

Parent Center and Protection and Advocacy Collaboration Resource Handbook

Developed in collaboration with the National Parent Technical Assistance Center at PACER, the National Disability Rights Network, Region 4 Parent Technical Assistance Center at WI FACETS, and the Center for Appropriate Dispute Resolution in Special Education

2013-2014

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Introduction to Collaboration Handbook for Parent Centers and Protection & Advocacy Agencies

We are pleased to share this resource handbook on the collaboration between the Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs), collectively known as the Parent Centers, and the Protection and Advocacy agencies (P&As).

As all of us know, it is critical that parents understand their rights and responsibilities under the Individuals with Disabilities Education Act (IDEA). Despite over 30 years of implementation, parents continue to need assistance when working with schools or the early intervention system to ensure that their children have access to services they are entitled to under IDEA. Families continue to look to Parent Centers and P&As for help with these processes.

Collaboration between the organizations that house our federally funded projects is increasingly important. The P&As and Parent Centers have complementary missions to ensure that all students with disabilities eligible for services under IDEA receive a free and appropriate public education and all infants and toddlers with disabilities and their families receive appropriate early intervention services and supports. By engaging in meaningful relationships, the federally funded Parent Centers and the federally funded P&As throughout the country can help ensure that the limited resources of both organizations are utilized in the most efficient manner to assist parents and infants, toddlers, children, and youth with disabilities.

The importance of collaboration between our programs is recognized in both the Developmental Disabilities Act and IDEA. In a letter to Parent Centers and P&A's in November 2011, Commissioner Sharon Lewis, Administration on Intellectual and Developmental Disabilities (AIDD), and Director Melody Musgrove, Office of Special Education Programs (OSEP), encouraged Parent Centers and P&As to work together to develop strategies for improved coordination and collaboration. Their letter has encouraged discussion of best practices in how to collaborate.

Building on successful collaboration in many states, the National Parent Technical Assistance Center (NPTAC) at PACER Center, National Disability Rights Network (NDRN), and Region 4 Parent Technical Assistance Center (RPTAC) at WI FACETS worked together to support collaboration across all states to assist families under IDEA.

It is our hope that this handbook will serve as a blueprint on how to begin, continue, and enhance collaboration. As Sharon Lewis and Melody Musgrove stated in their letter, "the PTIs and P&As bring different but equally valuable sets of skills and experience to the table." We hope this effort will result in new methods and ideas to build on our complementary skills and experiences to better serve families.

A special thank you to Marshall Peter, Center for Appropriate Dispute Resolution in Special Education (CADRE), who has provided input and reviewed materials for this project.

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National Disability Rights Network

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Acknowledgements

Special thanks to everyone who has helped create this valuable resource for Parent Centers and Protection and Advocacy agencies. The workgroup for this project included:

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- Jan Serak, Region 4 Parent Technical Assistance Center at WI FACETS, 414-374-4645
- Marshall Peter, Center for Appropriate Dispute Resolution in Special Education (CADRE), 541-686-5060
- Paula Goldberg, National Parent Technical Assistance Center at PACER, 952-838-9000
- Debbie Andrews, National Parent Technical Assistance Center at PACER, 952-838-9000

We also appreciate the input and assistance with this resource handbook, the videos, and webinars provided by the 3 exemplar pairs of PTIs and P&As:

- South Dakota Parent Connection and South Dakota Advocacy Services
- Parents Place of Maryland and Maryland Disability Law Center
- Statewide Parent Advocacy Network and Disability Rights New Jersey

Finally, a special thanks to Debbie Andrews at PACER for all her work in preparing this handbook. If there are questions about this handbook, please contact Debbie Andrews at 952-838-9000 or debbie.andrews@pacer.org.

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Statutory Requirements for Parent Centers:

The Statutory requirements for Parent Centers can be accessed using the following links.

PTI: <http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2CI%2CD%2C671%2C>

CPRC: <http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2CI%2CD%2C672%2C>

TA: <http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2CI%2CD%2C673%2C>

Authorizing Legislation Excerpted from IDEA 2004 (idea.ed.gov)

Section 671 – Parent Training and Information Centers.

(a) Program Authorized-

(1) In General- The Secretary may award grants to, and enter into contracts and cooperative agreements with, parent organizations to support parent training and information centers to carry out activities under this section.

(2) DEFINITION OF PARENT ORGANIZATION- In this section, the term 'parent organization' means a private nonprofit organization (other than an institution of higher education) that—

(A) has a board of directors--

(i) the majority of whom are parents of children with disabilities ages birth through 26;

(ii) that includes--

(I) individuals working in the fields of special education, related services, and early intervention; and

(II) individuals with disabilities; and

(iii) the parent and professional members of which are broadly representative of the population to be served, including low-income parents and parents of limited English proficient children; and

(B) has as its mission serving families of children with disabilities who--

(i) are ages birth through 26; and

(ii) have the full range of disabilities described in section 602(3).

(b) **Required Activities-** Each parent training and information center that receives assistance under this section shall--

(1) provide training and information that meets the needs of parents of children with disabilities living in the area served by the center, particularly underserved parents and parents of children who may be inappropriately identified, to enable their children with disabilities to--

(A) meet developmental and functional goals, and challenging academic achievement goals that have been established for all children; and

(B) be prepared to lead productive independent adult lives, to the maximum extent possible;

(2) serve the parents of infants, toddlers, and children with the full range of disabilities described in section 602(3);

(3) ensure that the training and information provided meets the needs of low-income parents and parents of limited English proficient children;

- (4) assist parents to--
 - (A) better understand the nature of their children's disabilities and their educational, developmental, and transitional needs;
 - (B) communicate effectively and work collaboratively with personnel responsible for providing special education, early intervention services, transition services, and related services;
 - (C) participate in decision making processes and the development of individualized education programs under part B and individualized family service plans under part C;
 - (D) obtain appropriate information about the range, type, and quality of--
 - (i) options, programs, services, technologies, practices and interventions based on scientifically based research, to the extent practicable; and
 - (ii) resources available to assist children with disabilities and their families in school and at home;
 - (E) understand the provisions of this title for the education of, and the provision of early intervention services to, children with disabilities;
 - (F) participate in activities at the school level that benefit their children; and
 - (G) participate in school reform activities;
- (5) in States where the State elects to contract with the parent training and information center, contract with State educational agencies to provide, consistent with subparagraphs (B) and (D) of section 615(e)(2), individuals who meet with parents to explain the mediation process to the parents;
- (6) assist parents in resolving disputes in the most expeditious and effective way possible, including encouraging the use, and explaining the benefits, of alternative methods of dispute resolution, such as the mediation process described in section 615(e);
- (7) assist parents and students with disabilities to understand their rights and responsibilities under this title, including those under section 615(m) upon the student's reaching the age of majority (as appropriate under State law);
- (8) assist parents to understand the availability of, and how to effectively use, procedural safeguards under this title, including the resolution session described in section 615(e);
- (9) assist parents in understanding, preparing for, and participating in, the process described in section 615(f)(1)(B);
- (10) establish cooperative partnerships with community parent resource centers funded under section 672;
- (11) network with appropriate clearinghouses, including organizations conducting national dissemination activities under section 663 and the Institute of Education Sciences, and with other national, State, and local organizations and agencies, such as protection and advocacy agencies, that serve parents and families of children with the full range of disabilities described in section 602(3); and
- (12) annually report to the Secretary on--
 - (A) the number and demographics of parents to whom the center provided information and training in the most recently concluded fiscal year;
 - (B) the effectiveness of strategies used to reach and serve parents, including underserved parents of children with disabilities; and
 - (C) the number of parents served who have resolved disputes through alternative methods of dispute resolution.

(c) **Optional Activities-** A parent training and information center that receives assistance under this section may provide information to teachers and other professionals to assist the teachers and professionals in improving results for children with disabilities.

(d) Application Requirements- Each application for assistance under this section shall identify with specificity the special efforts that the parent organization will undertake--

- (1) to ensure that the needs for training and information of underserved parents of children with disabilities in the area to be served are effectively met; and
- (2) to work with community based organizations, including community based organizations that work with low-income parents and parents of limited English proficient children.

(e) Distribution of Funds-

- (1) In general- The Secretary shall--
 - (A) make not less than 1 award to a parent organization in each State for a parent training and information center that is designated as the statewide parent training and information center; or
 - (B) in the case of a large State, make awards to multiple parent training and information centers, but only if the centers demonstrate that coordinated services and supports will occur among the multiple centers.
- (2) Selection requirement- The Secretary shall select among applications submitted by parent organizations in a State in a manner that ensures the most effective assistance to parents, including parents in urban and rural areas, in the State.

