

## X. Advocacy and Information Resources

### A. What Are Advocacy and Information Resources?

Virginians with disabilities are entitled to basic human and civil rights, which include the right to education, housing, employment, health care, and social and recreational opportunities, as well as full inclusion in the community. There are three basic, interrelated forms of advocacy. In general terms, **Self-advocacy** is an individual's pursuit of his or her own needs and choices. **Individual advocacy** involves efforts by another person or organization who works one-on-one with an individual to ensure that the individual receives the services to which he or she is entitled and is able to make meaningful life choices. **Systems advocacy** involves one or more individuals or organizations engaged in efforts to improve service delivery and quality of life for themselves, for others, or for all people.

Virginia's advocacy programs and services are very diverse and multilayered. They may operate independently or as a part of a program or agency. Often, government agencies initiate advocacy activities to ensure that persons with disabilities are better informed about available services and supports, how to access them, and how to improve their delivery. Similar advocacy initiatives are also undertaken by nonprofit organizations and coalitions of individuals, either independently, in collaboration with one another, or with governmental agencies. These advocacy services are distinct from formal appeals processes established by agencies and organizations that provide such services.

In addition to direct advocacy, Virginia offers a broad array of **resources and information** to support individuals with disabilities who need services and supports in early intervention, education, community living, institutional settings, or the other basic service areas covered by this report. Some of these resources and initiatives have been mentioned in the Evaluation and Monitoring sections of these chapters. This chapter provides basic information on some of the key resources available in Virginia that provide advocacy support. The listing and descriptions are not all-inclusive: only organizations that have a statewide office or chapter are included; and the primary focus is on organizations that work with or provide information to persons with developmental disabilities and their families.

### B. Who Is Eligible for Advocacy and Information Resources?

Eligibility criteria for individual advocacy programs and services vary. In general, if an advocacy program operates within an agency or program, individuals who are applicants for, or recipients of, a service from that agency are eligible for its associated advocacy services. External advocacy programs or services, such as those provided by the Virginia Office for Protection and Advocacy, may be subject to complex state or federal eligibility requirements. These eligibility criteria may be linked to programmatic requirements of a specific advocacy initiative or to the available resources and resulting priorities of the advocacy program. In addition, there are nonprofit organizations that also provide advocacy supports that are more community-based and receive less rigorous federal and regulatory oversight.

Generally, information on eligibility for advocacy services is readily available from state and local agencies, other service providers, and independent advocacy organizations through their Web sites or by contacting them directly. Some agencies and service providers are required to supply applicants and service recipients with information on available advocacy services.

Informational resources are available to any citizen through a variety of agencies, organizations, and on the Web, and have no eligibility criteria attached to their receipt.

### **C. How Are Advocacy and Information Resources Accessed and Delivered?**

Access and delivery mechanisms for advocacy services also vary by agency and program. With so many programs in existence, detailed descriptions are beyond the scope of this report. In general, access to internal agency advocacy programs (such as the Local Human Rights Committees supported by the Department of Mental Health, Mental Retardation and Substance Abuse Services) is through the service provider. External advocacy services, such as those provided by the Virginia Office for Protection and Advocacy, typically utilize an intake process that assesses the individual's needs and determine whether he or she falls within the purview and priorities of the program and its planning processes. Details on these access and delivery mechanisms can best be obtained from the advocacy services themselves, through their Web sites, or by contacting them directly.

Advocacy resource information can be accessed from many of the organizations that are listed below. Most organizations have printed materials and information available on their Web sites. Most state agencies also have a section of their Web site called "Links and Resources" that provides direct Internet links to other state agencies, as well as to public and private organizations that can provide additional information or assistance. Some agencies, but not all, provide their materials in alternative formats or other languages.

### **D. What Advocacy and Information Resources Are Available?**

The organizations or programs listed below (in alphabetical order) are engaged in individual and/or or systems advocacy on behalf of individuals with developmental or other disabilities and generally provide resource information for such individuals. Specific contact information for these advocacy services is not provided, because this information frequently changes and is likely be out of date within a short period of time. For information on these programs, readers are encouraged to contact their local agency by phone or online.

As already noted, the following list is not all-inclusive. The focus is on statewide organizations rather than regional or local organizations. Some entities not within the scope of this chapter may have been covered in other chapters of this report where relevant, particularly in the Monitoring and Evaluation section. The statewide entities included here are:

- Organizations that provide advocacy on behalf of agencies, organizations, and service providers;

- State and local boards, advisory councils, task forces, and workgroups;
- Agency appeal and complaint mechanisms that do not involve advocacy or investigation on behalf of individuals; and
- Federal advocacy agencies or programs that may be available to assist persons with disabilities, such as the Office of Civil Rights within the U.S. Department of Justice.

**Action Alliance for Virginia’s Children and Youth:** This statewide organization works to change state policy to improve services for children and youths in a variety of areas, including, but not limited to: early child care and intervention, education, health care, mental health, family economic success, foster care, and adoption.

**American Civil Liberties Union of Virginia (ACLU):** An affiliate of the national ACLU, the Virginia ACLU is a private, nonprofit organization that uses lobbying, litigation, and public education to promote the civil liberties and civil rights of all residents. The principal mission of the ACLU is to “protect constitutionally mandated freedoms that government tends to erode and to advance rights clearly intended by the Constitution but never fully implemented in our society.” The ACLU addresses a broad variety of issues, including: free expression, religious rights, access to government, the death penalty, due process and criminal justice, equality, prisoners’ rights, privacy rights, students’ rights, voters’ rights, and others.

**The Arc of Virginia:** This statewide organization advocates for individuals with intellectual disabilities (mental retardation) and developmental disabilities and their families. It promotes the creation of individualized, self-determined, community-based supports that enable people with disabilities to lead productive and fulfilling lives. The Arc of Virginia lists 21 local and area chapters within Virginia. To learn more about the local and state chapters, the reader can visit the Arc’s Web site or contact local chapters directly.

