Preface

Background

The Virginia Board for People with Disabilities, the Commonwealth's Developmental Disabilities (DD) Council, is pleased to publish the *2014 Assessment of Disability Services in Virginia*. This report was produced in accordance with the Code of Virginia § 51.5-33 [2] and the federal Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402, 2000). This is the fourth edition of the Board's *Assessment*. Previous editions were published in 2006, 2008, and 2011. To improve trend analysis, the 2008 General Assembly lengthened the interval between assessments from two to three years.

This Assessment is unique in that it offers a broad, comprehensive examination of how state-funded disability services are accessed, provided, evaluated, and funded. Through this document, the Board hopes to promote new policy discussions on the design and delivery of disability services from a systemic perspective and offers recommendations to resolve some of the major issues found. Now is the time for the Commonwealth to examine and evaluate how well current disability services are delivered and working to create a system with more effective, flexible, efficient, responsive, and cost-effective ways of delivering services.

Scope of the 2014 Assessment

This report examines and provides a factual description of the status of services at a pointin-time. Agency data are primarily based on annual counts at the end of several state fiscal years, ending in SFY 2013 (June 30). Information on agency policies, initiatives, and services as well as changes (positive and negative) occurring since the 2011 edition of the Board's *Assessment* are included, in most cases through January of 2014, although in several areas, significant information made available more recently also has been incorporated.

This Assessment does not, and cannot, address all of the services and programs available to persons with disabilities in the Commonwealth. Pursuant to the Board's federal requirements, authority, and funding, the Assessment focuses on services provided to Virginians with developmental disabilities (DD). Developmental disabilities are those that are (1) manifested before the age of 22, (2) result in substantial limitations in at least three key life areas, and (3) are likely to require services and supports across the lifespan. It is important to note, however, that many described services and the associated findings and recommendations are applicable to individuals with all types of disabilities. Examples include the discussion of areas such as housing, employment, and transportation.

The *Assessment* does not specifically cover the services and supports provided to individuals who have a serious mental illness or substance abuse disorder, with the exception of crisis intervention services for individuals with co-occurring disabilities. The report also does not specifically address services for individuals with disabilities who are in juvenile or adult

correctional settings, children with disabilities who are in foster care, and military personnel and veterans with disabilities who receive, for the most part, federally funded services.

The Board recognizes that other gaps in the scope may be identified. Despite its best efforts, there may be undetected errors or important issues that have not been fully addressed. Readers are encouraged to bring those oversights to the Board's attention, and efforts will be made to correct them in future editions.

Development Process

To create this *Assessment*, the Board sought public comment both on changes to and experiences with services since 2011 and also on ways the service system could and should be improved. To maximize feedback, a longer public comment period (March 1, 2013 through August 31, 2013) was held for this edition than was held for the 2010 edition. The Board also regularly solicited public comments through its newsletter, website, e-mail solicitations, and other means during that period. Based on experiences with and feedback from public comment efforts for previous editions, staff recognized that new approaches were needed.

Since January of 2011, transportation costs and time demands on individuals and families have increased, and substantial growth in new communication technologies has occurred. In 2013, the Board held two on-site forums: one in northern Virginia (Franconia), which had two sessions, and one at the annual Arc of Virginia state conference. For the first time, the Board obtained comments through three videoconferences held in collaboration with area Centers for Independent Living (CILs): far Southwest Virginia; Southern Valley area (Roanoke, Christiansburg); and Northwest Valley area (Harrisonburg, Winchester). Additionally, the Board solicited feedback by setting up information booths at several statewide conferences (including the annual Transition Forum and the Arc of Virginia State Convention). All public comments were compiled and analyzed by the Board and helped shape the *Assessment*.

Descriptive information in the *Assessment* was gathered from a wide variety of state resources: agency planning and performance reports, interagency task force and workgroup reports, legislative studies and presentations, state agency websites, direct communications with agency staff, and other available sources. As indicated, data and information were obtained from federal websites and documents as well as policy reports from various national, non-partisan research organizations. A draft of each chapter or relevant chapter sections were forwarded to each state agency for review not only to verify the accuracy of the information and data presented, but also to obtain clarification on factors affecting identified trends.

