



Special Education Advocacy and The Arc's Chapter Network: Findings from The Arc@School

April 2017

Since its founding in 1950, The Arc has advocated for students with intellectual and/or developmental disabilities (I/DD) to have access to educational supports and services. The Arc was a driving force in the passage of the Individuals with Disabilities Education Act in 1975, which required schools to educate **all** students with disabilities for the first time. In 2016, The Arc created The Arc@School, its newest initiative in special education. The Arc@School's mission is to build the capacity of The Arc's nationwide network of chapters to provide individual advocacy that helps students with I/DD and their families navigate the special education system. Improving the quality and availability of trained lay advocates to support the development and implementation of appropriate individualized education programs (IEPs) supports students with I/DD to graduate from high school and pursue post-secondary education and employment. The Arc@School is available to all chapter staff for technical assistance, training, and resources on special education advocacy.

As part of its program planning, The Arc@School conducted an investigation of existing special education advocacy practices. The investigation included a scan of academic research journals for articles on special education advocacy, identification of existing advocacy training programs, conversations with key special education advocacy stakeholders, and outreach to special education advocates in The Arc's chapter network. This report describes the information obtained from the investigation, including elements of existing advocacy training programs, how advocacy is being provided in The Arc's chapter network, and the research found regarding special education advocacy. The report concludes with program recommendations for The Arc@School.

Background

The Individuals with Disabilities Education Act (IDEA) requires schools to provide students with disabilities a free and appropriate public education (FAPE) in the least restrictive environment (LRE) through an individualized education program (IEP). FAPE means students with disabilities must receive all of the specialized supports and services that they need to benefit from their education, at no cost to them or their family. LRE means students with disabilities must learn in the same classes and same

schools that they would attend if they did not have a disability, as much as possible. Finally, an IEP is a document created annually that describes what the student already knows, what the student will learn in one year, and what services and supports the school will provide to help the student reach his or her educational goals.

The process for creating the IEP is meant to be one of collaboration between a student's parents, the student once he or she reaches age 16, teachers, service providers, and other school staff who know the student best. However, this collaborative process can break down due to disagreement between parents and school staff regarding the student's plan. The IDEA builds in a system of accountability where students and their parents have certain rights and can take certain actions when they do not feel that the school is meeting the student's needs appropriately. However, students and parents often struggle to advocate on their own for appropriate educational services. Therefore, some may seek help from a special education advocate to obtain the services they feel the student needs.

Both attorneys and non-attorney lay advocates are available to assist students and their families in advocating for special education services. While attorneys must attend law school and pass the bar, there is no required training, education, or experience to act as a lay advocate. In addition, while the practice of attorneys is overseen by their state's bar association and attorneys can be subject to disciplinary proceedings if they act in an unethical way, there is no nationally recognized certification or ethical guidelines for lay advocates. However, not all families can afford an attorney and involving an attorney can sometimes add tension to an already strained relationship between parents and their child's school.

Therefore, lay advocates are an important resource for students and their families. The practice of lay advocacy in special education has been growing for many years. To address concerns about the quality of lay advocacy, several training programs and peer-to-peer networks have arisen to help improve the professionalism of lay advocates.

Existing Advocate Training Programs

As part of its investigation, The Arc@School identified several existing programs that train advocates to assist parents of children with disabilities in special education matters. Each program has a unique curriculum, length, and cost.

The **Advocate Academy at the Advocacy Institute**¹ offers a package of online webinars to individuals interested in learning more about special education advocacy. The package includes fifty archived webinars, originally aired from 2006 through 2012, that are 90 minutes each for a total cost of \$50.

¹ <http://www.advocacyinstitute.org/academy/>

There are a wide variety of topics covered, including instructional methods or advocacy strategies in areas such as assistive technology, evaluations, behavior, Section 504, transition, and dispute resolution, for example. It would take 75 hours to view all the content, but because they are archived, they can be viewed on one's own time. Viewers would have to find alternate resources if they had additional questions, and it does not appear that the series is continuing to be updated.