**Area Agencies on Aging Long-Term Care Ombudsman Program:** The national Older Americans Act requires all states to provide advocacy services for older persons who are receiving long-term care. The Virginia Department for the Aging (VDA) contracts with local Area Agencies on Aging (AAA) to provide these services through the Long-Term Care Ombudsman Program. The State Long-Term Care Ombudsman, who has expertise in both long-term care and advocacy, provides coordination and support for designated local ombudsmen. The local ombudsmen, who have completed a certification curriculum, are based at each of the 25 Area Agencies on Aging. Ombudsmen identify, investigate, and resolve complaints made by, or on behalf of, older persons who receive long-term care services. Individuals needing advocacy services may contact the ombudsman at their local Area Agency on Aging directly or through the VDA’s statewide toll-free telephone hotline.

**Brain Injury Association of Virginia (BIAV):** On behalf of people with brain injury and their families, this nonprofit organization provides a variety of educational and supportive services to individuals with brain injury, to their families, and to service providers and advocates. BIAV’s mission is to improve the quality of life of persons with brain injury and their families as well as

to develop and support programs to prevent brain injury in Virginia. Its activities include: outreach to people with brain injuries; maintenance of an extensive clearinghouse of brain injury information; provision of referrals for additional information and services; operation of a toll-free Family Help Line; and the offer of training programs. BIAV also provides technical assistance to hospitals through the Virginia Central Registry for Brain Injury, and sponsors support groups and recreation programs.

**Care Connection for Children:** Sponsored by the **Virginia Department of Health**, this statewide network of regional programs provides health-care services, community support, and resources to children with special medical needs. Using a team-based approach, this network brings together case managers, medical personnel, educators, and family members to determine how individual children with special health-care needs can reach their maximum potential. Professional care coordinators work closely with children and their families to provide targeted, comprehensive, and culturally appropriate care. These professionals coordinate all services offered by the various providers to children in need, and they actively seek input from families and medical practitioners to achieve the best possible results. Each Care Connection for Children program offers counseling, information, education, social support, and, where appropriate, information and referrals.

**Center for Special Education Advocacy (CSEA):** Formerly known as the Coalition for Students with Disabilities Legal Advocacy Center, this independent, nonprofit, tax-exempt corporation, formed by advocates, is dedicated to improving educational services and outcomes for students with disabilities. CSEA fosters and supports legal services that will protect and advance the educational rights of students with disabilities. It offers basic and advanced training programs to parents, advocates, and attorneys throughout Virginia. These programs discuss current federal and state special education laws and regulations, as well as case law affecting the educational rights of students with disabilities. Through these training programs, CSEA carries out its goals and accomplishes its mission. The organization does not currently provide individual legal or advocacy services, but does maintain a referral list.

**Centers for Independent Living (CILs):** CILs are nonprofit, nonresidential places of action and coalition where persons with disabilities learn empowerment and develop the skills necessary to make lifestyle choices. Funded by federal, state, and local sources, CILs provide services and advocacy to promote the leadership, independence, and productivity of people with significant disabilities. CILs work with both individuals and local communities to remove barriers to independence and to ensure equal opportunities for persons with disabilities. All CILs provide the following core services: advocacy for individuals and systems change, information and referrals, peer counseling, and training in independent living. Community services include: disability awareness outreach, information on accessibility issues, disability rights advocacy, and general disability information and referrals.

The **Virginia Association of Centers for Independent Living** is a representative membership organization that provides guidance and policy support to the CILs, and in recent

years has improved uniform practices among the CILs. CILs have proved to be a consistent resource for those who wish to find community supports that can help them live independently.

**Cerebral Palsy of Virginia** is a 501(c)(3) nonprofit organization serving children and adults with cerebral palsy and other developmental disabilities (such as those with Down syndrome, autism, muscular dystrophy, intellectual disabilities [mental retardation, and learning disabilities]) as well as those with hearing, speech and visual impairments. Advocacy services are provided to adult and teen consumers, families, and cerebral palsy staff advocates to ensure the rights of persons with disabilities and to help address the important issues facing adults with disabilities or families who have a child with disabilities. The organization also provides guidance regarding the availability of assistive technology equipment, adaptive toys, communication devices, computer software programs, and books for loan to consumers and families throughout the Commonwealth. This lending program allows families to test and use equipment in their home with the child or adult family member with a disability to assure its efficiency before making an expensive purchase.

**Coalition for Virginians with Mental Disabilities** was formed twenty years ago to work on behalf of Virginians with mental illness, intellectual disabilities, and substance abuse challenges. The Coalition engages in legislative advocacy and public policy analysis. It promotes an array of community services that are sufficient to meet the needs of each individual and for a level of high-quality care in all service delivery systems and settings. Members of the Coalition are persons with mental disabilities, family members, and organizations that support people with disabilities. The coalition represents a broad array of organizations, including: Family Advocacy Creating Education and Services, the Federation of Families of Virginia, the Mental Health Association of Virginia, NAMI-Virginia, Parents and Associates of the Institutionalized Retarded, the Psychiatric Society of Virginia, the Substance Abuse and Addiction Recovery Alliance of Virginia, The Arc of Virginia, VaACCSES, the Virginia Network of Private Providers, Virginia Organization of Consumers Asserting Leadership, the Virginia Rehabilitation Association, and Voices for Virginia's Children.

**Commonwealth Autism Service (CAS)**: Formerly known as The Autism Program of Virginia, CAS provides leadership in implementing a statewide system of services to maximize the potential and quality of life across their lifespan of Virginians with autism. This agency is partially funded by the Virginia General Assembly to: provide ongoing support to families and professionals, develop regional networks, provide technical assistance, and conduct conferences related to pervasive developmental disorders.