(f) Quarterly Review-

- (1) Meetings- The board of directors of each parent organization that receives an award under this section shall meet not less than once in each calendar quarter to review the activities for which the award was made.
- (2) Continuation Award- When a parent organization requests a continuation award under this section, the board of directors shall submit to the Secretary a written review of the parent training and information program conducted by the parent organization during the preceding fiscal year.

Section 672 – Community Parent Resource Centers.

(a) Program Authorized-

- (1) In general- The Secretary may award grants to, and enter into contracts and cooperative agreements with, local parent organizations to support community parent resource centers that will help ensure that underserved parents of children with disabilities, including low income parents, parents of limited English proficient children, and parents with disabilities, have the training and information the parents need to enable the parents to participate effectively in helping their children with disabilities--
 - (A) to meet developmental and functional goals, and challenging academic achievement goals that have been established for all children; and
 - (B) to be prepared to lead productive independent adult lives, to the maximum extent possible.
- (2) Definition of local parent organization- In this section, the term 'local parent organization' means a parent organization, as defined in section 671(a)(2), that--
 - (A) has a board of directors the majority of whom are parents of children with disabilities ages birth through 26 from the community to be served; and
 - (B) has as its mission serving parents of children with disabilities who--
 - (i) are ages birth through 26; and
 - (ii) have the full range of disabilities described in section 602(3).

(b) Required Activities- Each community parent resource center assisted under this section shall--

- (1) provide training and information that meets the training and information needs of parents of children with disabilities proposed to be served by the grant, contract, or cooperative agreement;
- (2) carry out the activities required of parent training and information centers under paragraphs (2) through (9) of section 671(b);
- (3) establish cooperative partnerships with the parent training and information centers funded under section 671; and
- (4) be designed to meet the specific needs of families who experience significant isolation from available sources of information and support.

Statutory Requirements of P&As and the Client Assistance Program (CAPs)

The full text of the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program is laid out below. There are summaries of each of the other programs later in the handbook. A link to the full text of all the P&A/CAP statutes is available here:

http://dadsupport.ndrn.org/other/Statutory_Requirements_of_PAs.pdf

Protection and Advocacy for Individuals with Developmental Disabilities (PADD)

42 USC §§ 15041-15045

Title 42-- The Public Health and Welfare

Chapter 144-- Developmental Disabilities Assistance and Bill of Rights

Subchapter I--Programs for Individuals with Developmental Disabilities

Part C-- Protection and Advocacy of Individual Rights

42 USC § 15041-- Purpose

The purpose of this part is to provide for allotments to support a protection and advocacy system (referred to in this subtitle as a "system") in each State to protect the legal and human rights of individuals with developmental disabilities in accordance with this part.

42 USC § 15042-- Allotments and Payments

(a) Allotments:

(1) In General: To assist States in meeting the requirements of section 15043(a) of this title, the Secretary shall allot to the States the amounts appropriated under section 15045 of this title and not reserved under paragraph (6). Allotments and reallotments of such sums shall be made on the same basis as the allotments and reallotments are made under subsections (a)(1)(A) and (e) of section 15022 of this title, except as provided in paragraph (2).

(2) Minimum Allotments: In any case in which—

(A) the total amount appropriated under section 15045 of this title for a fiscal year is not less than \$20,000,000, the allotment under paragraph (1) for such fiscal year-

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than \$107,000; and

(ii) to any State not described in clause (i) may not be less than \$200,000; or

(B) the total amount appropriated under section 15045 of this title for a fiscal year is less than \$20,000,000, the allotment under paragraph (1) for such fiscal year-

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than \$80,000; and

(ii) to any State not described in clause (i) may not be less than \$150,000.

(3) Reduction of Allotment: Notwithstanding paragraphs (1) and (2), if the aggregate of the amounts to be allotted to the States pursuant to such paragraphs for any fiscal year exceeds the total amount appropriated for such allotments under section 15045 of this title for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) Increase in Allotments: In any year in which the total amount appropriated under section 15045 of this title for a fiscal year exceeds the total amount appropriated under such section (or a corresponding provision) for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720(c)(1) of Title 29 (if the percentage change indicates an increase), the Secretary shall increase each of the minimum allotments described in subparagraphs (A) and (B) of paragraph (2). The Secretary shall increase each minimum allotment by an amount that bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph (or a corresponding provision) for prior fiscal years) as the amount that is equal to the difference between-

(A) the total amount appropriated under section 15045 of this title for the fiscal year for which the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 15045 of this title (or a corresponding provision) for the immediately preceding fiscal year, bears to the total amount appropriated under section 15045 of this title (or a corresponding provision) for such preceding fiscal year.

(5) Monitoring the Administration of the System: In a State in which the system is housed in a State agency, the State may use not more than 5 percent of any allotment under this subsection for the costs of monitoring the administration of the system required under section 15043(a) of this title.

(6) Technical Assistance and American Indian Consortium: In any case in which the total amount appropriated under section 15045 of this title for a fiscal year is more than \$24,500,000, the Secretary shall-

(A) use not more than 2 percent of the amount appropriated to provide technical assistance to eligible systems with respect to activities carried out under this subtitle (consistent with requests by such systems for such assistance for the year); and

(B) provide a grant in accordance with section 15043(b) of this title, and in an amount described in paragraph (2)(A)(i), to an American Indian consortium to provide protection and advocacy services.

(b) Payment to Systems: Notwithstanding any other provision of law, the Secretary shall pay directly to any system in a State that complies with the provisions of this subtitle the amount of the allotment made for the State under this section, unless the system specifies otherwise.

(c) Unobligated Funds: Any amount paid to a system under this subtitle for a fiscal year and remaining unobligated at the end of such year shall remain available to such system for the next fiscal year, for the purposes for which such amount was paid.

42 USC § 15043-- System Required

(a) System Required: In order for a State to receive an allotment under part B of this subchapter or this part-

(1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;

(2) such system shall—

(A) have the authority to—

(i) pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups; and

(ii) provide information on and referral to programs and services addressing the needs of individuals with developmental disabilities;

(B) have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;

(C) on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system's activities;

(D) on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on-

- (i) the goals and priorities established by the system and the rationale for the establishment of such goals; and
 - (ii) the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (*29 U.S.C. 701 et seq.*), the Older Americans Act of 1965 (*42 U.S.C. 3001 et seq.*), and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (*42 U.S.C. 10801 et seq.*), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (*20 U.S.C. 1400 et seq.*), and activities authorized under section 3003 or 3004 of Title 29;
- (E) establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system;
- (F) not be administered by the State Council on Developmental Disabilities;
- (G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;
- (H) have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of this subtitle;
- (I) have access to all records of—
 - (i) any individual with a developmental disability who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access;
 - (ii) any individual with a developmental disability, in a situation in which—
 - (I) the individual, by reason of such individual's mental or physical condition, is unable to authorize the system to have such access;
 - (II) the individual does not have a legal guardian, conservator, or other legal representative, or the legal guardian of the individual is the State; and
 - (III) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect; and
 - (iii) any individual with a developmental disability, in a situation in which—
 - (I) the individual has a legal guardian, conservator, or other legal representative;

- (II) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect;
 - (III) such representative has been contacted by such system, upon receipt of the name and address of such representative;
 - (IV) such system has offered assistance to such representative to resolve the situation; and
 - (V) such representative has failed or refused to act on behalf of the individual;
 - (J)
 - (i) have access to the records of individuals described in subparagraphs (B) and (I), and other records that are relevant to conducting an investigation, under the circumstances described in those subparagraphs, not later than 3 business days after the system makes a written request for the records involved; and
 - (ii) have immediate access, not later than 24 hours after the system makes such a request, to the records without consent from another party, in a situation in which services, supports, and other assistance are provided to an individual with a developmental disability—
 - (I) if the system determines there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy; or
 - (II) in any case of death of an individual with a developmental disability;
 - (K) hire and maintain sufficient numbers and types of staff (qualified by training and experience) to carry out such system's functions, except that the State involved shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the system, to the extent that such policies would impact the staff or functions of the system funded with Federal funds or would prevent the system from carrying out the functions of the system under this part;
 - (L) have the authority to educate policymakers; and
 - (M) provide assurances to the Secretary that funds allotted to the State under section 15042 of this title will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the allotted funds are provided;
- (3) to the extent that information is available, the State shall provide to the system-
- (A) a copy of each independent review, pursuant to section 1396a(a)(30)(C) of this title, of an Intermediate Care Facility (Mental Retardation) within the State, not later than 30 days after the availability of such a review; and

- (B) information about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1396n(c) of this title) receive; and
- (4) the agency implementing the system shall not be redesignated unless-
 - (A) there is good cause for the redesignation;
 - (B) the State has given the agency notice of the intention to make such redesignation, including notice regarding the good cause for such redesignation, and given the agency an opportunity to respond to the assertion that good cause has been shown;
 - (C) the State has given timely notice and an opportunity for public comment in an accessible format to individuals with developmental disabilities or their representatives; and
 - (D) the system has an opportunity to appeal the redesignation to the Secretary, on the basis that the redesignation was not for good cause.

