

Virginia's Individual and Family Support Program
State Plan for Increasing Support for Virginians with Developmental Disabilities

Prepared by the Virginia Department of Behavioral Health and Developmental Services
in partnership with
The Individual and Family Support Program State and Regional Councils

Version Date: November 17, 2017

Executive Summary

In March 2013, the Department of Behavioral Health and Developmental Services (DBHDS) launched the Individual and Family Support Program (IFSP) to assist those on the state HCSB DD waiver waitlist. The IFSP's target population includes both individuals who have a development disability and their families. The goal is to connect them to community resources, supports, and services.

IFSP consists of two major components a funding program which provides direct assistance to families and individuals who are on the waitlist, and activities around community and state coordination with the purpose of obtaining additional family supports.

DBHDS, in partnership with the IFSP State and Regional Councils, has developed the following strategic plan to establish the Commonwealth's priorities for addressing the needs of individuals with developmental disabilities who are awaiting waiver services.

The plan focuses on four goals:

- 1) Ensuring that the Individual and Family Support Program (IFSP) funding serves individuals with Developmental Disabilities and their families by braiding and blending resources to focus on the needs of the whole person with emphasis on prioritizing those with the greatest needs and most at risk of institutionalization,
- 2) Creating a robust and holistic state-level family support program model that furthers the goal of continued residence of an individual with developmental disabilities in his/her own home or the family home,
- 3) Enhancing the knowledge of families, individuals with DD and community agencies about the Individual and Family Support Program through effective, coordinated, and comprehensive outreach, and
- 4) Administering a transparent and effective Family and Individual Support Program that seeks to incorporate the input of individuals with disabilities and families to ensure access to supports to all Virginians regardless of their waitlist status.

The plan will set the vision for the Department's efforts for the next 3-4 years, and it will provide the framework for the forthcoming annual work plan and community activities.

The purpose of Virginia's plan is to act as a catalyst for both state and local action for implementing a system of comprehensive and coordinated strategies that ensure that families who are assisting a family member with an intellectual or developmental disabilities ("ID/DD") or individuals with ID/DD who live independently have access to person-centered and family-centered resources, supports, services and other assistance.

Background

According to the National Association of State Directors of Developmental Disability Services' *National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities*,

"Today, there are more than 4.7 million American citizens with an intellectual or developmental disability. Most, 75%, of these individuals live in their communities without any formal disability services. They rely on their families for varying levels of support to have the lives they want to have. Of the 25% that are receiving services, over half live with their families, and in some states, that number is as high as 80%."

In Virginia, approximately, 12,000 individuals receive Developmental Disability waiver services, and there are currently over 11,000 people on the waitlist to receive Home and Community Based Medicaid Waiver Services.

Program Background

In March 2013, the Department of Behavioral Health and Developmental Services (DBHDS) launched the Individual and Family Support Program (IFSP) to assist individuals in the Commonwealth of Virginia who are on the waitlist for the waivers that were previously known as the Intellectual Disability (ID) Waiver, Day Support Waiver, or the Developmental Disability (DD) Waiver. The program was developed to support section III.C.2 of the Department of Justice (DOJ) Settlement Agreement. Since 2013, the IFSP program has operated primarily as a financial assistance program, serving over 8,942 individuals with over \$13,101,879 in direct financial assistance.

Evolution of the IFSP Council

While financial assistance is a critical program component, the Department has always had a long term goal of developing a robust program that provides more than financial supports.

In July 2015, in response to the many comments from community stakeholders, the Commonwealth and DBHDS determined it would be in the best interests of individuals with DD and their families to expand the Individual and Family Support Program. This resulted in the creation of the New Individual and Family Design Advisory Committee (NIDAC), which served as an advisory committee of families and self-advocates with a relative on one of the waiver waitlists. The mission of the committee was to develop a coordinated support model for individuals on the waiver wait lists.

From July 2015 to March 2016, the NIDAC met and reviewed the department's proposed vision which included recommendations for creating regional networks to carry out the expanded vision. During the 2016 General Assembly Session, DBHDS received authorization to hire staff to facilitate regional service coordination and to support the work of the proposed IFSP state and regional councils. This resulted in the department revising its initial approach of forming five regional councils. The revised plan would use one central council with support from five regional subcommittees. The central council became known as the Individual and Family Support Program State Council.