**Fair Housing Office**: The Virginia Fair Housing Law prohibits discrimination in residential housing on the basis of race, color, religion, national origin, sex, "elderliness," familial status, or disability. The law prohibits applying one standard to one class of individuals while applying a different standard to another class of individuals. For example, it is illegal in Virginia to ask a person with a disability who is applying for an apartment to provide a credit report if individuals without disabilities are not required to do so. This law applies to the rental of apartments or homes, home sales, mortgages, and other real estate financing; real estate insurance transactions;

and related advertising. In addition to those responsibilities, the Fair Housing Office provides free Fair Housing training for state and local officials, housing providers, and individuals. Details on the Fair Housing Office's investigation, conciliation, and determination practices with regard to Virginia's Fair Housing Law may be found in the Housing chapter of this report.

**Human Rights Council:** The mission of this state agency (formerly called the Council on Human Rights) is to promote and preserve the human rights of all individuals in the Commonwealth by raising the awareness of human rights and engaging in conflict resolution. The Council safeguards all individuals within the Commonwealth from unlawful discrimination because of race, color, religion, national origin, sex, pregnancy, childbirth, or related medical conditions, age, or disability. The Council has jurisdiction over places of public accommodation (including educational institutions), real estate transactions, and employment. It protects the interests, rights, and privileges of citizens, both from unlawful discrimination and from unfounded charges of unlawful discrimination. Complaints of discrimination in any of these areas may be filed with the Council. The Council receives and reviews those complaints, attempts mediation, conducts investigations, and renders determinations. The Council's Human Rights Act (Chapter 39) empowers the Council to investigate complaints under: the Human Rights Act, Title VII of the 1964 Act, as amended; the Americans with Disabilities Act; and the Age Discrimination in Employment Act.

**Infant and Toddler Connection Family Involvement Project:** Virginia's Infant and Toddler Connection program, which serves children with disabilities from birth to age three, is discussed in detail in the Early Intervention chapter of this report. Within this program is the Family Involvement Project. The Project works to strengthen and increase families' voices in related policy and fiscal decision-making councils at both state and local levels.

**Legal Aid Justice Center:** This nonprofit organization, which is supported by a combination of public and private funds, provides legal services to low-income families in central Virginia and to low-wage immigrant workers statewide. Through legal representation, community education, and statewide systems legal advocacy, the Center works to eliminate the immediate symptoms of poverty in Virginia and to address its underlying causes. The Center's **Civil Advocacy Program** addresses legal issues in housing, public benefits, employment, consumer protection, and the rights of the elderly and individuals with disabilities. The **Virginia Justice Center for Farm and Immigrant Workers** addresses employment concerns of farm workers, day laborers, and low-wage immigrant workers.

The **JustChildren** program works to ensure that young people have access to the services and supports necessary for them to live successfully in their communities. The JustChildren program provides direct legal services for local families with children from birth to age 18 through offices in Charlottesville, Richmond, and Petersburg. It also engages in statewide advocacy on important issues affecting Virginia children. Legal representation is provided in matters concerning appropriate education services for children with disabilities, necessary treatment services for children with psychiatric concerns, and services and supports required for children involved with the juvenile courts to remain in their communities. JustChildren also

engages in community education and works with other statewide advocacy efforts involving foster care, the juvenile justice system, and other issues.

**Medical Home Plus:** This nonprofit organization provides a leadership role in facilitating family, professional, and community partnerships that improve the quality of life for children with special health-care needs and/or disabilities—“connecting the dots” to create a more seamless system of service delivery. It provides resource information to families, and its projects and programs reflect working partnerships with public and private agencies in multiple capacities.

**Mental Health Association of Virginia (MHAV):** This nonprofit, nonpartisan advocacy organization, which is affiliated with the National Mental Health Association, promotes mental health, develops services to prevent mental illness, and ensures that children and adults with mental illness receive proper care and treatment. MHAV advocates for public and private sector policies, services, and financing to ensure adequate and appropriate detection, treatment, housing, and rehabilitation programs. It also works to raise public awareness of mental health and mental illness as well as eliminate the stigma that prevents individuals from seeking help when they need it. Services that meet the needs of individuals with mental illness, improve mental health, and/or reduce conditions that impede attainment of mental health are provided and promoted.

**National Alliance for the Mentally Ill (NAMI) of Virginia:** The NAMI affiliate in Virginia strives to provide information and support to everyone affected by mental illness—teens, family members, friends, veterans, and others. It maintains a helpline for information on mental illness and makes referrals to local self-help groups. These groups share information about community services with individuals and families, provide support to them, and advocate on their behalf. The state NAMI-VA office provides state-level policy and legislative advocacy on behalf of persons with mental illness and their families.

**Office of Human Rights:** The **Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)** Office of Human Rights fulfills the *Code of Virginia*, §37.1-84.1, requirement for the protection of legal and human rights of individuals receiving services in facilities or programs operated, licensed, or funded by DMHMRSAS. The Office of Human Rights promulgates and monitors compliance with state human rights regulations, promotes the basic precepts of human dignity, advocates for the rights of persons with disabilities in DMHMRSAS service delivery system, and manages the Human Rights dispute resolution program. The State Human Rights Director oversees statewide human rights activities and provides both guidance and direction to the human rights staff.

The **State Human Rights Committee**, which is appointed by the Mental Health, Mental Retardation and Substance Abuse Services State Board, consists of nine volunteers who broadly represent various professional groups, persons receiving disability services and their families, and geographic areas of the state. This Committee acts as an independent body to oversee implementation of the DMHMRSAS human rights program. It receives, coordinates, and makes

recommendations for revisions to human rights regulations; reviews and approves requests for variances to those regulations; and reviews the scope and content of related training programs. It also appoints members of the **Local Human Rights Committees (LHRC)**, reviews and approves their bylaws, and renders decisions on appeals of their decisions on human rights complaints.