(b) American Indian Consortium: Upon application to the Secretary, an American Indian consortium established to provide protection and advocacy services under this subtitle, shall receive funding pursuant to section 15042(a)(6) of this title to provide the services. Such consortium shall be considered to be a system for purposes of this subtitle and shall coordinate the services with other systems serving the same geographic area. The tribal council that designates the consortium shall carry out the responsibilities and exercise the authorities specified for a State in this subtitle, with regard to the consortium.

(c) Record: In this section, the term "record" includes--

- (1) a report prepared or received by any staff at any location at which services, supports, or other assistance is provided to individuals with developmental disabilities;
- (2) a report prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury, or death occurring at such location, that describes such incidents and the steps taken to investigate such incidents; and
- (3) a discharge planning record.

42 USC §15044--Administration

(a) Governing Board: In a State in which the system described in section 15043 of this title is organized as a private nonprofit entity with a multimember governing board, or a public system with a multimember governing board, such governing board shall be selected according to the policies and procedures of the system, except that-

- (1) (A) the governing board shall be composed of members who broadly represent or are knowledgeable about the needs of the individuals served by the system;

(B) a majority of the members of the board shall be-

- (i)** individuals with disabilities, including individuals with developmental disabilities, who are eligible for services, or have received or are receiving services through the system; or
- (ii)** parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i); and

(C) the board may include a representative of the State Council on Developmental Disabilities, the Centers in the State, and the self-advocacy organization described in section 15024(c)(4)(A)(ii)(I) of this title;

(2) not more than 1 /3 of the members of the governing board may be appointed by the chief executive officer of the State involved, in the case of any State in which such officer has the authority to appoint members of the board;

(3) the membership of the governing board shall be subject to term limits set by the system to ensure rotating membership;

(4) any vacancy in the board shall be filled not later than 60 days after the date on which the vacancy occurs; and

(5) in a State in which the system is organized as a public system without a multimember governing or advisory board, the system shall establish an advisory council—

(A) that shall advise the system on policies and priorities to be carried out in protecting and advocating the rights of individuals with developmental disabilities; and

(B) on which a majority of the members shall be-

- (i)** individuals with developmental disabilities who are eligible for services, or have received or are receiving services, through the system; or
- (ii)** parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i).

(b) Legal Action:

(1) In General: Nothing in this title shall preclude a system from bringing a suit on behalf of individuals with developmental disabilities against a State, or an agency or instrumentality of a State.

(2) Use of Amounts from Judgment: An amount received pursuant to a suit described in paragraph (1) through a court judgment may only be used by the system to further the purpose of this subtitle and shall not be used to augment payments to legal contractors or to award personal bonuses.

(3) Limitation: The system shall use assistance provided under this part in a manner consistent with section 14404 of this title.

(c) Disclosure of Information: For purposes of any periodic audit, report, or evaluation required under this part, the Secretary shall not require an entity carrying out a program to disclose the identity of, or any other personally identifiable information related to, any individual requesting assistance under such program.

(d) Public Notice of Federal Onsite Review: The Secretary shall provide advance public notice of any Federal programmatic or administrative onsite review of a system conducted under this part and solicit public comment on the system through such notice. The Secretary shall prepare an onsite visit report containing the results of such review, which shall be distributed to the Governor of the State and to other interested public and private parties. The comments received in response to the public comment solicitation notice shall be included in the onsite visit report.

(e) Reports: Beginning in fiscal year 2002, each system established in a State pursuant to this part shall annually prepare and transmit to the Secretary a report that describes the activities, accomplishments, and expenditures of the system during the preceding fiscal year, including a description of the system's goals, the extent to which the goals were achieved, barriers to their achievement, the process used to obtain public input, the nature of such input, and how such input was used.

42 USC §15045—Authorization of Appropriations

For allotments under section 15042 of this title, there are authorized to be appropriated \$32,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

Contact Information for Parent Centers and Protection and Advocacy Agencies

The most current contact information for the Parent Centers and Protection and Advocacy Agencies in each state and territory can be found using these interactive links. Both websites contain helpful resources for parents.

www.parentcenterhub.org

www.ndrn.org

Description of Parent Centers:

Parent Centers consist of both Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs). Every state has at least one Parent Center project that is federally funded by the U.S. Department of Education, Office of Special Education Programs; states with larger populations may have more. CPRCs work in smaller, targeted communities in defined geographic areas with underserved parents of children with disabilities, including low-income, limited English proficiency, and racially or culturally diverse families. Both PTIs and CPRCs work with families of children with a full range of disabilities, ages birth to 26. There are currently 98 federally funded Parent Center projects.

Parent Centers help families to:

- Better understand their children's disabilities and educational, developmental, and transitional needs
- More effectively communicate with special education, early intervention, and related professionals
- Understand their rights and responsibilities under the Individuals with Disabilities Education Act (IDEA), the federal special education law, and other disability laws such as Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and other non-discrimination and education laws
- Obtain appropriate services for their children through participation in Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) decision making process
- Resolve disagreements and understand the benefits of alternative methods of dispute resolution
- Connect with other local, state, and national resources that assist children with disabilities

Parent Centers provide a variety of services including one-to-one support and assistance, workshops, publications, and websites. Many Parent Center staff members and board members are parents of children with disabilities so they are able to bring personal experience, expertise, and empathy when working with families.

According to the 2012-2013 Parent Center Outcome Data book, 1,096,271 parents and professionals received individual assistance from Parent Centers. This assistance was delivered through phone calls, emails, letters, home visits, and meetings. The number of parents and professionals attending trainings or presentations by Parent Centers totaled 318,360.

Outcomes:

80% of parents reported their child had received more appropriate services because of the information they received from the Parent Center.

95% of parents reported that because of information they received from a Parent Center, to a great or some extent, they are more knowledgeable about how to work with schools.

89% of parents reported that because of the information they received from the Parent Center, they were able to work with the school to address a critical need related to their child's education.

83% of parents reported that the information and support they received from the Parent Center helped them to resolve a disagreement with the school.

Find a Parent Center in your state: <http://www.parentcenterhub.org>

Description of NDRN and P&A / CAP Programs

The National Disability Rights Network (www.ndrn.org) is the national nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) System and Client Assistance Program (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. NDRN's mission is to promote the integrity and capacity of the P&A/CAP network and to advocate for the enactment and enforcement of laws protecting the civil and human rights of people with disabilities. A major focus of the work of the P&A/CAP network has been on ensuring that children with disabilities have access to the services and supports needed for them to receive appropriate early intervention services and a quality education with their peers, and that students are safe in school.

The NDRN serves individuals with a wide range of disabilities, including, but not limited to, those with intellectual, mental, sensory, and physical disabilities. The P&A/CAP network advocates for the civil and human rights of persons with disabilities by ensuring accountability and enforcement in health care, education, employment, housing, transportation, the juvenile and criminal justice systems, and other areas that impact the daily lives of individuals with disabilities. The P&A/CAP network also investigates reports of abuse and neglect, and seeks individual and systematic change to prevent further incidents. The P&A/CAP Network is federally mandated to operate in every state, the District of Columbia, Puerto Rico, the U.S. territories of American Samoa, Guam, U.S. Virgin Islands, and the Northern Mariana Islands, and the federally-created Native American Consortium which includes the Hopi, Navajo and Piute Nations in the Four Corners region of the Southwest.

NDRN's P&A/CAP Directory: <http://www.ndrn.org>

Principles of the P&A / CAP network

- Client-directed
- Legally-based
- Independent Advocacy
- Client Managed

Continuum of Remedies

- Information and Referral
- Training Counseling and Advice
- Negotiation and Mediation
- Administrative Action
- Individual Litigation

- Monitoring
- Educating Policymakers
- Class Action Litigation or Other Systemic Remedies

The P&A / CAP's main role based on established yearly priorities is to “pursue legal, administrative, and other appropriate remedies and approaches” on behalf of persons with disabilities, and also to:

- Have access to people with disabilities in state institutions
- Have access to the records of people with disabilities
- Investigate incidents of abuse and neglect
- Educate policy makers
- Coordinate with other agencies
- Coordinate with PTIs

Each year, every P&A sets its priorities for the coming year. These priorities determine case acceptance decisions. Parent Centers should contact their P&A and participate in this process.