In the summer of 2016, DBHDS solicited applications for membership to the State Council and Regional Council. The department disseminated nomination forms to individuals on the waitlist, former NIDAC members, and to individuals who attended one of the previous DBHDS regional information sessions. An internal DBHDS review committee screened the applications and made recommendations to the Commissioner for appointment to either the state or one of the regional councils.¹ All applicants were appointed to either the State Council or to one of the Regional Councils.

The IFSP Council's target population includes individuals with a developmental disability who are on the waitlist for the Developmental Disability Waiver. The goal is to connect eligible individuals to community resources, supports, and services. The intended goal of the State Council was to provide guidance to the state that reflects the needs and desires of individuals and families across Virginia. The Regional Council was envisioned to liaison between the State Council meetings and local efforts to increase services to individuals on the waitlist.

State and Regional Council's Composition and Role

Members for both councils self-nominated, and DBHDS staff reviewed applications and recommended nominees for appointment by the Commissioner. Members were selected based on geographic representation and previous interest and/or commitment to supporting individuals with developmental disabilities. Almost all council members are care takers for a family member with a developmental disability.

The initial State Council included 15 members with at least two members from each of the five DBHDS service regions. Selected members agreed to serve one year terms and be responsible for:

- Defining a comprehensive set of strategies for a state plan,
- Establishing policies for implementing the strategies, and
- Monitoring the effectiveness of the strategies.

After developing the governance structure, DBHDS anticipates the State Council will formally advise it on the administration of the IFSP Funding Program and support the IFSP staff with the implementation of the state plan.

The Regional Council membership includes thirteen representatives from each of the five DBHDS regions with the goal of supporting families and individuals in local communities.

IFSP Advisory Committee

During the kick-off meeting of the IFSP State Council in October 2016, the State and Regional council members agreed to work as a merged group called the state IFSP Advisory Committee². The goal of the

¹ The Internal DBHDS Review Committee included Peggy Balak, Settlement Agreement Coordinator; Catherine Hancock, Early Intervention Program Manager; Tonya Carr, Family Resource Coordinator; Benita Holland, Community Resource Coordinator; and Cecily Rodriguez, Multicultural and Linguistic Coordinator.

² While the council has agreed to work as a merged group, in the future, the State Council will have final voting authority to proposed recommendations or changes.

combined committee was to establish the state IFSP Plan, ratify a relationship framework between DBHDS and the State Council, establish a governance structure for the councils, develop and approve strategies to implement the State Plan, and identify roles and responsibilities.

Establishment of the IFSP

As part of the requirements set in Virginia's Settlement Agreement with the U.S. Department of Justice the Commonwealth decided to establish an IFSP program to meet the needs of individuals and families on the waiver waitlists. The DBHDS, through Virginia Administrative Code, established the program's policies and administrative regulations. The sections below provide citations from the Settlement Agreement and the Administrative Code as authorized by the Virginia General Assembly that reference the IFSP.

The Settlement Agreement Authority Requirements for Establishing an IFSP Program

Section III.C.2 of Virginia's Settlement Agreement with the Department of Justice calls for the creation of an IFSP program.

“The Commonwealth shall create an individual and family support program for individuals with ID/DD whom the Commonwealth determines to be most at risk of institutionalization. “

Section II.D defines individual and family supports and provides the framework for assisting families. The section states:

“Individual and family supports are defined as a comprehensive and coordinated set of strategies that are designed to ensure that families who are assisting a family member with an intellectual or developmental disabilities (“ID/DD”) or individuals with ID/DD who live independently have access to person-centered and family-centered resources, supports, services and other assistance.”

Virginia State Administrative Code on the IFSP Program

The Virginia State Administrative Code, also known as the IFSP Program Regulations, details the expectations of how state allocated funds are to be administered via the IFSP Funding Program by defining the individual eligibility criteria and providing service definitions which govern the expenses the program can support.

