

**Society for Developmental and Behavioral Pediatrics (SDBP)
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The Kids Are Not All Right: Advocating for Equitable Outcomes Post-COVID using a Medical-Legal- Educational Advocacy Toolkit

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About this Toolkit:

This toolkit was developed to accompany the workshop of the same title presented at the 2021 Society for Developmental and Behavioral Pediatrics (SDBP) Annual Meeting. This workbook represents the collaborative effort of the authors to enhance this workshop while providing attendees a small resource guide.

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Workshop Description:

The impact of COVID-19 continues to be profound, especially for children with developmental disabilities. This workshop takes a medical-legal approach to educational advocacy to ensure equitable patient outcomes at the local/individual levels. Trainees/practicing professionals in DBP-related fields are invited to participate in skill-building case scenarios utilizing an ecosystems-based framework to approach the intersectionality of special education law and social inequalities. Attendees will analyze/process COVID-19's impact on patient access to services and appropriate educational planning. Our keynote speaker is Bonnie Roswig, JD, who will discuss the role of DB professionals working within medical-legal partnerships to advocate for patient educational rights.

The 2020 outbreak of a novel coronavirus resulted in a global pandemic that significantly disrupted life around the globe. Although DBP professionals may have felt well-equipped to advocate on behalf of their patients and families, rapid shifts in education and medical care delivery have proven difficult for professionals to navigate and provide guidance to families in their care. Providers have experienced significant variability in educational access between and within states. Consequently, DBP professionals have discovered that advocacy in these unusual times requires a specific skill set especially within education. Without proper support and understanding of education law, it is challenging to properly provide support and guidance to families and to advocate for local and state-level policies and changes to improve the lives of individuals with developmental and behavioral concerns.

Workshop Goals:

- Review, analyze, and process the intersectionality of educational, social, and mental health impact of children during the COVID-19 pandemic
- Become familiar with various levels of policy changes on local, state, and federal levels
- Provide and implement a toolkit of strategies to address common special education related challenges from a clinical-advocacy perspective and flexibly apply to anticipated challenges in response to COVID-19
- Inspire attendees to continue to advocate for children in new and unusual times

Workshop Objectives:

- Identify inequities in social and educational outcomes for children with disabilities as a result of the COVID-19 pandemic.
- Use an ecosystems-based framework to approach the intersectionality of special education law and social inequities, and identify opportunities for future systemic advocacy
- Analyze discrepancies between federal education law and its interpretation at the local and state levels and how DB Professionals can navigate these complexities
- Apply basic algorithms to navigate both common special education related issues and those anticipated as a result of COVID-19/social distancing from a clinical setting
- Develop a personal plan to develop a relationship with a local medical-legal partnership or other advocacy related non-profit organizations

How to Use this Workbook:

This is a take-away for you to use during today's workshop. It is also designed to be used afterward as well to help you reflect on your advocacy activities, jot down your ideas and potential topics for advocacy, and have a few resources available to help you on your advocacy journey.

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APPENDIX C:

Who makes the education decisions in your state?

Special education advocacy differs from federal policy advocacy in numerous ways. While it's still important to know who your legislators are (and the next section addresses how to find those individuals), there are many other players involved in decision making at the state, local and school district levels. Below is a link to help you understand the education system in your state:

- <https://www.ecs.org/50-state-comparison-k-12-governance/>

There are many key stakeholders to consider when determining your course of action with regard to education. States, counties/parishes, cities, and school districts may all be involved in education decision making and implementation, although all of these may not apply in your area. As a general rule, start your advocacy efforts at the local level (your “local education agency,” or “LEA”) and escalate higher as needed.

Use your favorite internet browser to search for “K-12 education system” in your state, and look up the following agencies as appropriate:

State Education Agency: _____

Superintendent/Director: _____

Special Education Director: _____

Commissioners/Board Members: _____

County/Parish Education Department: _____

Superintendent/Director: _____

Special Education Director: _____

Commissioners/Board Members: _____

City Board of Education: _____

Superintendent/Director: _____

Special Education Director: _____

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Commissioners/Board Members: _____

School District: _____

Superintendent/Director: _____

Special Education Director: _____

Commissioners/Board Members: _____

Finding your elected officials:

Use these resources to list your elected officials and their contact information. Make note if they have a specific legislative aide who is the contact for issues of a certain type (i.e. aide for education issues).