Although the P&A network did 11,475 cases related to education services for students with disabilities in 2011, special education is not the only or even primary area of focus for the P&A / CAP programs. The P&A / CAP programs may also provide legally-based advocacy services to individuals with disabilities in the following broad areas:

- Abuse, neglect, and rights violations in community living, and access to the community
- Abuse, neglect, and rights violations in facilities (including but not limited to hospitals, nursing homes, schools, or other treatment centers)
- Abuse, neglect, and rights violations in the criminal and juvenile justice systems
- Accessing and maintaining employment, or employment discrimination
- Accessing and/or maintaining disability-related public benefits (including but not limited to SSI, SSDI, Medicaid)
- Accessing services from the state vocational rehabilitation agency
- Accessing services or benefits from other state agencies (ex: housing, transportation, etc.)
- Other areas that are directly related to being a person with a disability

Link to further description of the cases P&As/CAP may take: <http://www.ndrn.org/en/ndrn-member-agencies.html>

Description of Protection and Advocacy and Client Assistance Programs:

- **CAP:** The Client Assistance Program (receiving services from vocational rehabilitation) was authorized under the 1984 amendments to the Rehabilitation Act of 1973 (29 U.S.C. §732). CAP agencies work primarily with clients seeking and receiving services from the federally funded state operated vocational rehabilitation (VR) system, the single largest program under the Act. CAP's role is to ensure that federally funded state VR systems and independent living programs support persons with disabilities to become employed and live independently as envisioned in the Rehabilitation Act.
- **PAIMI:** In 1986, Congress authorized the Protection and Advocacy for Individuals with Mental Illness program (PAIMI) in the Protection and Advocacy for Individuals with Mental Illness Act (42 U.S.C. §§10801 et seq.). Under the PAIMI program, P&As investigate abuse and neglect in all public and private facilities and community settings, including hospitals, nursing facilities, and group homes-and to oversee the effectiveness of state agencies that license and regulate these programs. PAIMI also protects the legal and human rights of persons with mental illness.
- **PAIR:** The Protection and Advocacy for Individual Rights (PAIR) program is designed to ensure and protect the rights of all people with disabilities not eligible for the two basic protection and advocacy programs PAIMI or PADD. PAIR was authorized by Congress through an amendment to the Rehabilitation Act in 1993 (29 U.S.C. §794e). PAIR protects legal and human rights of persons not covered by other programs – such as those with visual or hearing impairments or those with physical disabilities acquired as an adult.
- **PAAT:** The Assistive Technology (AT) Act was reauthorized with unanimous support in 2004 (29 U.S.C. §2201 et seq.). Since its creation almost two decades ago, the programs funded under the AT Act, such as the Protection and Advocacy for Assistive Technology (PAAT) program, have had a significant impact on the lives of people with disabilities. For many, these technologies are the difference between dependence and independence, lives in the community, or lives in institutions.
- **PABSS:** The Protection and Advocacy for Beneficiaries of Social Security Programs (PABSS) was created out of the Ticket to Work and Work Incentives Improvement Act of 1999 (42 U.S.C. §1320b-21). The Ticket to Work Act increases beneficiaries of Supplemental Security Income (SSI) and Social Security Disability (SSDI) choice in obtaining rehabilitation and vocational rehabilitation services to help individuals go to work and obtain employment. PABSS advocates work in collaboration with individuals with disabilities, employers, and other sources for employment supports and services, school to work transitions, and community integration.
- **PAVA:** In 2002, Congress passed the Help America Vote Act (HAVA) to make major improvements to voting systems across the country (42 U.S.C. §15461 et seq.). The law acknowledges the unique obstacles faced by people with disabilities at the polls. Protection and Advocacy for Voting Access (PAVA) staff is on the ground in communities and states, providing advice, technical assistance, and training to election officials about voting accessibility across the spectrum of disabilities. Passage of HAVA was a milestone for the disability community. Establishing federal legislation guaranteed voters with disabilities the right to a private and independent vote.

- **PATBI:** The Traumatic Brain Injury (TBI) Act was authorized as part of the Children's Health Act of 2000 (42 U.S.C. §201). Within the TBI Act, Congress created a Protection and Advocacy program for individuals with traumatic brain injury. Individuals with traumatic brain injuries, including returning veterans, have an array of protection and advocacy needs including assistance returning to work, finding a home, accessing needed supports and services such as attendant care and assistive technology, and obtaining appropriate mental health, substance abuse, and rehabilitation services.
- **Rep. Payee:** The project protects persons with disabilities receiving SSI or SSDI benefits from financial abuse by guardians.

Collaboration: Successful Elements in Formal and Informal Processes

Many organizations report collaboration among the Parent Centers and P&As through the use of either formal or informal processes. Collaboration is most successful when the organizations consistently ask “what can we do together to address issues that are of importance to both of our organizations and constituencies?”

Elements of successful collaboration may include:

- Scheduling regular meetings monthly, quarterly, or at other periodic intervals to learn about the other organization’s current priorities and projects, and to share information;
- Respecting each organization’s differing mission and responsibilities;
- Having a strong understanding of roles and responsibilities of the other organization;
- Involving the entire staff, not just the leadership of the organizations;
- Committing staff time; and
- Agreeing upon pre-determined expected outcomes for ongoing collaboration and for any specific activity or project.

It is also important to recognize that there will be times that one organization will take a leadership role in a particular project or activity, but that the input of the other organization is still valued. There will be times when the organizations cannot come to agreement on the process or expected outcomes of a project or activity. When organizations disagree on a project or activity, it should not discourage future collaboration. Both groups should agree to continue collaborative efforts on future activities.

Processes for Collaboration

Some organizations have formal memoranda of understanding that outline the nature of and process for the collaboration between Parent Centers and P&As. Other organizations have informal agreements on the processes used to collaborate. Both types of agreements have resulted in successful collaboration.

Informal Processes

Although many of the examples below are also frequently included in formal agreements, some of the more common examples of informal processes include:

- Mutual understanding of case referral – each organization understands the importance of a cross-agency referral and triage process
- Informal mechanisms for case referral – “just pick up the phone and call”
- Co-attending early intervention, special education, or disability coalition meetings
- Presenting at workshops, trainings, or conferences
- Sharing data and other information on emerging issues
- Discussing emerging policy issues at the state or federal level
- Promoting the other organization’s activities and trainings in newsletters, social media or other publications
- Discussing potential referrals for seats on each of the organizations Board of Directors

Formal Processes

There are numerous examples of formal processes for collaboration that can be explicitly stated in signed memoranda of understanding (MOU). These MOU’s outline joint agreement on how the collaborative activities will be carried out by each organization. Examples of processes that have been included in formal agreements include:

- Providing professional development trainings for the other organization on education or other topics concerning persons with disabilities
- Co-planning, co-sponsoring, or co-presenting at conferences or trainings, and possibly covering the event for the other organization in case of illness, scheduling conflicts, or other issues
- Determining a cross referral triage process which could include contracting for referrals to services that are outside of each organization’s priorities
- Creating or participating in coalitions to address systemic issues, including co-attending meetings with the state education agency or early intervention lead agency
- Engaging in systemic advocacy to educate policy makers, which could include co-participation at a Capitol Hill Day/Day of Action or a similar event each year
- Developing and submitting joint comments on proposed state and federal regulations
- Serving on the other organization’s Board of Directors
- Submitting joint funding applications for specific projects or activities
- Conducting surveys of parents to assess impact of policy or budget changes
- Facilitating a listserv for information among parent advocates, linking to the other organization on the organization’s website, and featuring upcoming events
- Co-publishing newsletters or other materials from each organization’s perspective
- Co-creating educational materials for parents and youth on their rights and early intervention education processes
- Sharing redacted sample correspondence and pleadings, articles on disability-related topics, web links and other online education related resources
- Reviewing the other organization’s materials prior to publication

- Developing and co-hosting websites and social media sites focused on early intervention, education services for students with disabilities, or other relevant topics
- Sharing space and its associated costs
- Signing an amicus brief: *While the parent center project itself may not sign an amicus brief submitted by the P&As, as federal money may not be used toward litigation, the non-profit organization that houses the parent center project may become a signatory on amicus briefs submitted by P&As.*

Specific Examples of Collaboration Between P&As and Parent Centers:

- In Arkansas, Disability Rights Center of Arkansas and the Parent Center refer parents to each other depending on the type of request for assistance; each organization participates in disability awareness and parent training events together; and the P&A contracts with the PTI for case advocacy, attending school conferences and providing technical assistance on cases as appropriate. The organizations also initiated Arkansas Parent Information Exchange (ArPIE), a consortium of all parent groups in AR that come together with the P&A to share resources, websites and information, share advocacy tips, plan statewide strategies and maintain the ArPIE listserv to report on training opportunities, support group meetings and other relevant information.
- In 2007, the Georgia Advocacy Office (GAO), which is the P&A, conducted in-depth regional trainings on educational advocacy with new staff members of Parent to Parent of Georgia (P2P) and staff (who were also parents) from Georgia Office of Developmental Disabilities. Training sessions were held over a period of 11 weeks for a total of 44 hours. Topics included “Values: How They Impact our Actions,” “A Quality Education for All Students: FAPE,” “Transition,” “Effective Letter Writing,” “Venues for Resolution Disagreement,” “Advocate Role Clarification,” and “Model Coherency.” Members of P2P have also attended the 13-week Parent Leadership Support Project training conducted by the P&A. In addition, P2P and GAO worked together as part of the Safe Schools Initiative to educate policymakers about the need to address the use of seclusion and restraint in Georgia schools. In July 2010, the State Board of Education voted unanimously to enact Rule 160-5-1-35. Lastly, GAO is providing technical assistance to P2P on a project that targets school “push out” and stopping the school to prison pipeline. In return, P2P provided feedback to GAO on an upcoming publication concerning home and community-based waivers.
- In Iowa, Disability Rights Iowa and ASK Parent Resource Center have for a number of years informally shared referrals and jointly solved problems. The collaboration has significantly increased in the last two years and has included a joint statewide training project called “Point-Counterpoint: What Attorneys Have to Say about the IDEA.” The P&A and Parent Center conducted three joint trainings in eastern Iowa in the fall of 2012 and planned three additional trainings in western Iowa in 2013. The P&A and Parent Center are currently formalizing partnerships to address needed statewide advocacy and access to lawyers familiar with various disability laws through a collaboration in a pilot legal clinic in northeast Des Moines where more than 20 percent of the students are in special education. Also, the Parent Center participates in the P&As monthly “Advocates Breakfast.”
- In Kansas, Disability Rights Center of Kansas and Families Together, Kansas’ Parent Center, have a formal memorandum of understanding detailing how their work together will benefit Kansas students

with disabilities and their parents. The organizations hold monthly conference calls to facilitate referrals between the two organizations, and discuss emerging issues. The P&A and Parent Center also closely collaborate through other disability stakeholder coalitions. The organizations also co-author and review each other's publications. Most recently, the P&A and Parent Center collaborated on work to have regulations in Kansas regarding the use of seclusion and restraint of children in schools. This activity included jointly publishing detailed policy papers, memos, and other materials to educate the public and policymakers on the need to address the use of these practices on students with disabilities.

- In Louisiana, a systematic case referral and triage process has been developed. When a case comes into the Advocacy Center that does not fall within the P&A priorities, or where the parent may need some assistance but the issues are not ready for legal intervention, the caller is directly referred to the PTI. Louisiana Parent Training Information Center will then either provide necessary information to the parent for them to advocate on their own, provide direct assistance, or refer the parent to the Families Helping Families Center in their specific area to obtain an advocate. Alternatively, when the PTI or a local Families Helping Families Center has a situation that needs legal intervention, the PTI point of contact reviews the information, and if warranted and agreed to by the parent, makes a direct referral to Advocacy Center's point of contact. If the Advocacy Center agrees to take the case, and with the parent's consent, the PTI shares the parent's file and associated documents with the Advocacy Center to aid and expedite their representation of the client.
- In New Jersey, the Statewide Parent Advocacy Network (SPAN), the PTI, and Disability Rights New Jersey (DRNJ), the P&A, have formal Memoranda of Understanding, including a general MOU regarding ongoing collaboration and several MOU focused on specific projects or topics, including Military Family Support and Transition to Adult Life intensive services. SPAN and DRNJ have influenced each other's priorities in several ways. For example, DRNJ participated in meetings to develop the PTI's grant application to the US DOE, and serves as a member of the PTI Stakeholder Council that was established in that application as well as the Military Family 360 Support Advisory Council and the Community of Care Consortium for Children/Youth with Special Needs. SPAN's Director of Family and Professional Development is a Board member of DRNJ, and several other SPAN staff sit on DRNJ Advisory Committees. Joint priorities for assisting underserved families are set as key members of the NJ Statewide Network on Cultural Competence which includes all three DD Act-funded agencies as well as the PTI.
- Disability Rights Montana and Parents, Let's Unite for Kids (PLUK) entered into a partnership to develop parent training groups in Montana (PAK - Parents Advocating for Kids). The organizations developed a strategic plan to help facilitate their efforts at the local level. The mission of the PAK group is to help prepare parents to act as informed advocates for their children so that they can effectively navigate the special education process. The vision of PAK is for parents to understand and work with school system special education procedures to secure appropriate services and placement to ensure that children receive a Free Appropriate Public Education (FAPE). To meet these goals, the organizations facilitate monthly forums for parents to help educate them on special education procedures and the legal requirements that are afforded to their children under IDEA. To offset budget cuts, grant applications have been submitted to continue to fund PAK. In addition to this joint effort, a PLUK special education advocate has served on the Board of Directors of Disability Rights Montana for ten years. The advocate has worked with the Board of Directors to help identify emerging issues in special education and to ensure program priorities are aligned with identified special education needs in the state.

- In North Dakota, the North Dakota Protection and Advocacy Project and North Dakota Pathfinder PTI have a formal memorandum of understanding. Through funding received from the Developmental Disabilities Council, the organizations are jointly developing a website known as the Parents Informed on Education (PIE).
- In Ohio, Disability Rights Ohio and the Ohio Coalition for the Education of Children with Disabilities (OCECD) have written joint letters and have collaborated on testifying before the State Board of Education about the impact of the use of restraint and seclusion on students with disabilities in Ohio's schools. The P&A and OCECD have also collaborated on litigation, including OCECD signing onto briefs written by the P&A. The P&A has also conducted trainings for OCECD staff and presented at conferences hosted by the PTI. The PTI advocates refer cases to the P&A's intake system. Lastly, the P&A uses the PTI's special education funding analyses and recommendations in their school funding cases and periodically exchanges information with the PTI about budget proposals.
- The collaboration between the Oklahoma Disability Law Center and NIPIC involves the P&A sharing office space for one of the NIPIC staff in Oklahoma. The P&A developed an "IEP Partner" training utilizing and adapting a training curriculum from the NIPIC. In addition, the organizations are involved in several joint training events each year.
- The Wisconsin Family Assistance Center for Education, Training, and Support, Inc. (WI FACETS) and Disability Rights Wisconsin (DRW) have had a long-term collaborative relationship since the founding of WI FACETS 18 years ago. The underpinning of the collaboration is a written memorandum of understanding. A few unique elements of the collaboration include: regular cross referral of clients per mutually agreed upon triage criteria; providing technical assistance and training by DRW staff to WI FACETS staff and volunteer parent leaders; co-sponsoring workshops and/or co-training; linking to WI FACETS on DRW's website and DRW linking to WI FACETS' site; collaboration on systemic issues, including participation in Wisconsin's only statewide coalition of parents, advocates and educators, working to improve Wisconsin's system of special education which includes quarterly meetings with the SEA to discuss and resolve systemic issues; and joint hosting of parent focus groups. In addition, the WI FACETS and DRW jointly plan Foro Latino, which is the only large scale English/Spanish conference in Wisconsin on topics of special education geared to parents.

Overcoming Barriers to Collaboration

Some Common Barriers

- Lack of collaboration by leadership
- Misunderstanding of each other's mission and duties
- Insufficient understanding of each organization's legal mandates and priorities
- Personality issues or distrust
- Differences of opinion on policy matters, such as:
 - Use of segregated classroom or other segregated placements
- Discomfort with different advocacy styles, such as:
 - Legal versus non-legal
 - Aggressive versus assertive
 - Systemic versus individual case work
 - Differences over how much to encourage stronger remedies
- Lack of finding meaningful ways to work together
- Need for more frequent meetings
- Lack of training for staff, parents, self-advocates
- Lack of effectively sharing resources
- Need for a process to ensure mutual accountability including evaluation of collaboration or how to increase collaboration

Some Examples of How to Overcome Barriers:

Changes in personnel, funding, and other situations can affect collaboration activities. Has your collaboration had to deal with any of these types of changes?

- We have supported each other through letters of support for grant applications, budget modifications, testimony, and sharing of appropriate resources.
- Throughout the many changes that have taken place with staff and leadership, the conference collaboration has remained strong due to the commitment of its partners.
- Recent changes in executive leadership and board governance for both organizations provided a perfect opportunity to bring both organizations together to strategize more robust work sharing and collaboration.
- Parent Center leadership changes over the years have required P&A leadership to educate and establish relationships. The P&A has always had a staff member on the PTI board of directors which facilitates transitions for both organizations. Funding issues for both organizations is a constant challenge. We share resource materials, staff time on projects, and support each other rather than duplicate programs or resources.
- Due to federal budget cuts, our agencies have had to respond proactively to meet programming demands. The special education program at the P&A is just one program among many in their

organization. To meet the growing demand for special education services, we identified potential funders to help support our efforts. Specifically, a recent grant application has been submitted to request financial support to help implement a project. Further, two other foundations have been identified and grant applications are being prepared to those organizations. The changes in personnel over the years have not presented a barrier to our collaboration primarily because we have been focused on issues and methodology rather than being personality driven.