Wrightslaw² is a website and training program created in the early 1990's by Pete and Pam Wright, an attorney and psychotherapist, respectively. The website has articles on dozens of special education topics, with a focus on providing advocacy tips to parents of children with disabilities, as well as an extensive "Yellow Pages for Kids with Disabilities" where visitors can find a lengthy list of resources by state, including consultants, advocates, attorneys, service providers, schools, and government programs. The Wrights also provide one and two-day trainings across the country on special education law and/or advocacy strategies in the special education process. Though anyone can attend, the content is typically geared toward empowering parents to advocate on behalf of their own child. A local host organization typically coordinates the training, including paying the speaker's fees. Attendees usually pay a fee to attend, which also covers purchase of at least one of the Wright's books: *Special Education Law*, *From Emotions to Advocacy*, and *All About IEPs*. A recorded version of the one-day Special Education Law training is also available for purchase for \$89.95. Like the Advocate Academy webinars, viewers could watch the training on their own time, but would need to find alternate resources if they had additional questions. The Wrightslaw website and trainings are often cited and highly regarded across the country. Many chapters of The Arc indicated that they have attended a Wrightslaw training in their area and that the information provided helped improve their advocacy practice.

The IDEA provides funds for at least one **Parent Training and Information (PTI) Center**³ in each US state and territory. PTI Centers provide training and information to parents of children with disabilities so that they can advocate on behalf of their own children in the special education process. Some PTI Centers also employ advocates who help parents negotiate with schools, typically through communication with schools or attendance at IEP meetings, for the services the child needs to make progress on their IEP goals. Many PTI Centers also provide parent-to-parent trainings where a group of parents is trained to advocate on behalf of other families of children with disabilities. One study of

² <http://www.wrightslaw.com/>

³ <http://www.parentcenterhub.org/>

PTI Centers found that obtaining support from their parent center did increase parents' sense of empowerment, satisfaction with their child's services, and special education knowledge.⁴ Some, but not all, chapters of The Arc indicated a familiarity with the PTI Center in their state. One chapter, The Arc of Michigan, has a formal partnership with the state's PTI Center to provide information, referral, and advocacy to eligible families who contact the PTI Center for help. Several local chapters in Michigan receive referrals and provide information or advocacy through this partnership with the PTI Center as well. More information is needed on how chapters of The Arc and PTI Centers collaborate to ensure their scarce resources are used in the most efficient manner possible.

The **Volunteer Advocacy Project (VAP)**⁵ is administered by the Vanderbilt Kennedy Center to train individuals who want to be advocates for families of children with disabilities, primarily in Tennessee. The curriculum includes 40 hours of classroom instruction over 12 weeks at a cost of \$30. Participants can attend the training in-person in Nashville, or via webinar at satellite locations hosted by local organizations throughout Tennessee and in some parts of Georgia. Participants must agree to advocate on behalf of four families free of charge after completing the program. Research conducted regarding the VAP found that the program was both feasible and effective. The program had a low cost, high attendance rate, low attrition rate, positive satisfaction ratings from attendees, and sustainability.⁶ In addition, participants made significant improvements in both their special education knowledge and advocacy skills.⁷ Research is still needed, however, on whether advocacy improved educational outcomes for students. The VAP training has been replicated by training programs in Illinois and Kentucky. Chapters of The Arc in Tennessee indicated that they have hosted satellite locations and participated in the VAP training in Tennessee, which improved their advocacy practice.

The **Latino Parent Leadership Support Project (LPLSP)** was created by Consuelo Puentes and Maria Castillo of the Family Resource Center on Disabilities⁸ to train Latino families of children with autism spectrum disorder in the Chicago, IL area to advocate for their own children and other families. Studies have found that Latino families face additional barriers to advocacy for

⁴ Burke, M.M. (2016). Effectiveness of parent training activities on parents of children and young adults with intellectual or developmental disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 3(1), 85-93.

⁵ <http://vkc.mc.vanderbilt.edu/vkc/services/project/volunteer-advocacy/>

⁶ Burke, M.M., Mello, M.P & Goldman, S.E. (2016). Examining the feasibility of a special education advocacy training program. *Journal of Developmental and Physical Disabilities*, 28(4), 539-556.

