PROJECT SUSTAINABILITY

28 MARCH 2019

PROJECT SUSTAINABILITY COMMISSION - WAY FORWARD

The Project Sustainability Commission will establish recommendations that will directly influence the "Vision" for the service system in Rhode Island and aim to achieve top National ranking among State operated Developmental Disability Systems.

RESPONSES

- Rebecca Boss
- Kerri Zanchi
- Heather Mincey
- Tina Spears
- Mary Madden
- Andrew McQuaide
- Regina Hayes
- Gloria Quinn

- Kelly Donovan
- Tony Antosh
- Kathleen Sherlock
- Chris Semonelli
- Kevin Nerney
- Tom Kane
- Peter Quattromani

REBECCA BOSS BHDDH

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... designed and implemented in such a way as to support their unique needs, desires and goals. Services will provide opportunities for community inclusion and integration to the degree desired by the individual.

- Goal #1: Service plans are developed with the person to address their unique needs and goals, by an entity that is conflict free and incorporates roles of natural allies and supports as well as provider organizations.
- Goal #2: Funding for the service delivery system is provided in a manner that promotes sustainability, transparency, consistency and flexibility.
- Goal #3: The quality of the service delivery system is evaluated systematically and results of evaluations are used to guide improvement recommendations, develop targeted technical assistance and training.

- Recommendation #1: Development and implementation of Health Homes as an independent entity for plan development and care coordination.
- Recommendation #2: Completion of rate review process, to include exploration of alternative payment methodologies. Continue efforts to rebalance system away from overreliance on congregate care to more community based investments. Commit to ongoing stakeholder engagement and improved communication.
- Recommendation #3: Create standardized process for quality improvement which includes analysis of data from various sources to evaluate service processes, outcome and performance. Conduct reviews of compliance with regulations and certification standards. Create process to use evaluations to guide technical assistance and training development.

KERRIZANCHI BHDDH

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... one that celebrates individual strengths and values self-determination for individuals to live the life they choose as part of their community.

- Goal #1: Person-centered system of services and supports that is responsive to individual needs and ensures that services and supports are provided at the right time, in the right place, in the right amount and in a manner consistent with the person's preferences and abilities.
- Goal #2: Expand system and service capacity to ensure access to community-based, integrated services.
- Goal #3: Planful and effective transitions into the adult service system and across the lifespan through collaboration with other state partners and through private-public partnerships.
- Goal #4: Accountability of the system through clarity of expectations, quality of practice, and transparency of outcomes.



- Recommendation #1: Increase comprehensive, conflict-free case management through the launch of an I/DD Health Home.
- Recommendation #2: Rebalancing through shifts from congregate, high cost residential and institutional models of support to individual and family services that promote whole life planning and build upon community and natural supports
- Recommendation #3: Development of alternative community models to support diversion and transition from hospital levels of care
- Recommendation #4: Evaluate the system rates and finance models to inform and explore alternatives to promote and support high quality, person-centered integrated community-based services.

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HEATHER MINCEY BHDDH

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual will ... successfully self determine what their life will look like and who they will share it with in a system that supports and promotes individuality.

- Goal #I: Build/create capacity that addresses the needs of all individuals within the adult service system and is integrated within the community.
- Goal #2: Person centered thinking system of supports and services, paid and unpaid, that encourages self determination and dignity of risk.
- Goal #3: Transitions that are seamless, person directed and focused on whole life planning.

- Recommendation #1: Rebalance the service system by moving away from congregate care settings, maintaining/enhancing family supports and optimizing natural supports.
- Recommendation #2: Align policies and procedures with person centered thinking, continue trainings and TA, conflict-free case management through I/DD Health Home and continued partnerships with all stakeholders.
- Recommendation #3: Development of I/DD Health Home, LTSS redesign "No Wrong Door", continued engagement with LEAs/RIDE/ORS and other stakeholders.

TINA SPEARS CONSENT DECREE COORDINATOR

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual will ... receive high quality services that enable an individual to lead a self-determined life—in all aspects and on a equal basis as all Rhode Islanders.

- Goal #1: Reform Payment Model away from unique units toward a payment model that will drive quality and outcomes.
- Goal #2: Establish plan to stabilize workforce and elevate the profession of direct support professionals.
- Goal #3: Advance the Statewide Employment First Policy to strengthen community and business awareness and inclusion of Rhode Islanders with intellectual and developmental disabilities.

- Recommendation #1: Restructure payment model to support ideals of workforce stabilization, employment first, HCBS rule and self-determination.
- Recommendation #2: Establish a base wage rate and develop career path for DSPs in partnership with CCRI
- Recommendation #3: Establish a cross agency public awareness campaign (DLT, ORS, BHDDH, RIDE, DHS, etc.)

MARY MADDEN

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual will ...

- have been well-prepared for the transition from school to the world of employment, independent living and community engagement.
- understand the full range of supports and services available and to be able to access and customize those supports to live his/her best life.
- have adequate resources to support his/her current as well as changing needs and goals over the lifespan.
- have access to reliable, safe and efficient transportation to support in them in pursuing employment, education, relationships and community.
- have access to accessible, safe and affordable housing to insure "real" choice of living.

- Goal #1: Individually determined funding, which is adequate to meet essential needs and can be fully accessed and flexibly applied to achieve valued outcomes.
- Goal #2: A robust cadre of well-trained frontline professionals (DSPs) who earn a living wage, have essential benefits and a career path, and demonstrate strong person-centered values and practices.
- Goal #3: DD organizations that people rely on for supports have a stable base of funding and the capacity to meet the increased expectations and complexity of new, young people entering the systems as well as the changing needs of aging adults.
- Goal #4: Intensive, experience-based training around self-determination and skill development for people supported.