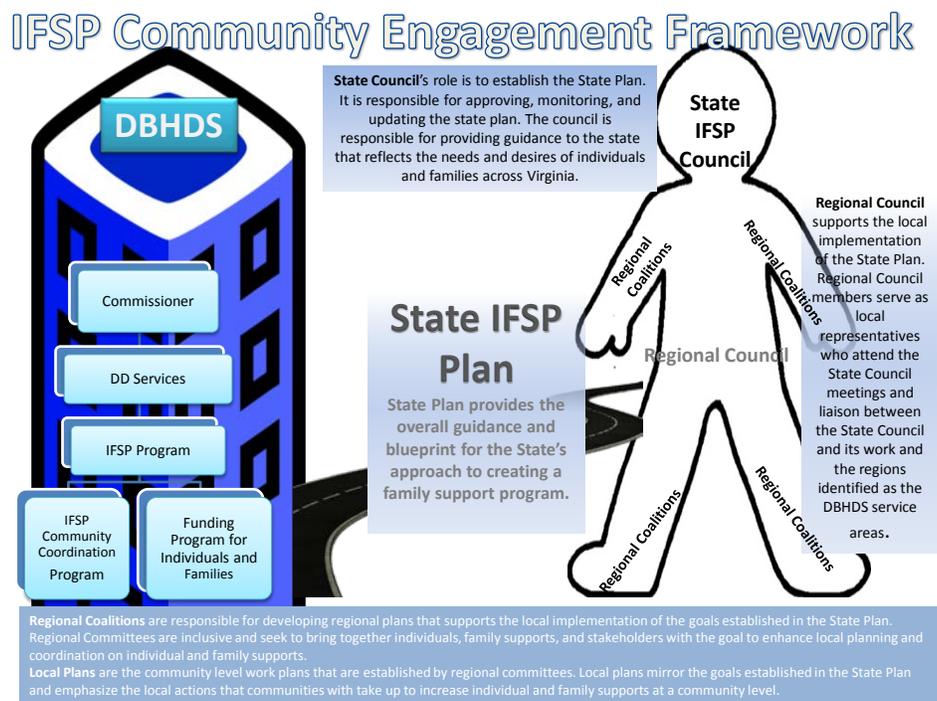
The IFSP Funding Program's purpose is to support the continued residence of an individual with intellectual or developmental disabilities in his own home or family home, which includes the home of the principal caregiver. The regulations state that applications must be submitted to DBHDS, and funds must be distributed directly to the requesting individual, a responsible party family member, or a third party designee. It also establishes the General Assembly as the entity for allocating funds. Funds cannot exceed the amount allocated, and the financial assistance program is operated based on the availability of funds. The regulations gives the Department the authority to set the maximum award amount and requires that awards must be made on a first come first served basis. Families and individuals are

allowed to submit multiple applications as long as the requests do not exceed the maximum award amount, and all requests must be substantiated with receipts after the funds are expended. The regulations require documentation that no other public funding sources are available to support the request.

While the existing regulations establish the funding program, DBHDS established the IFSP Community Coordination Program through its administrative authority to develop additional policies and procedures.

Relationship between the Council and DBHDS

The following graphic is an illustration of the relationship between DBHDS and the IFSP Council.



IFSP State Plan Background

During the November 2016 meeting, the State IFSP Advisory Committee approved the following areas to address in the forthcoming State Plan:

- Enhancements to the IFSP Funding Program
- Creating a robust family support program that increases the number of resources for families and individuals
- Prioritizing those most at-risk of institutionalization

- Outreach to families and individuals currently on the waitlist

Appendix A includes goals and objectives established by the IFSP State and Regional Councils from November 2016 to March 2017. The Plan is designed to be implemented over the course of four years from 2017 to 2021 and to provide a person-centered approach to implementing a holistic state family support program.

The plan, through the input of the State and Regional Councils, reflects DBHDS' commitment to seeking out and incorporating the input of individuals and families. DBHDS is focused on keeping individuals and families at the center of its efforts for enhancing and growing the IFSP Program. And, it will rely on the IFSP State and Regional Councils to give voice to the needs of individuals and families and better incorporate public input.

DRAFT: GOALS AND OBJECTIVES FOR IFSP STATE PLAN

4/17/2017

Goal One: Ensure that the Individual and Family Support Program (IFSP) funding serves individuals with Developmental Disabilities and their families by braiding and blending resources to focus on the needs of the whole person with emphasis on prioritizing those with the greatest needs and most at risk of institutionalization.