⁷ Burke, M. M., Goldman, S.E., Hart, M.S., and Hodapp, R.M. (2016). Evaluating the efficacy of a special education advocacy training program. *Journal of Policy and Practice in Intellectual Disabilities*, 13(4), 269-276.

⁸ <https://frcd.org/>

special education services, including documents not being made available in Spanish, educational jargon that is difficult to translate, and a lack of information about autism. The LPLSP curriculum includes 36 hours of classroom instruction over 9 weeks at no cost to participants. Similar to research of the VAP, research found the program to be both feasible and effective for Latino families with good attendance and satisfaction rates, as well as improved special education knowledge and empowerment to advocate for themselves and others.⁹ No chapter of The Arc indicated a knowledge of this training program.

The **Council of Parent Attorneys and Advocates** (COPAA)¹⁰ was founded in 1998 as a non-profit, membership-based organization open to families of students with disabilities, attorneys, non-attorney advocates, and other professionals who advocate from a family perspective, rather than a school perspective, for the legal rights of students with disabilities. COPAA hosts an annual conference, ranging in price from \$295 to \$495 depending on membership category, where participants learn about the most recent cases, legislation, and educational interventions in special education. In 2005, COPAA collaborated with the University of Southern California University Center for Excellence in Developmental Disabilities to create its Special Education Advocate Training (SEAT) program. The current curriculum includes 48 hours of classroom instruction over 24 weeks, with an estimated 72 to 96 hours of out-of-classroom work, at a cost of \$1,250 for COPAA members and \$1,400 for non-members. Completion of the program also requires 40 hours of “practicum” work, advocating on behalf of children in IEP matters, under the supervision of an experienced advocate. The program was created with input from experienced special education advocates in the field, field-tested over a three-year period with three cohorts of participants, and revised based on feedback from instructors, participants, an advisory panel, and two independent experts. COPAA’s Executive Director indicates that the program has assessed both its passing rate and completion rate and found that participants who already had some advocacy experience tended to do well with the program, while parents who were seeking information to become a better advocate for their own child tended to struggle to complete the program. More research is needed on whether advocacy of the program’s alumni has improved educational outcomes for students. The program is highly regarded, and much thought, planning, and collaboration appears to have gone into the creation of the SEAT curriculum. It could be a valuable source of training for chapters of The Arc, but only a few

⁹ Burke, M.M., Magaña, S., Garcia, M. & Mello, M. (2016). Brief Report: The Feasibility and Effectiveness of an Advocacy Program for Latino Families of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 46, 2532-2538.

¹⁰ <http://www.copaa.org/>

chapters of The Arc indicated that they have taken advantage of membership or training through COPAA.

The **National Special Education Advocacy Institute** (NSEAI)¹¹ was incorporated in 2008 to create a professional certification and provide professional development for educational advocates. The curriculum includes 66 hours of classroom instruction over 12 weeks, with more than 130 hours of estimated out-of-classroom work, at a cost of \$1,995. The program indicates that it awards a Board Certified Education Advocate (BCEA) credential to participants who have completed the program's curriculum, passed an examination, agreed to abide by the program's practice guidelines, and shown that they have a level of education or experience sufficient to be a professional education advocate. However, the BCEA credential is not nationally-recognized. The NSEAI program is not approved by the National Commission of Certifying Agencies and only has authority to issue a certificate of completion. Further, the founder has been the subject of an investigation¹² regarding her educational credentials. Though it is unnecessary to have any particular level of education to be an effective special education advocate, it is concerning that the founder did not disclose that her masters and PhD degrees were awarded by unaccredited institutions prior to being investigated. At least one chapter of The Arc has participated in the NSEAI training curriculum and indicated that the information gained was valuable. However, more information is needed about how the training was created and has been reviewed and vetted to determine if it is an appropriate source of training for special education advocates.

Though these programs have many benefits, and many advocates within The Arc network have participated in them, several chapters indicated that it would be beneficial to have a training offered by The Arc to help chapters train new advocates. The ideal training would not be in a particular place at a particular time, but would be available online so that it could be downloaded at times convenient for each chapter and advocate. Further, the time commitment and cost would not be as long or as much as the COPAA or NSEAI trainings so that chapters could train advocates more quickly and inexpensively. In addition, unlike current online programs, there could be an evaluative component built into the online training so that it could be determined whether the participant increased their special education knowledge and/or advocacy skills. If not, The Arc@School could be available to provide additional technical assistance.