- <https://www.usa.gov/elected-officials>
- <https://www.commoncause.org/find-your-representative/>

LOCAL:

Mayor: _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Political Interests: _____

Aide/Assistant: _____

Contact: _____

Alderman/County/Parish Exec: _____

Term ends/next election: _____

Phone/email: _____

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Address: _____

Political Interests: _____

STATE:

State Senator: _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Committee involvement: _____

Political Interests: _____

State Representative: _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Committee involvement: _____

Political Interests: _____

Governor: _____

Term ends/next election: _____

Phone/email: _____

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Address: _____

Political Interests: _____

Aide/Assistant: _____

Contact: _____

FEDERAL:

US Representative: _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Committee involvement: _____

Political Interests: _____

Aide/Assistant: _____

Contact: _____

US Senator (1): _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Committee involvement: _____

Political Interests: _____

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Aide/Assistant: _____

Contact: _____

US Senator (2): _____

Term ends/next election: _____

Phone/email: _____

Address: _____

Committee involvement: _____

Political Interests: _____

Aide/Assistant: _____

Contact: _____

US President: _____

Term ends/next election: _____

Contact: Online: <https://www.whitehouse.gov/contact/>
 Phone: White House switchboard: 202-456-1414
 White House comments line: 202-456-1111
 (regular business hours)

Political Interests: _____

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Finding your advocacy partners:

Please, please, please, do not reinvent the wheel if it already exists. Take some time and reflect upon the following:

Which professional societies are you a member of? Are you connected to their advocacy committee/division/workgroup? If they do not have one, are you interested in starting one? Whom should you contact? Are you subscribed to their advocacy briefings/ mailing list?

Organization:	Active member? (i.e. Dues Paid)	Is there an Advocacy Cmt/ Div/ Group?	Registered with group?	Subscribed to listserv?	Contact person:	Personal goals:
<i>SDBP</i>	<i>(Hope so!)</i>	<i>Yes!</i>	<i>Please do!</i>	<i>Did it!</i>	<i>Rob Keder / Jenna Wallace</i>	

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If your list is a little on the empty side or if you are looking to expand, take some time to map out other organizations that exist.

- Your workplace: Does your institution have a Medical-Legal Partnership (MLP)? If so, please check out the next section for tips on engaging with this great resource. Who can you contact for more information about your MLP?

- Professional societies/organizations (i.e. SDBP, AAP, SPP, APA, NASW, etc.) Who else can you get involved with that has goals that align with yours?

- Education/child development and disability-related organizations (i.e. Council for Exceptional Children, Zero To Three, Autism Speaks, AAIDD, CHADD, Learning Disabilities Association of America, etc.). Whose goals align with yours? Do they align with your clinical/research work? How much time/talent/donations will you need to contribute?

- Local grassroots coalitions. Similar to above. Grassroots coalitions can be effective, but can also be a big time commitment (literally herding cats and also moving at a glacial pace, even for advocacy).

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Collaborating with a Medical Legal Partnership (MLP):

A Medical Legal Partnership (MLP) is a medical-legal model that is becoming increasingly more common in healthcare settings nationwide. An MLP is a group of attorneys embedded within a healthcare system who function as part of the interdisciplinary team. MLP attorneys may be utilized for individual consultation with families but may also use their expertise to advance local and state policies that influence societal factors directly related to poor health outcomes. Building a relationship with your hospital MLP can be a great way to learn more about advocating on behalf of your patients.

- *Become familiar with your organization's legislative priorities.*
 - Does your organization have a Center for Policy and Advocacy?
 - What issues are important on an institutional level and do any of these align with your specific area of advocacy interest?
 - What are your organization's policies around employee advocacy participation?
 - On what levels of advocacy has your MLP been involved in the past and regarding what issues?
- *Get to know your hospital's MLP program.*
 - Where is the MLP located within your organization?
 - What types of issues does the MLP help with?
 - Are there lawyers within your organization that patients are assigned to or does your organization partner with other volunteer lawyer programs in the community?
 - Are there other providers you know who have utilized the MLP for their patients? If so, ask about their experiences.
 - Learn how to make a referral to the MLP.
- *Build a relationship with your MLP.*
 - Schedule a meeting to introduce yourself.
 - At this meeting, make sure you give them information about the types of patients and issues you see most common.
 - Get their insights into current legislative priorities and where you may be most helpful.
 - Make sure other members of your staff (particularly your social worker-if applicable) are receptive to the MLP and can foster trust between patients and the legal team.
- *Prioritize education regarding social determinants of health within your clinic setting.*
 - Hospital MLPs can be a helpful resource for education regarding social determinants of health and related effects within your practice setting. National MLPs have conducted a variety of educational seminars for providers nationwide including didactic education sessions, poverty simulations, case samples, etc.
 - Your MLP may also be interested in providing educational seminars for families as well. For example, some MLPs have provided group education to families regarding topics such as guardianship and alternatives, immigration issues, special education services, etc. Caregivers may be more open to legal consultation and education within a healthcare setting they know and trust.

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- *If you do not have an MLP at your institution, consider advocating for one using the resource below.*
 - National Center for Medical Legal Partnership
<https://medical-legalpartnership.org/>
 - Medical-Legal Partnership Toolkit
<https://www.medical-legalpartnership.org/wp-content/uploads/2014/03/MLP-Toolkit-Phase-I-FINAL-FILLABLE.pdf>

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ADVOCACY: BACK TO THE BASICS

1. First and foremost, remember that advocacy begins with the ballot box, even for individual-level advocacy issues such as special education services. State and local elected officials make decisions about funding priorities and appoint people to boards and committees who influence curriculum and service decisions. Make sure you are registered to vote, preferably at your current address. Look up voter registration information for your current residence and fill out an on-line voter registration form or apply for absentee voting. www.vote411.org. Encourage others to register to vote!