1. Enhance the IFSP Funding Program so that those with complex circumstances and with the greatest support needs are prioritized.
 - a. Develop a data-driven process for shifting away from first come/ first served to establishing priorities based on individual circumstances and/or the criticality of the request.
 - i. Analysis of waitlist individuals (including using data of individual critical needs score, VIDES and input from waiver redesign public comment sessions)
 - ii. Conducting analysis of previous IFSP funding data for trends- including identifying geographic coverage gaps
 - iii. Identify common needs that are not covered by IFSP Funds under current regulation and assess for possible inclusion as a covered cost item under funding program regulations
 - iv. Assist local communities with establishing strategies to obtain additional supports to address needs not covered by state IFSP Funds.
 - b. Administer an IFSP Funding Program that incorporates input from families and individuals and is responsive to their needs
 - i. Task the IFSP State Council with annually identifying priority populations/needs in order to establish the priorities for the annual IFSP funding process
 - ii. Review the existing IFSP regulations and policies to align with the Council's annual priorities, improve access and/or efficiencies for families while complying with state administrative guidelines
 - 1) Assess enacting retroactive reimbursement policy and assessing the feasibility and impact of multiple funding cycles
 - 2) Create contingencies to support emergency needs
 - a) Review models of emergency funding (i.e., % of total IFSP funds or a set amount of funds annually reserved for emergencies) and what happens if those funds are not used
 - b) Develop policies and materials explaining emergency funds
 - iii. Develop administrative policies and procedures that support the council's established priorities

Projected Outcomes:

- Summary of identified regulations that may impact access or ease of use

- Emergency funding pool
 - Revised regulations and program guidelines/processes/procedures
 - Summary document of trends in past covered needs and demographic characteristics of the recipients
 - Summary of waitlist individuals and analysis of their needs
2. Leverage IFSP funding application process to connect families with additional resources.
 - a. Create a plan for collecting additional data that can be requested during the IFSP Funding Application (e.g., asking about uses of other services like Crisis Services, EMS, Medical/Health)
 - b. Utilize the information from enhanced data collection to identify unmet supportive service needs and to identify possible IFSP program enhancements to address the needs

Projected Outcomes:

- Summary reports detailing commonly used services.
 - Revised application
3. Streamline the IFSP Funding Process to better rely on technology and efficiency
 - a. Map out IFSP Funding Process and include timelines, milestones, and outcomes including addressing the following
 - i. Partnerships to increase access and efficiencies
 - ii. Bankcard/ EFT
 - iii. On-line application
 - iv. Application receipt process and notifications
 - b. Integrate prioritization and outreach in the IFSP Funding process into the application technology enhancements
 - i. Identify supplemental application questions that collect additional information that may indicate need

Projected Outcomes:

- Application process map
 - Work plan to implement the efficiencies
4. Develop a formal feedback process for stakeholders to report satisfaction with the IFSP Funding Program and to recommend improvements and changes
 - a. Implement annual satisfaction surveys of individuals receiving funds
 - b. Conduct annual analysis that includes an analysis of the take-up of the IFSP Funding Program of those on the waitlist, to identify trends in who applies for the funds, annual rates of eligibility determinations, and trends in how funds are used
 - c. Create an annual public comment process for input on the IFSP Funding Program
 - d. Provide an annual accounting of IFSP funds including breakdowns of direct assistance

and administrative costs

Projected Outcomes:

- Annual Satisfaction survey
- Public comment sessions
- Annual funding summary
- Map of family support organizations

Goal Two: Create a robust and holistic state-level family support program model that furthers the goal of continued residence of an individual with developmental disabilities in his/her own home or the family home.

1. Increase the availability of resources at the state and local level to address the needs of those in the target population.³
 - a. Create a uniform assessment process for individuals and families to identify families in the following categories:
 - i. those with knowledge of resources and who are well connected
 - ii. those who do not know of resources and are not connected but need a robust array of service/resource options
 - iii. those who know of resources but are not interested or are stable at this time.
 - b. Collect information from DBHDS or 40 CSBs/BHAs on locally funded family support programs operated by their agency to better understand what formal community sponsored supports already exist.
 - c. Catalog a list of organizations in Virginia who provide comprehensive supports to families and individuals with DD (i.e., information, referral, training, peer support, parent support, concrete services, cash subsidies)

Projected Outcomes:

- Uniform community assessment of resources
 - Summary document with information on locally sponsored supports and support organizations
2. Explore building an interactive web-based portal for families and individuals with information on existing local/regional/state organizations/agency resources
 - a. Draft a plan for the web platform that:
 - i. supports ensuring equal access to information
 - ii. supports establishing quality standards for information
 - iii. ensures uniform information for communities regardless of location
 - iv. plans for multiple platforms for sharing information including web, phone, and in-person
 - v. appropriately interfaces with the existing My Life/ My Community webpage

Projected Outcome:

- Family focused web design
3. Create an IFSP Community Coordination Program that has the ability to
 - a. Provide oversight of regional plans and efforts to implement the State IFSP Plan in the