¹¹ <https://www.nseai.org/>

¹² Cole, Jeff. Fox 29 Investigates: Education Advocate's Credentials. <http://www.fox29.com/archive/4133458-story>

Advocacy within The Arc's Network

The Arc is the largest national community-based organization advocating for and serving people with intellectual and/or developmental disabilities (I/DD) and their families. The Arc has more than 650 state and local chapters across 47 states (there are currently no chapters in Maine, Nevada, or Vermont). The chapters each determine what services they offer to their local area. Many chapters provide direct services to people with I/DD, such as respite services, early intervention services, transition services, employment and other day supports, residential supports, speech, occupational, and physical therapy. Some chapters also offer individual advocacy services to people with I/DD and their families, such as advocacy for special education services, Home and Community-Based Waiver services, and public benefits. In a survey of the chapter network in 2011, nearly three quarters of chapters indicated that they advocate for or with people with I/DD on IEP matters.

To obtain information about the current capacity of The Arc's chapter network to assist students with disabilities and their families in IEP matters, The Arc@School conducted an on-line, network-wide survey in July 2016. We received responses from 110 state and local chapters across 31 states (yielding a 17% response rate). In-depth telephone interviews with 20 of those chapters were conducted between September and December 2016. Key insights included:

- Of the chapters who responded, 80% indicated that they provide some level of special education advocacy. Almost all respondents provide information and referral (98%) and brief advice on special education matters (92%). More than three quarters assist families in preparing for IEP meetings (75%) or attend IEP meetings with families (79%). Nearly half of respondents advocated for families in the more formal state complaint process (44%) or in mediation (50%).
- Most respondents use paid staff (72%), rather than volunteers, to provide special education advocacy. Chapters expressed concern about the resources needed to oversee and ensure quality advocacy when using volunteers.
- Most chapter advocates' previous training comes from personal advocacy (66%) or previous professional experience (67%), rather than an undergraduate, graduate, or other certified training program.
- Most staff are trained through mentoring (54%) or informal policies and practices (50%), rather than a formal training manual or curriculum. However, more than three quarters of respondents did send advocates to trainings offered by other advocacy organizations (78%), most often those given by Wrightslaw (57%). Interviews revealed that these were the most cost and time-effective trainings for chapters to utilize. Many of the chapters interviewed expressed an interest in The Arc creating its own trainings, based on The Arc's philosophies and chapter needs.

- Most chapters use a standard intake form (56%) and release of information form (53%), but few chapters have a standard advocacy agreement (16%) or closing form (6%), which could aid in ensuring more clear and efficient management of cases.
- About half of respondents indicated use of a case management system (62%) and collection of data about the students and families they serve (61%) or the outcomes of their advocacy (50%). However, interviews revealed that spreadsheets or other manual systems for tracking cases were the primary systems being used, which cannot as easily generate reports or search for trends in demographics, issues addressed, and outcomes obtained as a commercially available system.
- Almost no respondents (5%) directly charge students or their families a fee for advocacy services. Interviews revealed that most advocacy is funded through grants, Medicaid, or administrative fees from the direct services that larger chapters provide. Nearly all chapters that have provided feedback to The Arc@School have expressed concern about the stability of their funding sources and their ability to continue offering advocacy services if those sources were reduced or eliminated.
- Most of the respondents (65%) that do not provide special education advocacy services indicated that they did not have the resources to hire and train advocates.
- In interviews, chapters indicated that they could benefit from a system of peer-to-peer support, materials they could download and share with families, ongoing professional development for their advocates to stay up-to-date on changes in educational law, and assistance with finding additional funding to support their advocacy work.