- There are times when cuts in funding or changes in staffing have affected our ability to continue work uninterrupted. However, we have been able to talk with each other and work through the issues to resolve them, generally with a simple phone call. We recognize that together we are definitely stronger and more effective in helping families of children with disabilities.
- We cover trainings for each other when staff is unable to attend due to illness, scheduling conflicts, or other issues.
- There were changes in personnel and funding of the P&A and leadership at the PTI during our years of collaboration. In each case, there was a need to revisit past collaboration and to update each of our responsibilities in the relationship.

What Makes it Work?

- Shared values
- Mutual respect formed over many years
- Intentional proactive efforts to maintain relationship after changes in leadership
- Deep understanding of mandates, strengths, and limitations of each partner
- Commitment to avoid duplication of effort and maximize scarce resources
- Investing in meaningful and impactful collaborative work

Collaborative Resources and Materials

Many P&As and Parent Centers report that they have jointly developed conference PowerPoints, training materials, sample letters, articles, and other materials. Some additional examples of joint development of resources include:

Maine - three video clips on special education law for parents were created by the P&A and posted on the Maine Parent Federation website

Michigan – a DVD was developed: [Early On DVD](#)

New Jersey - a parent's guide titled [“What Parents Should Know About the Use of Restraints and Seclusion.”](#)

North Carolina - a parent's guide titled “Parent's Together.”

Massachusetts - a transition manual at <http://www.dlc-ma.org/manual/index.htm>

Wisconsin - Publication of [“Out of Darkness...Into the Light: New Approaches to Reducing the Use of Seclusion and Restraint with Wisconsin Children”](#) and [parent friendly charts](#) educating readers on voucher and charter schools.

<http://www.disabilityrightswi.org/wp-content/uploads/2009/04/out-of-darkness-full-report.pdf>

<http://www.wifacets.org/sites/default/files/schoolchoicecharts.pdf>

Results of Collaboration

Parent Centers and P&A agencies reported some very positive results from their collaboration. Below are some examples of the results of the collaborative activities as reported by the Parent Centers and P&As:

- Significant changes in state laws, rules, and regulations that benefit children with disabilities and their families as a result of jointly engaging and educating policy makers
- Feelings of “strength in numbers” in confronting difficult systemic issues such as seclusion and restraint and bullying in schools
- Expanded coverage and presence working on individual and systemic levels which has led to improved results for children, youth, and families
- Enhanced continuity for families seeking assistance from either organization
- Decrease in duplication of materials and overlap of other resources through prioritizing activities and sharing materials and staff time on projects. This is accomplished by informally supporting the projects and activities of the other organization or methodically and thoughtfully examining what each organization must accomplish during the year, and then planning ways to commit to collectively impact the other organization’s expected outcomes by offering well-synchronized supports and services.
- Staff comfort and willingness to contact the other organization for input and information by “picking up the phone” in an informal type of relationship

Evaluating Collaborative Activities

Some of the Parent Centers and P&A’s are evaluating their collaboration. Methods used to evaluate the impact of their collaboration include:

- When educating policy makers, the outcomes are measured on whether the preferred outcome is achieved on the specific issues. This method has also been used to measure the success of working in coalitions.
- When conducting trainings, the outcomes have been evaluated using evaluations specifically developed for the training.
- When materials have been developed by both organizations, the outcomes have been evaluated through tracking the distribution of materials.
- When examining the impact of a cross-referral triage processes, collecting data on the number of referrals made, number of shared clients, and the outcomes of those referrals.

P&A/Parent Center Memorandum of Understanding Template

I. INTRODUCTION

A. Parties Involved

[Parent Center] and [Protection and Advocacy Agency]

B. Purpose

The purpose of this agreement is to improve outcomes for children and youth with disabilities in [State]. [Parent Center] and [Protection and Advocacy Agency] agree to collaborate to maximize the use of our respective resources and complement each other's efforts to meet the goals of the work of both agencies, as we each strive to meet the needs of children and youth with disabilities and their families.

II. AGREEMENT

A. [Parent Center] and [Protection and Advocacy Agency] propose to work together in the following collaborative manner:

[1.]

[2.]

[etc.] (see page 31 for examples)

B. A joint priority will be on reaching underserved families (low income families, racially and ethnically diverse families, non-English speaking families, immigrant families, families of adults with disabilities or with low literacy levels, and families living in physically isolated locations).

III. DURATION OF THE AGREEMENT

This agreement is for the []-year period, [], 20[] through [], 20[], until further modified by mutual consent or terminated by either organization with notification to the other organization.

We, the undersigned, have read and agree with this Memorandum of Understanding:

DATED THIS ____ DAY OF _____ 20__

BY: _____
Name

Position

[Parent Center]

BY: _____
Name

Position

[Protection and Advocacy Agency]

Examples of Collaborative Work Include:

- Protocol for shared problem-solving, referrals, etc.
- Jointly-determined case triage process
- Having regular meetings or conference calls
- Involving many staff members at both agencies
- Serving on Board(s) of the other's agency
- Co-sponsoring training events
- Providing professional development opportunities for the other organization
- Co-planning and implementing a conference for disability organizations, culturally diverse families, and community-based organizations
- Co-developing and implementing trainings related to special education topics
- Data sharing on emerging issues
- Helping prioritize issues for each other each year
- Sharing resource materials with each other
- Sharing information sheets, newsletters, and some training materials
- Sharing redacted sample correspondence, pleadings, articles on disability-related topics, web links, and other on-line education resources
- Jointly developing publications
- Reviewing each other's materials before publication
- Working together on legislative issues
- Working together on state level systems change initiatives
- Developing and submitting comments on proposed state and federal regulations
- Linking to each other's websites, including featuring each other's upcoming events
- Collaborative training of all early intervention service coordinators and service providers on procedural safeguards
- Supporting each other as participants of State Performance Plan/Annual Performance Report Stakeholder groups

Links to Exemplar Videos:

[12-9-13 Parent Center and Protection and Advocacy Collaboration Webinar](#)

[Maryland Exemplar Video](#)

[New Jersey Exemplar Video](#)

[South Dakota Exemplar Video](#)

Examples of Memorandums of Understanding from:

- ☐ Families Together, Inc. and Disability Rights Center of Kansas
- ☐ South Dakota Parent Connection and South Dakota Advocacy Services
- ☐ Statewide Parent Advocacy Network and Disability Rights New Jersey
- ☐ WI-FACETS and Disability Rights Wisconsin

INTERAGENCY COLLABORATION PLAN

Families Together, Inc. & DRC

Mission of DRC: *The Disability Rights Center of Kansas (DRC) will zealously advocate for the legal and civil rights of individuals with disabilities that ensure their dignity and empowerment.*

Who DRC serves: *DRC provides advocacy and legal representation to protect and enhance the disability rights of Kansans*

Mission of Families Together: *Families Together, Inc. is dedicated to a society that includes and values all people. Our mission is to encourage, educate, and empower families that include children/youth with disabilities and/or special health care needs. Through support, information and training, we hope to enable families and communities to maximize the abilities of individuals who learn differently.*

Who Families Together Serves: *Families Together is a statewide non-profit organization serving families in Kansas. Families Together is the federally designated Parent Training and Information Center (PTI) and Family-to-Family Health Information Center.*

In order to best meet the needs of children and youth in Kansas and their families and to maximize the resources available, Families Together and DRC propose to address the issues in the following collaborative manner.

Special Education calls/contacts appear to fall into the following categories:

1. Behaviors/BIP/FBA
2. Evaluations
3. IEP development and implementation
4. Discipline/Suspension/Expulsion/Alternative School Placement
5. Program/Placement Options/LRE
6. Related Services (i.e. transportation)
7. Transition from School to Adulthood
8. Emergency Safety Interventions (Seclusion and Restraint)
9. Filing for Compliance Complaints, Mediation, Due Process
10. Parent Rights and Procedural Safeguards
11. Juvenile Justice System (JJA) and CINC referrals
12. Section 504

Staff at Families Together has extensive expertise and experience in working with families on the above identified issues. Families Together help parents through a peer to peer parent connection with information delivered by parents who have faced similar challenges. Families Together will take the lead in all the categories of issues except the due process, mediation and compliance complaint category, which DRC will take the lead. Individuals will be referred to Families Together for assistance on these categories of issues. DRC will provide backup assistance through the monthly conference calls or individual case calls for categories of issues where Families Together seeks DRC's legal expertise.

DRC Attorneys/Advocates will work with Families Together staff to support families of children with disabilities and/or special health care needs through the IEP process by identifying content to include in Individualized Education Programs that will ensure children are successfully supported in the least restrictive and most integrated setting. This content might typically be in the form of parental input made directly by parents/caregivers; or as requests for the inclusion of evaluation results from professionals. The DRC and Families Together will work with families of children with disabilities and/or special health care needs to support this process.