³ Note: The IFSP target population includes individuals on the DD Waiver Waitlist.

five DBHDS regions

- b. Create content for standard materials, protocols, and processes that can be used in communities across the state

Projected Outcomes:

- Regional Council Charters
 - Marketing Materials
4. Work to obtain additional financial, in-kind, and relational supports to address varying needs.
 - a. Identifying areas where there are no resources available to fill the need and develop a plan to build capacity to address need gaps

Projected Outcome:

- Strategy document that identifies gaps and describes potential resources for obtaining additional financial or in-kind supports

Goal Three: Families, individuals with DD and community agencies are knowledgeable about the Individual and Family Support Program through effective, coordinated, and comprehensive outreach

1. Create a comprehensive communication plan that establishes communication priorities and strategies to address the needs of communities and organizations.
 - a. Develop a comprehensive list of entities that should be outreached
 - b. Draft a strategy for sharing general information with partners and stakeholders (including outreach at local and state fairs and conferences)
 - c. Create partnerships with schools to provide explanatory marketing materials that can be distributed to families at IEP meeting
 - d. Develop educational materials that build on existing marketing material (including creating materials when they do not exist and the use of traditional media and social media) that targets institutions and communities

2. Create a comprehensive communication plan that establishes communication priorities and strategies to address the needs of individuals and families
 - a. Draft a strategy for sharing information with families based on their connectedness to resources. Including aligning notifications of IFSP funds with communications to families upon waiver waitlist entry
 - b. Review and assess the idea of a single point of information and referral clearinghouse using the “No Wrong Door” model and develop a blueprint for implementing the model
 - c. Develop community ambassadors that can serve as peer support providers for families and individuals who are not connected to services and/or resources
 - d. Develop educational materials for families with an emphasis on 1) incorporating existing partners’ marketing material, 2) creating new materials for families if other resources do not exist, and 3) that incorporates social media strategies to engage families.
 - e. Coordinate communication updates with My Life/ Community Web Pages for regular updates

Projected Outcomes:

- Marketing and communication plan for families and institutions/communities/organizations, educational materials
- Single point of information
- Community ambassador training model
- Educational materials for families
- Educational materials for institutions/communities/organizations

Need Goal Four: Administer a transparent and effective Family and Individual Support Program that seeks to incorporate the input of individuals with disabilities and families to ensure access to supports to all Virginians regardless of their waitlist status.⁴

1. Establish an IFSP State Council that advises DBHDS on the priorities and operation for Virginia's Individual and Family Support Program
 - a) Establish a State IFSP Council that is inclusive and emphasizes individual and family leadership
 - b) Recruit, identify, and select members from across the state with emphasis on diversity of experiences- including those who are self-advocates, family caregivers, community stakeholders, and support providers
 - c) Develop a governance structure for the State Council that details the expectations and authority of the council
 - d) Establish, approve, and regularly update and review Virginia's Plan for Individual and Family Support for success towards meeting the identified goals and objectives.

2. Foster regional coordination to increase the number and type of supports to families and individuals.
 - a) Establish a Regional Council that liaisons between the IFSP State Council; to regional increase supports for individuals and families
 - b) Recruit, identify, and select members from across the five DBHDS designated regions to participate as Regional Council members
 - c) Develop a governance structure for the IFSP Regional Council that details the expectations of regional council members and their responsibilities to support local coalition development
 - d) Identify smaller regional subdivisions for planning and coordination activities
 - e) Develop regional coalitions that are responsible for creating local plans that increase the number supports available to families and individuals

3. Operate Virginia's Individual and Family Support Program activities in order to maximize community input, demonstrate transparency, increase access and encourage accountability.
 - a) Support the implementation of Virginia's State Plan for Individual and Family Support Program
 - b) Regularly seek input from stakeholders on DBHDS's administration of the IFSP Program and all of its components including the funding program and the planning and coordination activities
 - c) Establish annual work plans and benchmarks for DBHDS activities and programs
 - d) Regularly evaluate DBHDS IFSP program activities and provide information to the public

⁴ Note: IFSP Funding is only available to individuals on the waitlist. Supports for individuals receiving waiver services are limited to technical supports.

on outcomes

- e) Develop policies and procedures that support program operations and regularly review them to identify areas for improvements

Projected Outcomes:

- Virginia State Plan for Individual Family Support
- DBHDS Annual IFSP Work Plan
- State council governance document
- Regional council governance document
- Regional coalition governance documents
- Annual outcome reports and evaluation document