Volunteers on Local Human Rights Committees represent professionals and persons with disabilities and their families in their communities. The LHRCs review policies, procedures, and practices, as well as make recommendations for regulatory changes or variances. They review human rights complaints that are not resolved at the program level, conduct additional investigations as warranted, and recommend corrective actions.

At the program level, advocates are appointed by the DMHMRSAS Commissioner in consultation with the State Human Rights Director. The role of these advocates is to prevent human rights violations and to represent individuals whose rights are alleged to have been violated. Each state-operated facility has at least one advocate, and regional advocates located across the state are responsible for community programs. Advocate duties include investigating complaints, examining conditions that affect the human rights of service recipients, and monitoring compliance with human rights regulations.

**Parents and Associates of the Institutionalized Retarded (PAIR)**: As the state affiliate of the national Voice of the Retarded, PAIR represents individuals with intellectual disabilities and their families. PAIR supports the provision of a full array of quality residential options, including congregate/institutional options, and of other supports for individuals with intellectual disabilities. PAIR helps maintain the Training Centers operated by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) while recognizing the need for expanded, better-funded, community-based services and supports.

**Parent Educational Advocacy Training Center (PEATC)**: Funded under a grant from the U.S. Department of Education, PEATC is Virginia's parent education, support, training, and information center committed to building better futures for children with disabilities. It works collaboratively with families, schools, and service professionals to improve opportunities for excellence in education and personal success in school and community life. PEATC offers services and support for families and professionals; experience-based program development and training curricula; and easy to understand, research-based disability education information, training, and support.

**Parent to Parent of Virginia** offers "one-to-one emotional and informational support to parents of children with special health care needs." The organization provides IEP advocacy and training focused on helping parents become more active in the financing and coordination of their child's health care and education.

**Partnership for People with Disabilities**: This extension of Virginia Commonwealth University is recognized by the federal Administration on Developmental Disabilities as the

Commonwealth's University Center for Excellence in Developmental Disabilities. Referred to simply as "the Partnership," it operates more than 20 federal and state programs, staffed by more than 100 professionals and students, to provide support to individuals with disabilities and their families. The Partnership maintains an interdisciplinary approach in all its activities as it expands opportunities for individuals with disabilities. It strives to help create communities in which all people live, work, and play together with choices and independence. The Partnership collaborates with numerous disability service providers, K-12 schools and school divisions, universities and colleges, state and local agencies, and professional organizations. The Partnership's activities include, but are not limited to, advocacy on behalf of issues affecting individuals with developmental disabilities, and the promotion of state-level policy changes, training, and development of resource information and products for families and professionals.

**VA-INFO Center:** The Family to Family Health Information and Education Center of Virginia's Integrated Network of Family Organizations (VA-INFO) is a collaborative effort between Parent to Parent of Virginia and Family Voices of Virginia. Accessed through its Web site or by a toll-free telephone number, VA-INFO brings parents of children with disabilities together to exchange information and to provide peer support. It also develops educational materials, sponsors training materials, and advocates on behalf of children with disabilities and their families. Monthly meetings bring together families and representatives from state agencies, community organizations, and service providers.

**Virginia Assistive Technology System (VATS):** Assistive Technology Regional Sites provide local contact points for the VATS statewide network of information and resources on assistive technology. These regional sites promote public awareness and provide training and technical assistance to promote the availability and use of assistive technology for people with disabilities.

**Virginia Association of Community Services Boards (VACSB):** As the statewide organization for Virginia's network of 37 local Community Services Boards (CSBs) and three Behavioral Health Authorities (BHAs), the VACSB promotes coordination, improvement, and expansion of prevention, treatment, and rehabilitation services for individuals with mental illness, intellectual disabilities, or substance abuse problems. The mission of the VACSB is to achieve a public system of services in Virginia that is responsive to the needs of individuals with these disabilities and that is based in community care.

**Virginia Autism Resource Center (VARC):** VARC is a division of Grafton School, Inc., a private, nonprofit residential school serving students diagnosed with emotional disorders, mental retardation, behavioral disorders, and autism. VARC provides information and referral, training, and direct consultation to families, school divisions, and other agencies.

**Virginia Board for People with Disabilities:** The Virginia Board, author of this assessment report, is the state's federally authorized Developmental Disabilities (DD) Council. These DD Councils are mandated by statute to engage in advocacy, to build service capacity, and to develop systems changes that contribute to the development of a coordinated, comprehensive system of services, individualized supports, and other forms of assistance. The Virginia Board is

consumer- and family-centered and consumer- and family-directed, and enables individuals with developmental disabilities to exercise maximum self-determination and independence and to be fully integrated into all facets of community life. Activities are accomplished by informing policymakers, by demonstrating new approaches to services and supports, and by conducting or facilitating outreach, training, technical assistance, advocacy, and education. The purposes of Board activities are to promote barrier elimination, system design/redesign, coalition development, and citizen participation, among others.

**Virginia Coalition for Students with Disabilities:** This statewide organization promotes educational rights and opportunities for students with disabilities. Its expressed goals are to:

- Organize an annual “Call to Action” event to discuss current events and stimulate actions to improve educational opportunities for students with disabilities;
- Meet to discuss activities that affect education, such as monitoring school compliance with federal and state disability laws, state-level education standards, implementation of the Individuals with Disabilities Education Improvement Act, and the State Special Education Regulations and legislation;
- Monitor activities of the state legislature and the Virginia Department of Education; and
- Encourage advocates to work together to address educational deficiencies in Virginia.

**Virginia Department for the Aging (VDA) Center for Elder Rights:** The VDA works with public and private organizations to help older Virginians and their families find the services and information they need. VDA’s **Center for Elder Rights** brings together a variety of consumer, legal, aging, and long-term care information, and serves as a central referral source to local Area Agencies on Aging. Center services emphasize “low tech” and “high touch,” providing direct person-to-person contact with knowledgeable staff members rather than through an automated telephone menu system. These staff members help older Virginians and their families to evaluate their needs and to understand the resources that may be available to assist them in their local communities. As part of its high-touch emphasis, Center staff members follow up with callers after five days to see if the information they received was helpful, if they have followed through with referrals, and if they have additional questions.

