As we parents share our stories and raise awareness, we can pave the way for experts to get a foot in the door and advise on best practice. You can get started on your own or with a small group of like-minded individuals...
Here’s what you need to do:

1. **Define your movement and outline your purpose.**

   What are the issues families face when trying to access services and supports for their children? What do you want to change in your state regarding the way schools address dyslexia? It is important that you figure this out and finalize it before moving forward. Write up a mission statement or a “manifesto” you can use as your group develops. Figure out your “pitch” or the story you are trying to tell. It needs to summarize and relate to your mission. All members of the movement need to clearly articulate a central message. And others need to easily understand what your group is all about so they can join the cause. Taking the time to do this early on will ensure that the group is consistent and has maximum impact.

   **TIP:** Decide on a name and slogan for your movement that is self-explanatory. If you have any skilled members, create a logo as well!

If you are interested in starting a Decoding Dyslexia group in your state, you should contact DD-NJ to discuss the use of its mission statement and talking point materials. You can also have a Decoding Dyslexia logo developed incorporating the shape of your state, like DD-NJ uses the shape of NJ! See Appendix A.

2. **Spread the word, build membership and inspire others to action.**

   Reach out to others in multiple, creative ways. Utilize flyers, postcards, word of mouth, email campaigns, social media tools and/or press releases. Make sure that all the information that people need in order to join and support your campaign can be found in these outreach materials.

   Get in front of as many people as you can and tell them about your mission. Exposure gets the ball rolling. Advertise in high traffic areas, such as tutoring centers, libraries, therapy centers. Network with other local organizations focused on dyslexia in your community and state. Scour the Internet for dyslexia or learning disability based social networks. A well placed post or comment can introduce your organization to a whole new audience. Go beyond your comfort zone... you never know who is going to connect to your message and have something awesome to offer your cause.

   You can even plan and host events to raise dyslexia awareness and gain supporters. Send invitations to the local newspaper and television stations, which encourages free exposure. Submit “letters to the editor” which highlight your awareness events or action alert campaigns.

   **TIP:** Create business cards, T-shirts, or car magnets with your group’s name, logo and contact information. See if a local retailer or manufacturer will donate any goods or give a discount. Ask members to chip in or see if you can find a sponsor.
3. Develop ways to keep in touch.

Use email groups, phone lists, or regular meetings to keep your members connected and on the same page. This is critically important to the core, active members who are steering the direction of the group.

Be sure to create pages and groups within social media networking sites, such as Facebook, Twitter and LinkedIn. Ask all of your friends, family members and acquaintances to join and pass along the links. Administer these networking sites well. Post new information regularly and keep it streamlined to information that promotes your very specific mission of dyslexia awareness and policy change. The point is to encourage people to visit the site often and to share comments and content. You just might get new ideas from recent members and be able to encourage them to take the lead on bringing them to fruition!

Create a stand-alone website and provide a link to it on the social-networking site homepage. This is also critically important. An effective website should efficiently communicate all the information about your movement in a permanent location. Social network sites are great but the information shared is transient and not all individuals are members.

**TIP:** When inviting others to connect to the movement via your social media sites, website or email groups, tailor the message to different people by appealing to their interests. For instance, a parent might be interested to receive twitter action alerts but may not have the time to participate in the planning discussions that take place within your Yahoo Email Group. Have plenty of options for people to stay connected so that when the time comes to call everyone together for that important rally, you can reach them easily.

DD-NJ has developed many different avenues for individuals to get and stay connected. There is a stand-alone website at www.decodingdyslexianj.org. There is also a Facebook group, a Twitter account, and various Yahoo Email Groups. Members are asked to consistently brainstorm new ways to outreach and build networks!

4. Delegate! This is hard work so make sure you have good help.

Develop an internal structure that delegates responsibility for specific tasks. One person cannot be in charge of everything. Let smaller groups develop to address specific concerns or accomplish specific goals. Get to know your members so that you develop a sense of people’s strengths and interests. Encourage active participation and celebrate each individual’s contribution no matter how small. Make it your goal to transform passive supporters into more engaged members.
TIP: A public thank you or message of appreciation can go a long way to solidifying someone’s continued interest and future action. Always respond when someone reaches out to your group. A quick “like” or short response to a Facebook comment goes a long way. Recognize each contribution that people make to the common mission.

Develop good spokespeople. Your movement needs to have a consistent voice. You need to have a pool of people you can turn to when there needs to be a public face to the cause. You will need individuals who can compel policy-makers with their story. You will need individuals who can navigate the media well. Take the time to help members develop their personal story so that it correlates to the central mission of the movement. It’s all about the human connection. Teach members to build an emotional connection with the audience by sharing their true story of a real child’s or family’s journey.