2. Find your key players. It is important to know whom to work with to make change. Elected officials are the key players to legislative change. Knowing names is not always enough. Take some of your blocked off time and do some research. What are they passionate about? How have they voted in the past? Are they sitting on any committees? Use some of these tools provided to find out who your elected officials are. Then commit some web browser time to look them up and see where their thoughts, attitudes, beliefs, and values line up. Follow them on Facebook/Twitter!

3. Find your partners. Our voices are stronger together, but sometimes it is hard to find similar voices among the cacophony of political advocates. There are often so many places to begin but we do not have to reinvent the wheel if there is already a team on the ground. Look for who is already working in your areas of interest; it could be:

- Your workplace
- Professional societies/organizations (i.e. SDBP, AAP, SPP, APA, NASW, etc.)
- Disability-related organizations (i.e. Autism Speaks, AAIDD, CHADD, Zero to Three, etc.)
- Child development and education organizations (i.e. Zero to Three, etc.)
- Local grassroots coalitions.

Research them to see if their goals/values align with yours. If you think they are a good fit, sign up for their mailing list, donate, or consider joining.

Look for local chapters within larger organizations. This is the easiest and most efficacious way to get involved!

4. Engaging your partners.

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Look in the right places. The best coalitions engage partners who have compelling relationships to either the problem or potential solutions and can add value by providing any of the following resources:

- Information
- Access to influencers (e.g. policymakers) and key messengers (e.g. press)
- Expertise and credibility
- Time
- Money
- Large base of support

Pitch your vision. Potential partners likely already understand the extent of the problem you're trying to address. They need to know the anticipated outcomes of your efforts so they can assess their willingness and capacity to contribute. Be descriptive, yet concise, and always do your research. Help potential partners draw explicit connections between their goals and the vision you've put forth.

Be mindful of equity issues. Those most significantly impacted by the problem you're trying to address, especially partners representing traditionally underserved (cultural and other identity) groups, must be "at the table" and positioned to drive collective decisions.

Proceed with flexibility and caution. Accommodating thoughtful changes to the collective vision based on the input of potential partners can encourage investment, but aligning too closely with the strategic priorities of some can cause friction and even derail efforts.

5. Stay informed. Continue to sharpen your skills and stay up to date on topics.

Subscribe to information about the topics that you are passionate about. You can use these websites. I also strongly recommend signing up through your professional societies/interest organizations.

You can also use this workbook as well as other online resources to help sharpen your skill set.

- Bill Tracking: <https://www.govtrack.us/>
- AAP Policy Page :<https://www.aap.org/en-us/advocacy-and-policy/Pages/Advocacy-and-Policy.aspx>; <http://federaladvocacy.aap.org>; www.aap.org/moc/stgovaffairs
 - Sign up for the weekly email policy brief.
 - They have excellent training modules.
- Follow your legislators on Facebook/Twitter!

6. Put your specific skill set to use! Remember that we are not community organizers or event planners; use your team to round out your skill set.

Use your own skills in the most effective manner possible. Speak out on topics as they relate to your patients. Plan time to make a phone call to a legislator's office, write an op ed piece, attend a town hall, start/attend a committee, and/or teach others about how to be advocates.

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Advocacy Resources

www.apa.org/advocacy	Advocacy page of the American Psychological Association (APA) website; includes information on APA advocacy initiatives and current legislation that affects practice.
www.aucd.org	Website for the Association of University Centers on Disabilities, which includes information and advocacy guidance on issues related to disability.
www.childrensdefense.org	Website for the Children’s Defense Fund, a nonprofit child advocacy organization that provides information and recommendations regarding legislation that affects children across all domains.
www.childrenshospitals.org	Website for the Children’s Hospital Association, includes information regarding child advocacy with an emphasis on healthcare issues. The CHA’s “Speak Now for Kids” campaign provides advocacy tools and guidance for professionals and families.
www.congress.gov	Official website of the United States Congress (Senate and House), including links to contact your legislators, committee structure and membership, explanations of the legislative process, status of current legislation, etc.
www.copaa.org	Website for the Council of Parent Attorneys and Advocates, an organization whose mission is to protect the legal and civil rights of students with disabilities.
www.govtrack.us	Online resource for tracking legislation (including predictions regarding likelihood of passage), identifying your legislators, tracking legislators’ voting records, and other advocacy-related information.
www.icivics.org	Founded by Justice Sandra Day O’Connor, this interactive website offers free instructional tools, games and lesson plans designed to enhance civics instruction. Though intended for schoolteachers, the tools and games can be useful for medical learners and other audiences as well.

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www.kff.org	Website for the Henry J. Kaiser Family Foundation, an independent foundation that engages in research and education regarding national health issues.
www.5calls.org	Provides a simplified framework for advocacy, encouraging individuals to make 5 calls to legislators regarding specific issues. This website does present issues in a partisan manner.
www.ncsl.org	Website for the National Conference of State Legislatures; includes a searchable bill tracking database for all 50 states (located under the Research tab on the home page).
www.wrightslaw.com	Detailed information and case law regarding special education, 504, education law and advocacy.