Many of the education and outreach activities of the Center focus on empowering individuals by informing them of their rights and options so that they can advocate on their own behalf and make informed choices about the services and opportunities available to them. The Center also reviews, analyzes, and advocates for policies and about issues that may affect the health, safety, welfare, or rights of vulnerable older persons. The Center maintains a registry of more than 100 attorneys across the state who can provide legal services to indigent and low-income older Virginians, including those with disabilities.

**Virginia Department of Education (VDOE) Ombudsman Program:** The VDOE **Ombudsman** acts as a source of information and referral, aids in answering an individual’s questions, and assists in the resolution of concerns and issues. Although this program does not

provide direct advocacy, it does serve as a resource to parents in nonlegal special education matters. Unlike an advocate, the Ombudsman has a neutral role, being an independent advocate for a fair process and encouraging parties to resolve issues at the lowest organizational level through appropriate formal and informal processes for dispute resolution. In considering any given instance or concern, the interests and rights of all parties who might be involved are taken into account. The role of the Ombudsman is informal, with a focus on listening and providing information, discussing issues and options, and making referrals to other services, including mediation. There is no formal complaint form or documentation.

**Parent Resource Centers**, which are located in many school divisions, are an additional source of assistance, referrals, and workshops on special education issues for parents and educators. These centers draw on a variety of state and local resources as well as assistance and information from VDOE.

**Virginia Legal Aid Society (VLAS)**: This nonprofit law firm provides free civil legal services to eligible low-income residents in twenty counties and seven cities in the central, Southside, and western Tidewater areas. VLAS provides free legal information, advice, and representation in areas such as housing, health care, economic self-sufficiency, education, public benefits, consumer purchases, and family relations. Financial eligibility for general legal services is based on income and assets available to the family using Federal Poverty Income Guidelines. To be eligible for free VLAS services, a family must generally have income of less than 125 percent of the federal poverty level, but there are some exceptions to this income limit.

**Virginia Medicaid Waiver Network**: The network includes individuals and organizations who wish to work together to improve Virginia's Home and Community Based Waivers. The network is a cross-disability, collaborative advocacy group. It is not controlled by any organization. Its decisions and positions are determined by those who choose to be involved in the network; and the only requirement for participation is a commitment to work together. Initially, the network's meetings and communications were managed by the Medicaid Waiver Technical Assistance Center at the Endependence Center in Norfolk, with grant funding from the Virginia Board for People with Disabilities. Although the grant period has ended, the organizations involved in the network are committed to keeping the network a viable entity.

**Virginia Office for Protection and Advocacy (VOPA)**: VOPA is the Commonwealth's Protection and Advocacy entity. It operates advocacy and legal services under nine federal and state programs, which provide funding and authority for its operations. VOPA helps with disability-related problems such as abuse, neglect, and discrimination. It also helps people with disabilities obtain services and treatment. All callers receive help with these problems. Individuals with problems targeted in VOPA goals and priorities may be provided with advocacy or legal assistance. Information on specific VOPA programs, goals, and objectives is located at its Web site or through a toll-free telephone number.

**Virginia Organization of Consumers Affecting Leadership (VOCAL)**: Initially formed to address mental health and mental illness concerns, VOCAL is increasingly involved in providing

services for individuals with multiple disabilities, including intellectual disabilities. The VOCAL Network is a statewide coalition of individuals with disabilities and their families united to provide a voice for individual empowerment and to foster a mental health system driven by individuals with disabilities themselves. The coalition partners in the VOCAL Network act as peer mentors and work with other advocacy organizations to protect individual rights and to fight discrimination, encourage the exchange of information, build the capacity of service systems, improve state mental health policies, and increase the well-being of individuals with mental illness, intellectual disabilities, or substance abuse problems.

**Virginia Poverty Law Center (VPLC):** This nonprofit organization advocates on behalf of low-income Virginians on poverty issues of statewide importance. Serving local legal aid staff members, private attorneys, and people with low incomes, VPLC supplies technical assistance, training, and publications that exclusively address the legal rights of Virginia's poor. It also sponsors an annual legal aid conference and provides assistance with legislative and administrative proposals affecting low-income Virginians. VPLC areas of interest include: consumer, elder, and family rights; health care; housing; and public benefits.

## **E. Cost and Payment for Advocacy and Information Resources**

Many advocacy services are free to the individual seeking assistance; and most organizations provide their resource information on their Web site and/or make them available free of charge. As indicated by examples in the previous section, however, some private agencies and organizations may charge fees for advocacy services. Such fees are sometimes on a sliding scale based on ability to pay.

Collection and analysis of more specific information about costs and budgets for the many advocacy services included in this chapter are beyond the scope of this report. For additional cost and payment information, readers should contact individual service providers.

## **F. Monitoring and Evaluation of Advocacy and Information Resources**

Collection and analysis of detailed quality-assurance information on the advocacy organizations identified in this chapter are also beyond the Board's current resources. Some general information about monitoring and evaluation of these resources, however, can be provided.

State agency-operated or -funded programs generally have more formal procedures for measuring quality of services. For example, the Virginia Office for Protection and Advocacy (VOVA) is required by federal regulations to submit an annual performance report on each of its advocacy programs. The federal agencies that provide funding for VOVA may also conduct on-site visits to monitor program activities and, if deficiencies are found, require corrective actions.

Nonprofit organizations, such as The Arc, usually have a Board of Directors with oversight responsibility for monitoring and ensuring program effectiveness. Financial audits are

required for all 501(c)(3) tax-exempt organizations. Unless an organization receives state or federal funding, however, it may not be required to have a formal quality-assurance mechanism.