DRC will take the lead with Discipline/Suspension/Alternative School Placement and Due Process and Mediation cases that require the use of an attorney and that fit DRC's priorities and tenants for accepting Special Education cases.

Referrals will be made from and between Families Together and DRC in accordance with the above priority areas.

Families Together will:

- Use their expertise in Special Education and Community services for persons with disabilities and/or special health care needs to assist families individually and in group training sessions.

- Teach parents the tools to advocate for their own children receiving special education services, helping parents to become effective advocates for their sons and daughters with disabilities and/or special health care needs.

- Due Process & Mediation - Families Together, Inc. staff members may attend mediations and pre-hearing conferences prior to due process, on a very limited basis. Families Together staff members are not allowed to attend due process hearings unless subpoenaed by the court. However, Families Together staff will assist parents in understanding the processes and their rights therein.

DRC will:

Maintain specialized knowledge in the special education advocacy/law realm with a team of Attorneys/Advocates at DRC. A portion of each of these staff members time would be devoted to special education issues and helping to carry out the specific steps of this plan.

Technical Advice and Assistance - DRC will participate in regular case review conference calls with Families Together. DRC will act as a resource to be available to help with the tough legal issues at these regular times and when called upon. DRC, however, cannot provide legal advice about a particular student's problem to Families Together. DRC can provide legal services, such as advice and representation, only to a client who is eligible for its services. DRC will continue to provide technical assistance and collaborate on these issues through the regular conference calls.

Represent children in Special Education mediation and due process of hearings where significant non-compliance occurs and where the case fits within DRC's priorities and factors for acceptance of special education cases. Work with Families Together to help prioritize and identify these prospective cases.

A Regular Consultation Conference Call will be maintained and facilitated by DRC staff.

These conference calls will be set up by DRC on a regular basis. Currently the calls are monthly on the third Tuesday of each month. Families Together will select their representatives to participate in the call. Participation in the call is optional for each agency; however, every effort will be made to have these conference calls monthly or at least regularly.

In addition, a DRC attorney will be available from time to time to provide support outside of these scheduled conference calls.

Participation in these case conference calls will help identify emerging issues, brainstorm better ways to serve our customers and facilitate referrals.

Due Process / Legal Representation Work in Special Education:

DRC and Families Together will work together to try to better identify priority areas for providing representation in Special Education Due Process and Mediation. DRC and Families Together need to work together to identify emerging issues and potential impact litigation cases for Special Education in Kansas. DRC wants Families Together to “work up” a case and try to resolve it short of legal representation, and to turn to DRC when legal representation is necessary. DRC values these referrals where avenues short of litigation have been thoroughly pursued. Some factors of due process/mediation special education cases that DRC looks for in deciding representation are:

- 1) Whether significant non-compliance of IDEA has occurred or where a systemic violation of federal law has occurred.
- 2) Where the desired result of the student and parent is congruent with DRC’s underlying priority of promoting independence, dignity and respect in the most inclusive setting.
- 3) Where the facts of the case and the law are favorable to the student and parents desired result.
- 4) Where a student has significant disabilities and is significantly disadvantaged economically and socially.
- 5) Where there is a clear issue of IDEA law and where winning the case will positively enhance the legal and civil rights of students with disabilities in Kansas.
- 6) Whether the case is within DRC’s priorities and DRC has the resources to accept the case for legal representation.

This collaboration plan is mutually agreed upon by the Executive Directors of the Disability Rights Center of Kansas and Families Together.

Updated May, 2013

Memorandum of Understanding

WHEREAS, South Dakota Advocacy Services (SDAS) and South Dakota Parent Connection (SDPC), manager of the South Dakota Navigator Program (SDNP) had entered into a protocol entitled "Guidelines for South Dakota Advocacy Services and South Dakota Navigator Program" which became effective on September 17, 2007, was updated on November 26, 2007 and further affirmed in July and October 2008, and on June 4, 2010 and March 10, 2011; and

WHEREAS, SDAS and SDPC have now come together to clarify their mutual interest and activities to be conducted by SDAS and SDPC through the SDNP in assisting students in South Dakota with education needs typically addressed through special education and Sec. 504 laws and regulations and in collaborating in those areas where it is appropriate and within the operational intent of its programs; and

WHEREAS, the following are guidelines regarding points of connection, collaboration and separation of functions regarding SDAS and SDNP in the conduct of their activities within the state of South Dakota; and

WHEREAS, the partners herein desire to enter into this Memorandum of Understanding (MOU) setting forth the services to be provided by each entity in relation to the other and where collaborative efforts may take place; as set out below;

NOW, THEREFORE, it is hereby agreed by and between the SDAS and SDNP (herein after program/s) as follows:

The services of both programs are equally available to parents, guardians or those with decision making authority regarding children eligible for (or potentially eligible for) services from a school district or service providers;

Parties seeking assistance from either program will be queried whether they are currently actively involved with the other program and if so, asked to select one program or the other in order to proceed;

Parties engaged with either program have the option to seek the assistance of the other program at any time and, if they do so, the original program will withdraw from further services and staff/contractor will notify their respective program directors;

Both programs will refer parties seeking assistance to the other program if the party seeking assistance cannot be served by the program or the issue at hand would be more appropriately addressed by the other program;

Persons working in the programs may seek assistance from persons in the other program to include but not limited to technical assistance such as understanding applicable statute or regulation subject to the internal procedures of either program.

Information, including client specific data may be shared between programs provided required confidentiality and release of information requirements are complied with.

Sufficient contact will be maintained between the programs to address items of mutual interest and to resolve questions that arise in the course of providing assistance.

The mutual roles, responsibilities and understandings described above are ongoing from the date this MOU is signed by representatives of both programs until further modified by mutual consent or terminated by either program with notification to the other program.

Nothing in this MOU shall create a fiscal or compensatory obligation of one program upon the other program.

We, the undersigned have read and agree with this MOU.

MEMORANDUM OF UNDERSTANDING

I. INTRODUCTION

a. PARTIES INVOLVED

Disability Rights New Jersey

And

Statewide Parent Advocacy Network, Inc.

b. PURPOSE

This agreement is established between Disability Rights New Jersey (DRNJ) and the Statewide Parent Advocacy Network, Inc. (SPAN).

The purpose of this agreement is to enhance, to the greatest extent possible, the best possible educational outcomes for the children eligible for early intervention, special education programs, and/or transition services in New Jersey in accordance with the goals and objectives defined in the Parent Training and Information Center grant submitted to the U.S. Department of Education Office of Special Education by the Statewide Parent Advocacy Network on behalf of families and individuals in New Jersey, and the goals and objectives identified by Disability Rights New Jersey, as the New Jersey Protection and Advocacy agency.

II. JOINT AGREEMENT

- a. To establish an agreement between DRNJ and SPAN to work together to complement each other's respective efforts to meet the goals of both the work of DRNJ and SPAN's PTI grant as each group strives to meet the needs of families and their children eligible for early intervention, special education, and/or transition services.
- b. To cooperate in the operation of a statewide system of seamless service provision which ensures maximum use of limited resources, aims to avoid duplication of services, and concentrates on the sharing of information and support between DRNJ and SPAN.

III. SPAN AGREES TO:

- a. Provide information and referral support via a toll free line when DRNJ Advocacy Specialists are unavailable, or unable, to assist parents with school or early intervention issues, particularly at the early conflict resolution stages.
- b. Provide individual support to parents referred to SPAN by DRNJ, especially at the early conflict resolution stages to help support parents in articulating their needs.

- c. Collaborate or co-sponsor, with DRNJ, at least one workshop and/or webinar, on systems change issues, transition, juvenile justice issues, mental health issues and other education-related issues, including provision of materials to participants and maintenance of records of individuals trained, each year.
- d. Provide a link on the SPAN website to the DRNJ website.
- e. Promote, to parents and others, systems change efforts, trainings and other supports available from DRNJ.
- f. Share training materials and other printed information developed by SPAN, or mutually written with DRNJ.
- g. Continue to collaborate on policy issues impacting infants, toddlers, children and youth with disabilities and their families, including through submission of collaborative testimony to policymakers, joint efforts on stakeholder groups such as the Early Intervention and Special Education SPP/APR Stakeholder groups, State Interagency Coordinating Council, and Special Education Advisory Council, among others.
- h. Continue to collaborate to enhance services and supports to underserved families of infants, toddlers, children and youth with disabilities through joint planning and implementation of conferences and forums aimed at specific underserved populations.
- i. Assist DRNJ to prioritize its efforts through participation on DRNJ Board and/or Consumer Advisory Councils and through publicizing with families DRNJ's periodic needs identification and prioritization survey.