Though The Arc@School does not have the current capacity to assess the overall success of the advocacy chapters are providing, several chapters were able to highlight successful outcomes obtained through their advocacy. For example:

- In just the 20 chapters that The Arc@School interviewed, they advocated on behalf of more than 1500 students with I/DD and their families.
- One chapter advocated for a 17-year-old with an intellectual disability and ADHD who had been suspended multiple times and was considering dropping out of school to receive more independent study time in his IEP. The advocate also helped the student find an afterschool program that offered leadership opportunities and raised his confidence and drive to succeed in school. The student is set to graduate at the end of this year.
- Another chapter advocated for a 5-year-old with a developmental disability, hearing delays, and who spoke English as a second language to receive services in an inclusive classroom rather than being segregated, which ensured the

student would continue to access the general education curriculum alongside peers without disabilities.

- Another chapter advocated for an 18-year-old with developmental disabilities who had developed a school phobia in her junior year to create a plan allowing her to come to school after hours, slowly increasing her hours into the school day, until she was attending school again full-time and able to graduate with her peers.
- Another chapter worked with a senior with autism who struggled with communication and self-advocacy skills. He was attending his neighborhood high school and simultaneously taking two courses at the local community college. However, the community college was not implementing the accommodations identified for the student to succeed, so The Arc helped the student file a complaint with the Office of Disability Services. The community college Dean found that the student's accommodations were not being implemented fully and consistently and resolved the situation. However, the chapter felt the greater achievement was watching the student grow into his voice and become prepared to advocate in future classes and employment, having obtained a better understanding of what he needs to be successful.

Research on Advocacy Practices

There is very limited academic research on best practices in special education advocacy or effectiveness of special education advocates. The majority of research around special education advocacy appears to study ways that parents can better advocate for services for their own children rather than how advocates can assist parents in advocating for appropriate services. What research does exist must be viewed with caution. The Arc@School was not able to locate any studies that used the “gold standard” of research, a random sample of parents who had the assistance of an advocate compared to a control group of parents who did not have the help of an advocate. One study did use a control group, but it was only quasi-randomized.¹³ Most existing studies typically used a small sample size of parents or advocates who volunteered to participate in the study from a particular program or limited geographic area.

One study discussed the role that a non-attorney advocate can play, including providing parents a copy of relevant laws; gathering, organizing, and reviewing records; making recommendations about the child's educational program; writing letters on behalf of the parent; and attending meetings with the parent.¹⁴ Another study identified five stages of advocacy, including developing rapport with parents; establishing clear expectations about what the advocate can and cannot do; learning

¹³ See supra FN9.

¹⁴ Goldman, S.E., Burke, M.M., Mason, C.Q., & Hodapp, R.M. (2016). Correlates of sustained volunteering: Advocacy for students with disabilities. *Exceptionality*, 25(1), 40-53.

about the child and family; empowering parents to advocate on their child's behalf; and participating in IEP meetings with parents.¹⁵ Another study discussed some of the skills that a "successful advocate" must possess, including knowledge of the IDEA and local special education laws; an ability to manage large amounts of written and verbal information; skills to work with schools in an assertive but non-adversarial manner; and confidence in requesting services, asking questions, and challenging school officials.¹⁶ However, The Arc@School was unable to locate research on the outcomes for students when they or their parents utilized the services of an advocate.

Studies have uncovered potential challenges for parents trying to advocate on their own, which could be remedied if parents had access to a well-trained advocate. One study concluded that parental advocacy efforts fail in obtaining desired outcomes when the parents lacked information about appropriate services, how to appeal, or were not persistent enough in using multiple strategies to obtain requested services.¹⁷ Other studies have identified barriers to parent advocacy including a lack of knowledge of special education, concern about sharing personal information with schools, feeling intimidated, and lacking the power of an "expert" compared to school staff.¹⁸ Further, special education relies heavily on a medical view of disability, which lends more power to the professionals who can speak in medical terminology; state and local policies may leave room for schools to interpret and implement services differently from a parent's understanding; and a lack of flexibility in meeting times, meeting practices, and electronic systems make it hard for parents and schools to come to a consensus beyond what is pre-scripted by the school.¹⁹ Finally, research has shown that although parents of children with disabilities identify advocacy as a necessary means for obtaining appropriate services for their children, advocacy is also related to increased parental stress and worse parent-school relationships.²⁰ Having access to well-trained and effective advocates to ensure their children have appropriate services could address some of these challenges, particularly decreasing the added stress advocacy places on parents of children with disabilities.