While the Virginia Board for People with Disabilities is not responsible for evaluating advocacy programs, it does have an overall responsibility, through both federal and state statutes, to conduct assessments of the service system for people with disabilities. Acquisition of relevant, up-to-date evaluation of outcomes, policies, practices, and programs is essential to the goals of informing public policy, effecting service delivery changes, and influencing funding decisions related to persons with developmental disabilities. This is particularly true in Virginia, where there is no single agency with the specific responsibility to provide oversight of policies or services to those individuals with developmental disabilities who do **not** have a co-occurring diagnosis of intellectual disability (mental retardation). The Board continues its efforts to strengthen its capacity to assess the service system. As the Commonwealth's Developmental Disabilities (DD) Planning Council, the Board represents an independent voice and strives to serve as a knowledge and information resource on many issues affecting its constituents.

## **G. Areas of Concern for Advocacy and Information Resources**

This section provides information on advocacy resources and services available to persons with disabilities. While this list is not all-inclusive or exhaustive, it does focus on specific areas where further improvements may be needed to advance advocacy in the Commonwealth. The Virginia Board for People with Disabilities (VBPD) has identified the following concerns through a variety of mechanisms, including: (1) review and analysis of the numerous source documents listed at the end of this chapter, (2) public comment received via six public forums that VBPD held throughout the state in the spring of 2007, and (3) written comments and information provided and verified by state agencies in their reviews. VBPD has identified the following issues as essential to the improvement of both individual quality of life and the success of systems overall:

- 1. Challenges in Obtaining Information about Rights and Available Services:** Individuals and their families continue to report a lack of awareness and inadequate information regarding the programs and services that may be available to them. This extends throughout the lifespan and across agencies, programs, and services. Comments made at VBPD's 2007 public comment events, and through numerous constituent contacts by individuals with disabilities and their families, indicate that individuals with disabilities and their family members encounter significant difficulty in learning about their rights or services to which they are entitled, even when the provider has the legal responsibility to provide such information. These individuals report that they are unable to receive clear answers or receive multiple, sometimes conflicting, responses, often from the same entity. Comments also indicate that, too often, agency staff members (local and state) only know or share information about their own agency's services, and do not know about other disability resources. Families report that once their children leave secondary school, they have no access to a single information source on services and supports.

- 2. Lack of Disability-Friendly State Web Sites:** In response to a request by the Office of the Governor, VBPD specifically queried participants at its 2007 public comment events about their experiences with state agency Web sites as well as their perceptions of site usefulness and accessibility. Agency Web sites were described as being very challenging to navigate, sometimes lacking accessible formats. Frequent complaints were that the information most important to them—available services, eligibility criteria, and application process—was very difficult to find and that the language used was too bureaucratic or technical. Two central concerns voiced by participants were: (a) the quality and usefulness of Web site information, and (b) the lack of access to computers for many persons with disabilities (a “digital divide”). One comment summarized the first concern: “I don’t care about the mission statement or what the Commissioner thinks. What does your agency do? How do I figure out whether I am eligible? Use simple language.” The second concern related to income level and age differences. Another common complaint was the absence of contact information to a person who could help answer questions. In addition, comments indicated that, too often, Web site information is not kept current. One region-specific problem was noted: that downloading information was difficult in rural areas where only the slower, dial-up connections were available, rather than faster broadband connections. In conducting research for this *Assessment*, VBPD itself found that some state agency Web sites had out-of-date, undated, or undocumented information. VBPD also found that the reliability of search functions was extremely variable; it was often difficult to locate specific reports on agency Web sites, even knowing the title and date of the report. It should be noted that the Department of Mental Health, Mental Retardation and Substance Abuse Services recently updated and improved its Web site. The Disability Service agencies under the leadership of the Department of Rehabilitative Services (DRS) have also made improvements, but all state agencies need to do more work in this area.
- 3. Need for Increased Disability Advocacy and Awareness Training:** Individuals with disabilities, family members, and advocates note the need for increased training opportunities for themselves, for professionals, and for providers. Problems of basic accessibility and reasonable accommodation continue to exist in nondisability-friendly arenas such as Board of Supervisor meetings, Parent Teacher Association (PTA) meetings, and public forums held by state and local agencies. This is often attributed to lack of knowledge regarding the needs or resources available, not to a lack of desire to provide accommodations. Participants at Virginia Board for People with Disabilities (VBPD) public comment events statewide described encountering barriers on a daily basis that reflect the absence of consideration of persons with disabilities: For example, school personnel continue to have lowered expectations for students with disabilities; use accessible restrooms for storing supplies, thereby infringing on the space needed for wheelchair access; pile snow into accessible parking spaces, thereby blocking access; or fail to provide interpreters for deaf or hard-of-hearing hospital patients, leaving them without vital communications support in emergencies.
- 4. Inadequate Individual Advocacy Resources:** Although the Virginia Office for Protection and Advocacy (VOPA) has the most significant funding for rights protection in the

Commonwealth, this agency's services are limited by distinct program eligibility criteria, federal funding restrictions, and the requirement to establish annual program priorities. These factors limit the number of persons served and the issues addressed. Most public or private nonprofit organizations, even those focused on advocacy, do not have the staff or funding resources sufficient to provide individual-based advocacy. This situation has not changed since the 2006 *Biennial Assessment*, and is unlikely to change unless substantial new federal or state resources devoted to advocacy are made available. The need for advocacy assistance was poignantly voiced by participants during VBPD's 2007 public comment forums. Individuals reported being "ground down" by the system, feeling like they are in a "war zone," and being "exhausted" by efforts to obtain services to the point of not having energy left for advocacy.