At DD-NJ individuals work on different tasks and have different roles within the group. Some are social media administrators and some write press releases. Some take minutes at meetings or develop agendas while others organize awareness events or focus on parent support initiatives. Monthly meetings and email groups are the places where everyone reports out their progress on current goals and puts forward future plans. Members are committed and volunteer consistently to help each other on tasks.

At DD-NJ members worked on developing a consistent voice very early on. Everyone was asked to put their personal stories in writing. We shared our talking points and asked parents to gear their stories to support those items. The goal is to get policy-makers to care about your child’s struggle. They do not need to hear about every injustice or a play by play account of the family-school conflict. They need to quickly come to know the roadblocks you faced, how they affected your child and what needs to be done to correct the problem. Once parents have this planned out and written down… they are in the perfect frame of mind to meet with legislators or shoot off letters to the Department of Education!

5. Remove barriers to participation.

Make it easy for your followers to promote your cause.

TIP: Create shareable content, such as formatted letters and emails, and always provide phone numbers and addresses if you are asking them to contact policymakers.

Try not to introduce “mandatory” events or tasks. Do not require membership fees. This can drive people away. There should be a core group of people who do the work of steering the ship, but an outer ring of followers should be cultivated. These are the individuals that bulk up your mailing lists, increase your “Likes”, sign your petitions and show up when the stakes are high to testify or write a letter. Ensure that your volunteers feel that they are big part of the movement! Encourage them to help create momentum and spread your message.

Letting people participate on their own terms can build a strong base of support. Participation that comes in many forms helps to propel the cause forward. Understand that people will be motivated by different things. By emphasizing the value of low-commitment activities such as “Liking,” or signing a petition, you can broaden your group’s appeal.
6. **Action! Start effective lobbying campaigns for dyslexia.**

Here comes the important work. Have your supporters contact local, state and federal representatives. Encourage them to reach out repeatedly, both by email and phone. Be persistent and don’t let yourselves be ignored. Don’t give up. At times you may feel discouraged but don’t lose momentum. It may just be that next phone call that connects your group to that empathic ear!

Schedule appointments with your local educational leaders and state/federal legislators who can institute change. When communicating with these legislators you need to have clearly outlined objectives. Are you requesting that they write future legislation? Support an existing bill? Talk to them about dyslexia and share those personal stories. Ask them to help make change or to become advocates for your cause.

**TIP:** Do your research and stay abreast of what is happening legislatively in other states and at the national level. You need to be knowledgeable and share information that is supportive of your cause.

Not only do DD-NJ members meet regularly with their local state politicians, but they also organized a lobbying day on Capitol Hill this past summer. Members and their families spent a full day meeting with NJ Representatives in Washington DC encouraging them to join the US BiPartisan Congressional Dyslexia Caucus. This endeavor was a huge success. Eight of the ten representatives they met with joined the caucus!

6. **Take advantage of opportunities and momentum.**

As your movement gets rolling... brainstorm often and try new things. Keep opening doors to see where they lead you. Find creative ways to get more exposure and ask others for opinions on how to increase your impact. Look for opportunities to network or piggyback on the efforts of other like-minded organizations.

Building a successful grassroots movement for dyslexia is not only about the mission but your passion and effectiveness at inspiring others to action. Set a strong, positive example and support your followers well!

**Good luck from Decoding Dyslexia - NJ**
If you are interested to share in the “Decoding Dyslexia” movement, please contact DD-NJ at info@decodingdyslexianj.org. We can send you a Decoding Dyslexia logo with your state’s outline as well as connect you to our growing network of state parent leaders. DD-NJ asks that you coordinate your group’s mission and goals with those stated below. There is much to be gained by building a coalition of Decoding Dyslexia groups across states. Together we can work to build momentum and finally bring dyslexia to a national platform.

Decoding Dyslexia Mission Statement

Decoding Dyslexia – (Your state abbreviation) is a grassroots movement driven by (your state abbreviation) families concerned with the limited access to educational interventions for dyslexia within our public schools. We aim to raise dyslexia awareness, empower families to support their children and inform policy-makers on best practices to identify, remediate and support students with dyslexia in (your state abbreviation) public schools.

Decoding Dyslexia Policy Goals

We are advocating for (your state abbreviation) to implement:

- A universal definition and understanding of “dyslexia” in the state education code
- Mandatory teacher training on dyslexia, its warning signs and appropriate intervention strategies
- Mandatory early screening tests for dyslexia
- Mandatory evidence-based dyslexia remediation programs implemented with fidelity, which can be accessed by both general and special education populations
- Access to appropriate “assistive technologies” in the public school setting for students with dyslexia