Further research has shown a potential benefit to parents from having an advocate. Though many jurisdictions do not allow non-attorney advocates to represent parents

¹⁵ Burke, M.M. & Goldman, S.E. (2016). Documenting the experiences of special education advocates. *The Journal of Special Education*. Prepublished April 15, 2016, DOI: 10.1177/0022466916643714.

¹⁶ See supra FN7.

¹⁷ Rehm, R.S., Fisher, L.T., Fuentes-Allick, E., & Chesla, C.A. (2013). Parental advocacy styles for special education students during transition to adulthood. *Qualitative Health Research*, 23(10), 1377-1387.

¹⁸ Burke, M.M., Patton, K.A., & Lee, C. (2016). Parent advocacy across the lifespan. *International Review of Research in Developmental Disabilities*, 51, 193-231.

¹⁹ Bacon, J.K. & Causton-Theoharis, J. (2012). 'It should be teamwork:' a critical investigation of school practices and parent advocacy in special education. *International Journal of Inclusive Education*, 17(7), 682-699.

²⁰ Wang, M., Mannan, H., Poston, D., Turnbull, A.P., & Summers, J.A. (2004). Parents' perceptions of advocacy activities and their impacts on family quality of life. *Research and Practice for Persons with Severe Disabilities*, 29(2), 144-155.

in due process hearings, a study in one state that does found that parents who had support from an advocate at their due process hearing won more often than parents who represented themselves, though not as often as parents who were represented by attorneys.²¹ Parents' views on the fairness of mediation in another study was strongly correlated to whether they felt their advocate – both attorney and non-attorney advocates – was effective, though again, parents felt the mediation process, outcome, and implementation was most fair when they had an attorney.²² Parents who had an advocate in another study showed a significantly higher level of contribution at their child's IEP meeting compared to parents who received more minimal assistance in preparing for the meeting and parents who received no assistance before or during the meeting.²³

Additional research, using a much broader scope of families and advocates, is needed to study the types of methods used by lay advocates, the efficacy of those methods, and the benefits of lay advocacy, including outcomes for individual students, changes in school practices that benefit multiple students, and benefits to parents who use an advocate.

Recommendations for The Arc@School

Based on the research we conducted, feedback from our Advisory Panel, outreach to key stakeholders, and information from our chapter network, The Arc@School has the following recommendations for future activities:

1. The Arc@School should create a comprehensive, online special education advocacy training curriculum for The Arc's chapter network.
2. The Arc@School should create informational materials that chapters of The Arc can download to share with families.
3. The Arc@School should create sample forms, facts sheets, presentations, and other advocacy tools for chapter staff to easily customize for their state and use in their advocacy.
4. The Arc@School should facilitate communication regarding advocacy strategies and program structure among chapters providing special education advocacy services.
5. The Arc@School should ensure chapter staff are educated about important new resources, guidance, and legal decisions that impact special education advocacy.

²¹ Blackwell, W.H. & Blackwell, V.V. (2015). A longitudinal study of special education due process in Massachusetts: Issues, representation, and student characteristics. *SAGE Open*, 5(1), DOI: 10.1177/2158244015577669.

²² Kuriloff, P.J. & Goldberg, S.S. (1997). Is mediation a fair way to resolve special education disputes? First Empirical Findings. *Harvard Negotiation Law Review*, 2, 35-67.

²³ Goldstein, S. & Turnbull, A.P. (1982). Strategies to increase parent participation in IEP conferences. *Exceptional Children*, 48(4), 360-361.

6. The Arc@School should collaborate with program and development staff at The Arc to identify alternative ways to fund special education advocacy services in the chapter network.
7. The Arc@School should collaborate with the COPAA and PTI Center networks to ensure that the scarce resources of our networks are used in the most efficient means possible so that as many families as possible can access special education advocacy services.
8. More research is needed regarding outcomes for students with disabilities when they utilize the services of an educational advocate, as well as the methods of individual advocacy that lead to the best outcomes for students with disabilities. The Arc@School could partner with a university researcher to study the outcomes of the network's special education advocacy and invite the COPAA and PTI Center networks to participate, if there is interest, to broaden the scope of advocates and types of advocacy being studied.

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