- 5. Lack of Reliable Data on Long-Term Systems Needs:** As noted earlier, public comment received by the Board emphasized the importance of advocacy to policymakers and decision-makers that accurately projects actual service needs, both current and long-range. Advocates expressed particular frustration with the lack of reliable data on the number of persons with disabilities and their families. Such data is essential to the accurate projection of needs for the next five to ten years.

The Virginia Board for People with Disabilities (VBPD) shares these concerns. While data regarding the needs of persons with disabilities, programs available to them, numbers of persons served, and outcomes are gathered by numerous agencies, data collection processes are extremely varied by agency. Further, because of legal requirements, data often cannot be shared among agencies, other than in an aggregate manner. The lack of uniformity in data collection, analysis, and reporting—not only among agencies, but sometimes within the same agency from one year to another—makes it difficult to plan and assess needs accurately. VBPD recognizes that data collection is made more complex by varying and ever-changing requirements at the federal, state, and local levels. The result, however, is that information regarding the needs of individuals with disabilities is often inconsistently maintained and data on waiting lists (for Home and Community Based Waivers and all other programs and services) are fluid and do not necessarily accurately portray either short- or long-term needs. All of these factors make it difficult for the General Assembly and the Governor to make informed decisions about long-term services, supports, and appropriate resource allocation.

- 6. Need for Increased Use of Person First Language:** Statutes, regulations, policies and practices in Virginia use antiquated and sometimes offensive language, albeit not by intent. The Commonwealth should be a leader in using language that is respectful of persons with disabilities and conveys that they are a "person first." One noteworthy model of language change in state regulations are the revised *Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers of Mental Health, Mental Retardation and Substance Abuse Services*, 12VAC35-115-10 et seq., issued in the fall of 2007. The Department of Mental Health, Mental Retardation and Substance Abuse Services is to be commended for its adoption of person-first and person-centered language throughout this regulation. Other recent positive developments are reflected in numerous bills in the 2008

General Assembly, including the proposal that the term “mental retardation” be changed to “intellectual disability.” This language reflects a national trend to focus on the individual rather than the person’s disability category or diagnosis.

## **H. Board Recommendations for Advocacy and Information Resources**

Individuals with disabilities and their families need access to accurate and up-to-date information and in order to make decisions about health care, education, employment, and other areas of daily life. Many advocacy resources exist and technology has vastly improved access to information. More challenging than information access, however, is the availability of individual advocacy resources, legal representation when needed, and training on rights and responsibilities. The Virginia Board for People with Disabilities (VBPD) offers the following broad recommendations with respect to improving these opportunities around the Commonwealth.

- 1. Provide Continued Education and Training to Individuals with Disabilities and Their Families:** VBPD recommends continued and ongoing investment by agencies and organizations tasked with providing advocacy and information resources to individuals with disabilities and their families. This is a never-ending need as laws, regulations, policies, and practices change. Access to information and training is important for individuals residing in the community, but it is also important that individuals with disabilities residing in institutions, their families, and surrogate decision-makers be educated about rights and choices about community living options, as such individuals who may be the least likely to be informed about community programs and services available to meet their needs. Agencies and organizations must carry out their responsibility, legal and moral, to inform individuals with disabilities, family members, and advocates, of their rights in an ongoing, accessible, user-friendly manner. Specific, creative, and proactive strategies must be developed and undertaken to ensure that consistent, reliable, and accurate information is provided on legal and civil rights, best practices, and community opportunities.
- 2. Increase Involvement of the Disability Community in Planning and Assessment of Services:** With the establishment of a senior advisor position in the Governor’s office and the establishment and work of the Office of Community Integration, also in the Governor’s office, much progress has been made with respect to involving the disability community in planning and service development. Likewise, agencies such as the Department of Mental Health, Mental Retardation and Substance Abuse; the Department of Medical Assistance Services; and the Department of Education—all of which are involved in various system transformation efforts—have demonstrated a strong commitment to involving individuals with disabilities and their families in planning work groups and task forces. This type of involvement, however, is generally limited to agencies that are directly responsible for disability services and/or programs. The work of numerous other state and local agencies also directly affects individuals with disabilities and their families. VBPD recommends that all state and local agencies facilitate meaningful participation in program and service planning by all those who are affected by them. These individuals need to be involved from

the very onset of service system planning to ensure that their voices are heard and their needs are met. Each agency should conduct (or continue to conduct) periodic, routine assessments of citizen satisfaction—including input from individuals with disabilities and family members—with respect to their involvement in planning, implementing, and receiving services.

3. **Improve Reliable Data Collection and Assessment:** VBPD recommends that, from a disability service standpoint, agency partners strive to identify accurately how many need a given service, await services, are receiving some but not all the services they need, and other important planning factors. We realize that this would be a large and difficult undertaking and recommend that, as a first step, data collection practices in other states be reviewed to determine what state, if any, may have successfully addressed this challenge. Virginia has recently been awarded a grant to implement a “State Profile Tool” that will ensure that long-term care activities can be monitored and that the Commonwealth can assess its progress toward improving community supports. The tool is anticipated to be developed by April 2009. This grant, in concert with the Systems Transformation and Money Follows the Person Demonstration, will substantially improve the service delivery system for seniors and individuals with disabilities.
4. **Promote Common Ground:** While Virginia’s public and private disability advocacy organizations cannot be expected to agree on all issues, it is essential that advocates come together when they can to identify common concerns and pool their individually limited resources to advocate for systems change. VBPD has worked to enhance its partnerships with other agencies and organizations and recommends continued expansion of coalition-building to identify and address areas of common concern.
5. **Improve Accessibility of State Agency Web sites:** VBPD recommends continued work on improving the accessibility of state agency Web sites. The efforts initiated through the Governor’s office are an excellent start, but more work is needed to develop user-friendly Web sites. In addition to the Web sites themselves, the content should be provided in multiple formats, to allow individuals with disabilities access to information utilizing special software. VBPD further recommends that state agencies ensure that print materials posted on Web sites are available in alternate formats.
6. **Need for Additional Advocacy Resources and Increased Commitment to Advocacy:** Individuals with disabilities need advocacy services, which are often either costly or difficult to access. Many programs (such as the Virginia Office for Protection and Advocacy) have very strict eligibility requirements; others have limited funding and staffing (such as Centers for Independent Living). VBPD recommends that local and state agency staff members, including case managers, consider individual advocacy to be an integral part of their job. Often heavy workloads and conflicting priorities affect the willingness and ability of agency staff members to advocate. Yet these services are important to ensuring that the voices of individuals with disabilities are heard and respected throughout the service delivery process.