An ad hoc committee of Board members worked with staff to review and consider all public comment as well as the data and information from chapter drafts. After thorough consideration, the committee identified key findings and developed recommendations for system improvements. These were approved by the full Board at its June 2014 meeting. The Board's findings and recommendations are consistent with the values and tenets of the 2000 Developmental Disabilities Assistance and Bill of Rights Act. Board recommendations are based on the overarching goal of developing disability services statewide that create a coordinated, consumer- and family-centered and directed comprehensive system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise selfdetermination, be independent, be productive, and be integrated and included in all facets of community life.

In developing the 2014 Assessment, the Board relied on information provided either directly by a state agency or indirectly through agency websites and published documents or reports. Over the past three years, the Health and Human Resources (HHR) Secretariat has made agency data improvement a priority. While several agencies made significant strides in tracking meaningful data, some have made little progress since 2010. In general, the primary data collected consistently across state agencies for its programs or services were expenditures and the "number served" (which sometimes is quite broadly defined). In a few instances, program/service data were not available.

The task of ensuring data quality and reliability is challenging but essential. Limited fiscal resources and manpower hinder smaller disability agencies. Obtaining data from larger agencies typically involved multiple staff across various divisions or programs within them. Data submitted to the State by local systems is often inconsistent between jurisdictions in both the manner it is reported and the content. Examination of longitudinal trends over time often was limited by changes in data definitions and collection methodologies. While some changes were due to revised reporting requirements by federal funding sources, sometimes the state agency itself had made the changes. In addition, some state agency websites were significantly out of date.

Throughout the development of the *Assessment*, Board staff consulted, as indicated, with designated agency staff for clarification of information and data. In addition, the Board provided all participating state agencies a draft copy of each *Assessment* chapter that addressed their programs and services for review of content for accuracy.

Organization and Content Changes

There are several significant format and content changes in this edition. A key change is the separation of the *Assessment* into two volumes. *Volume 1* includes the Board's *Key Findings and Recommendations*. *Volume 2* contains the detailed information and data on the specific services and supports reviewed that, in addition to public comment, form the basis for the findings and recommendations. These are designed to be companion documents. Due to the length of *Volume 2* and the Board's limited resources, access to that document will be primarily online in accessible electronic and audio versions. A limited number of hard copies will be made available.

The Assessment's chapters are organized by the core categories of services/supports needed by Virginians with developmental and related disabilities across the lifespan: Early Intervention, Education, Employment, Health Care, Medicaid, Community Living Supports, Institutional Supports, Community Housing, and Transportation. References are included at the 2014 Assessment of Disability Services in Virginia, Volume 2 Virginia Board for People with Disabilities

end of each chapter. Information on statewide advocacy groups is provided in Appendix A, and information on preparing for emergencies is contained in Appendix B. Appendix C contains a list of acronyms. Each chapter's introduction provides a summary of key changes made since January of 2011 in regulations, funding, and service design as well as a summary of external forces (the economy, federal government initiatives, etc.). This edition's individual chapters are organized by program or service areas to improve readability and provide a user-friendlier format. When applicable, graphics are used to help depict changes over multiple years. Due to the complexity and length of the *Assessment*, readers are referred to state websites or local agencies for additional information or description throughout the document.

Acknowledgements

The Board expresses its deep appreciation to all those who contributed to the development of its 2014 Assessment, which was possible only with the information and cooperation provided by a host of individuals from both inside and outside of state government. The Board is especially grateful to the numerous state agency officials and staff who responded to requests for information, data, and content reviews. Their assistance in clarifying or describing data or information and in ensuring content accuracy was invaluable. The guidance of individuals with disabilities, advocates, and others who provided public comments—whether in person or by mail, videoconference, or phone—is greatly appreciated.