IV. DRNJ AGREES TO:

- a. Receive referrals, for consideration, from SPAN of cases that may need more in-depth advocacy or legal intervention, especially related to discipline/expulsion, inclusion, graduation, juvenile justice and other DRNJ priority areas.
- b. Provide referrals to SPAN of families with children in special education as needed, either for information and referral assistance or individual support.
- c. Provide consultation and information for SPAN related to more difficult cases with which SPAN may be working.
- d. Share training materials and other printed information developed by DRNJ, or mutually written with SPAN.
- e. Collaborate or co-sponsor, with SPAN, at least one workshop and/or webinar, on systems change issues, transition, juvenile justice issues, mental health issues and other education-related issues, including provision of materials to participants.
- f. Provide a link on the DRNJ website to the SPAN website.
- g. Collaborate and assist SPAN with the identification of "flash point" areas, school districts, certain populations which have a high degree of need that may require focused intervention by SPAN.
- h. Continue to collaborate on policy issues impacting infants, toddlers, children and youth with disabilities and their families, including through submission of collaborative testimony to policymakers, joint efforts on stakeholder groups such

MEMORANDUM OF UNDERSTANDING

I. INTRODUCTION

a. PARTIES INVOLVED

Disability Rights New Jersey

And

Statewide Parent Advocacy Network, Inc.

b. PURPOSE

This agreement is established between Disability Rights New Jersey (DRNJ) and the Statewide Parent Advocacy Network, Inc. (SPAN).

The purpose of this agreement is to enhance, to the greatest extent possible, the best possible educational outcomes for the children eligible for early intervention, special education programs, and/or transition services in New Jersey in accordance with the goals and objectives defined in the Parent Training and Information Center grant submitted to the U.S. Department of Education Office of Special Education by the Statewide Parent Advocacy Network on behalf of families and individuals in New Jersey, and the goals and objectives identified by Disability Rights New Jersey, as the New Jersey Protection and Advocacy agency.

II. JOINT AGREEMENT

- a. To establish an agreement between DRNJ and SPAN to work together to complement each other's respective efforts to meet the goals of both the work of DRNJ and SPAN's PTI grant as each group strives to meet the needs of families and their children eligible for early intervention, special education, and/or transition services.
- b. To cooperate in the operation of a statewide system of seamless service provision which ensures maximum use of limited resources, aims to avoid duplication of services, and concentrates on the sharing of information and support between DRNJ and SPAN.

III. SPAN AGREES TO:

- a. Provide information and referral support via a toll free line when DRNJ Advocacy Specialists are unavailable, or unable, to assist parents with school or early intervention issues, particularly at the early conflict resolution stages.
- b. Provide individual support to parents referred to SPAN by DRNJ, especially at the early conflict resolution stages to help support parents in articulating their needs.

- c. Collaborate or co-sponsor, with DRNJ, at least one workshop and/or webinar, on systems change issues, transition, juvenile justice issues, mental health issues and other education-related issues, including provision of materials to participants and maintenance of records of individuals trained, each year.
- d. Provide a link on the SPAN website to the DRNJ website.
- e. Promote, to parents and others, systems change efforts, trainings and other supports available from DRNJ.
- f. Share training materials and other printed information developed by SPAN, or mutually written with DRNJ.
- g. Continue to collaborate on policy issues impacting infants, toddlers, children and youth with disabilities and their families, including through submission of collaborative testimony to policymakers, joint efforts on stakeholder groups such as the Early Intervention and Special Education SPP/APR Stakeholder groups, State Interagency Coordinating Council, and Special Education Advisory Council, among others.
- h. Continue to collaborate to enhance services and supports to underserved families of infants, toddlers, children and youth with disabilities through joint planning and implementation of conferences and forums aimed at specific underserved populations.
- i. Assist DRNJ to prioritize its efforts through participation on DRNJ Board and/or Consumer Advisory Councils and through publicizing with families DRNJ's periodic needs identification and prioritization survey.

IV. DRNJ AGREES TO:

- a. Receive referrals, for consideration, from SPAN of cases that may need more in-depth advocacy or legal intervention, especially related to discipline/expulsion, inclusion, graduation, juvenile justice and other DRNJ priority areas.
- b. Provide referrals to SPAN of families with children in special education as needed, either for information and referral assistance or individual support.
- c. Provide consultation and information for SPAN related to more difficult cases with which SPAN may be working.
- d. Share training materials and other printed information developed by DRNJ, or mutually written with SPAN.
- e. Collaborate or co-sponsor, with SPAN, at least one workshop and/or webinar, on systems change issues, transition, juvenile justice issues, mental health issues and other education-related issues, including provision of materials to participants.
- f. Provide a link on the DRNJ website to the SPAN website.
- g. Collaborate and assist SPAN with the identification of "flash point" areas, school districts, certain populations which have a high degree of need that may require focused intervention by SPAN.
- h. Continue to collaborate on policy issues impacting infants, toddlers, children and youth with disabilities and their families, including through submission of collaborative testimony to policymakers, joint efforts on stakeholder groups such

as the Early Intervention and Special Education SPP/APR Stakeholder groups, State Interagency Coordinating Council, and Special Education Advisory Council, among others.

- i. Continue to collaborate to enhance services and supports to underserved families of infants, toddlers, children and youth with disabilities through joint planning and implementation of conferences and forums aimed at specific underserved populations.
- j. Assist SPAN to prioritize its efforts through participation on SPAN's PTI Stakeholder Advisory Council and through publicizing with families SPAN's periodic needs identification and prioritization survey

V. **DURATION OF AGREEMENT:**

This agreement is for the current 3-year period of the Parent Training and Information Center grant and is subject to review/revision or **termination by Disability Rights New Jersey or Statewide Parent Advocacy Network at any time.**

MEMORANDUM OF UNDERSTANDING

I. INTRODUCTION

A. PARTIES INVOLVED

Disability Rights Wisconsin
and

Wisconsin Family Assistance Center for Education, Training and Support, Inc.

B. PURPOSE

This agreement is established between Wisconsin Family Assistance Center for Education, Training and Support, Inc. (WI FACETS) and the Disability Rights Wisconsin (DRW).

This purpose of this agreement is to enhance, to the greatest extent possible, the best possible educational outcomes for the children enrolled in special education programs in Wisconsin in accordance with the goals and objectives defined in the Parent Training and Information Center grant submitted to the U.S. Department of Education Office of Special Education Programs by WI FACETS on behalf of families and individuals in Wisconsin, and the goals and objectives identified by DRW, as the Wisconsin **Protection and Advocacy** agency.

II. JOINT AGREEMENT

- A. To establish an agreement between DRW and WI FACETS to work together to complement each other's respective efforts to meet the goals of both the work of DRW and the WI FACETS' PTI grant as each group strives to meet the needs of schools and parents and their children enrolled in special education programs.
- B. To cooperate in the operation of a statewide system of seamless service provision which ensures maximum use of limited resources, aims to avoid duplication of services, and concentrates on the sharing of information and support between DRW and WI FACETS.

III. WI FACETS AGREES TO:

- A. Provide information and referral support via a toll free line when DRW Advocacy Specialists are unavailable, or unable, to assist parents with school or early intervention issues, particularly at the early conflict resolution stages.
- B. Provide individual support to parents referred to WI FACETS by DRW, especially at the early conflict resolution stages to help support parents in articulating their needs.
- C. Co-sponsor and/or co-train, with DRW, at least 4 workshops during the grant period, on systems change issues, transition, and educational topics, including provision of materials to participants and maintenance of records of individuals trained.
- D. Provide a link on the WI FACETS website to the DRW website.
- E. Serve with DRW on the Wisconsin Quality Education Coalition.
- F. Promote, to parents and others, systems change efforts, trainings and other supports available from DRW.
- G. Share training materials and other printed information developed by WI FACETS, or mutually written with DRW.

MEMORANDUM OF UNDERSTANDING

IV. DRW AGREES TO:

- A.** Receive referrals, for consideration, from WI FACETS of cases that may need more in-depth advocacy or legal intervention, especially related to discipline/expulsion, inclusion, graduation, and other DRW priority areas.
- B.** Provide referrals to WI FACETS of families with children in special education as needed, either for information and referral assistance or individual support.
- C.** Provide consultation and information for WI FACETS related to more difficult cases with which WI FACETS may be working.
- D.** Share training materials and other printed information developed by DRW, or mutually written with WI FACETS.
- E.** Provide training (at least 4 workshops) during the grant period to parents or WI FACETS staff on systems change issues, transition, juvenile justice issues, mental health issues and other education-related issues, including provision of materials to participants.
- F.** Provide a link on the DRW website to the WI FACETS website.
- G.** Assist WI FACETS with identification of "flash point" areas, school districts, certain populations which appear to have a high degree of need that may require focused intervention by WI FACETS.

V. DURATION OF AGREEMENT:

The agreement is for the 4-year period of the Parent Training and Information Center grant, should the grant be funded, and is subject to review/revision or termination by Disability Rights Wisconsin or WI FACETS at any time.