## Advocacy and Information Resources Referenced in This Chapter

### Web Sites:

Action Alliance for Virginia's Children and Youth: [www.vakids.org](http://www.vakids.org)

American Civil Liberties Union of Virginia: <http://www.acluva.org/>

Area Agencies on Aging Long-Term Care Ombudsman Program:  
<http://www.vda.virginia.gov/ombudsman.asp>

Arc of Virginia, The: <http://www.arcofva.org/>  
Infant and Toddler Connection Family Involvement Project: [www.arcfip.org](http://www.arcfip.org)

Brain Injury Association of Virginia (BIAV): [www.biav.net/](http://www.biav.net/)

Care Connection for Children: [www.careconnections.vcu.edu/](http://www.careconnections.vcu.edu/)

Center for Special Education Advocacy: <http://www.spedadvocacy.org/>

Centers for Independent Living (CILS): [www.vadrs.org/CBS/CILs.htm](http://www.vadrs.org/CBS/CILs.htm)

Cerebral Palsy of Virginia: [www.cerebralpalsyofvirginia.org](http://www.cerebralpalsyofvirginia.org)

Coalition for Virginians with Mental Disabilities:  
[www.poac-nova.org/newsmanager/news\\_article.cgi?news\\_id=1031](http://www.poac-nova.org/newsmanager/news_article.cgi?news_id=1031)

Commonwealth Autism Services (CAS): [www.autismva.org/](http://www.autismva.org/)

Human Rights Council of Virginia: [www.chr.state.va.us](http://www.chr.state.va.us)

Infant and Toddler Connection of Virginia: [www.earlyintervention-va.com/](http://www.earlyintervention-va.com/)

Legal Aid Justice Center: [www.justice4all.org/](http://www.justice4all.org/)

Medical Home Plus: [www.medicalhomeinfo.org/states/state/virginia.html](http://www.medicalhomeinfo.org/states/state/virginia.html)

Mental Health Association of Virginia (MHAV): [www.mhav.org/](http://www.mhav.org/)

National Alliance for the Mentally Ill (NAMI) of Virginia: [www.namivirginia.org](http://www.namivirginia.org)

Office of Human Rights, Virginia Department of Mental Health, Mental Retardation and  
Substance Abuse Services: [www.dmhmrzas.virginia.gov/OHR-default.htm](http://www.dmhmrzas.virginia.gov/OHR-default.htm)

Parents and Associates of the Institutionalized Retarded (PAIR): National organization is Voice  
of the Retarded (VOR): [www.vor.net](http://www.vor.net)

Parent Educational Advocacy Training Center (PEATC): [www.peatc.org](http://www.peatc.org)

Parent to Parent of Virginia: [www.ptpofva.com](http://www.ptpofva.com)

Partnership for People with Disabilities: [www.vcu.edu/partnership](http://www.vcu.edu/partnership)

VA-INFO Center: [www.medhomeplus.org/vainfo.html](http://www.medhomeplus.org/vainfo.html)

Virginia Assistive Technology System (VATS): [www.vats.org](http://www.vats.org)

Virginia Association of Community Services Boards (VACSB): [www.vacsb.org](http://www.vacsb.org)

Virginia Autism Resource Center (VARC): [www.varc.org](http://www.varc.org)

Virginia Board for People with Disabilities (VBPD): [www.vaboard.org](http://www.vaboard.org)

Virginia Office of Licensure and Certification, Long Term Care Division:  
<http://www.vdh.virginia.gov/OLC/LongTermCare/survey.htm>

Virginia Coalition for Students with Disabilities: [www.spedadvocacy.org](http://www.spedadvocacy.org)

Virginia Department of Education, Division of Special Education and Administrative Services:  
Parent Ombudsman: <http://www.doe.virginia.gov/VDOE/sess/>

Virginia Fair Housing Office: [www.dpor.virginia.gov/dporweb/fho\\_index.cfm](http://www.dpor.virginia.gov/dporweb/fho_index.cfm)

Virginia Legal Aid Society (VLAS): [www.vlas.org/](http://www.vlas.org/)

Virginia Office for Protection and Advocacy (VOPA): [www.vopa.state.va.us](http://www.vopa.state.va.us)  
Programs: [www.vopa.state.va.us/Programs%20and%20Goals/Programs.htm](http://www.vopa.state.va.us/Programs%20and%20Goals/Programs.htm)

Virginia Organization of Consumers Affecting Leadership (VOCAL):  
[www.vocalsupportcenter.org/](http://www.vocalsupportcenter.org/)

Virginia Poverty Law Center (VPLC): <http://www.vplc.org/>

### **Documents:**

Code of Virginia. *Virginians with Disabilities Act (VDA)*. Sections 51.5-1 et seq. Retrieved from: <http://leg1.state.va.us/cgi-bin/legp504.exe?000+cod+51.5-1>.

Virginia Department of Medical Assistance Services. (No date) *Commonwealth of Virginia Roadmap to Services: A Resource Guide for People with Disabilities, Long-Term Illnesses, and the Elderly*. Retrieved from:  
[www.dmas.virginia.gov/downloads/pdfs/Road\\_Map\\_to\\_Va\\_services.pdf](http://www.dmas.virginia.gov/downloads/pdfs/Road_Map_to_Va_services.pdf).