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- Recommendation #1: Streamline and simplify the DD funding system in order to make it accessible and understandable to individuals/families and to enable DD organizations to operate with stability and predictability.
- Recommendation #2: Create a work group to identify and catalog available technology assistance including equipment, devices, and software, that can afford greater independence both at home and at work and may reduce reliance on staff-intensive support solutions.
- Recommendation #3: Develop a community-based, high quality, responsive crisis intervention capacity to more appropriately support people and potentially divert them from psychiatric admissions and hospitalizations.

ANDREW MCQUAIDE PERSPECTIVES CORPORATION

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... rooted in control (self determination), choice (real options), and resources (information and funding) to live a quality life (health, housing, employment, community, etc.); marked by people (relationships) who walk alongside an individual over time.

- Goal #I: A funded system.
- Goal #2: A responsive experience.
- Goal #3: The conditions for a more stable workforce.
- Goal #4: Collaborative governance structure.

- Recommendation #1: Investments proposed by the Division, supported by the Secretary and Governor, and funded by the General Assembly.
- Recommendation #2: A coordinated effort to advance self-determination.
- Recommendation #3: A workgroup that produces specific recommendations to maximize our waiver and maps/integrates nontraditional resources.
- Recommendation #4: Public/private partnership that engages leaders (faith-based, universities...) to create connections and advance inclusion.

REGINA HAYES SPURWINK RI

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... person centered, meaning each person will be able to choose a meaningful life in their community with quality healthcare and access to individualized supports, including employment services and integrated community activities, which are adequately funded and provided by well trained, fairly compensated support staff.

- Goal #1: Increase funding for I/DD programs to adequately fund a service system to support a stable workforce of well trained, fairly compensated support staff, inclusive of provider operating costs.
- Goal #2: Annual funding authorization with the ability to access funding for supports as needed.
- Goal #3: Efficient, reliable, affordable statewide transportation.
- Goal #4: State Legislature that supports and values full community integration for all RI citizens with I/DD.

- Recommendation #1: Governor needs to increase (and General Assembly needs to approve)
 I/DD budget to appropriately fund service system.
- Recommendation #2: Eliminate quarterly authorizations and replace with annual authorizations. Implement bundled rates, eliminate ratios and incorporate less cumbersome billing procedures.
- Recommendation #3: In collaboration with RIPTA, and/or private transportation companies, the provider community and individuals with I/DD convene a commission to assess the availability of transportation capacity, geographical capacity and funding streams.
- Recommendation #4: Continue education and advocacy of the State Legislature. Increase presence of I/DD community at the State House. Ensure voter registration and education.

GLORIA QUINN WEST BAY RESIDENTIAL

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... a fully integrated life of one's choosing, with access to the same opportunities as other RI citizens, including employment, social opportunities and community life. Supports will be tailored, responsive and flexible as one's needs and choices change, and will happen through a network of people including a well trained and compensated workforce.

- Goal #1: Individualized and self-determined supports design as well as corresponding funding that can be used in flexible ways and fully accessed by the individual/family.
- Goal #2: Ensure adequate funding for identified support needs including appropriate compensation for a well trained workforce.
- Goal #3: Ensure full access to services, and corresponding funding, for all individuals with I/DD who need it to assure and sustain a fully integrated life of choice, with the same opportunities as other RI citizens.
- Goal #4: An alternative annualized and flexible funding model that provides full access to one's funding and eliminates quarterly authorizations and use of ratios.

- Recommendation #1: Revise the funding and billing procedures to ensure full access to flexible funding, eliminating the quarterly authorizations and ratio requirements.
- Recommendation #2: Include DD in caseload priorities more accurately informing state budget.
- Recommendation #3: Develop a work group to explore successful models and practices in supporting individuals with complex behavioral and mental health needs in the community thereby minimizing excessive psychiatric hospitalizations.

- Recommendation #4: Create legislation that would tie in an annual cost of living increase (COLA) to the base funding for individuals with I/DD in order to fairly compensate their staff.
- Recommendation #5: Create an innovation work group focused on creative models of support and use of resources, including use of technology and alternative staffing and scheduling options to enhance life options and better meet needs of the individual/family.

KELLY DONOVAN PEER MENTOR SPECIALIST

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... for individuals to understand what options they have more fully and be able to make a wide arrange of choices of what they wish to do, live life to their fullest and happiest, and not have negative feelings of stigma and prejudice surrounding who they are.

- Goal #1: Create publicly accessible educational resources (AIA workshops) and promote them at a greater level so more people will know about them and have access to them.
- Goal #2: Gather informational feedback on satisfaction with services and connect and collaborate with other agencies to help with executing action on said feedback.
- Goal #3: Host events and workshops related to self acceptance and self discovery, but promote them on a wider level.

- Recommendation #1: Encourage agencies to host educational events about things individuals can do that they did not know about (possibly in collaboration with Advocates in Action).
- Recommendation #2: Create a committee with members of state agencies focusing on taking feedback from clients and working to implement said feedback.
- Recommendation #3: Taking action to decrease stigma towards disabled individuals by hosting educational sessions, going to workplaces and teaching businesses how to be accommodating of individuals with disabilities.

TONYANTOSH SHERLOCK CENTER ON DISABILITIES

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual will ... have greater control of their life; will experience greater flexibility in both funding and supports; and will have increased responsibility for design and implementation of services and supports they receive.

- Goal #1: Individuals and families (in expansion of the eligibility by 17 policy) will receive annual funding for exploration and discovery across all life domains, for plan development and for systems navigation from date of eligibility determination through 21.
- Goal #2: Funding and support levels will be based on an evidence-based multi-factor approach. Each person will have an individual budget. Using a "bottom-up approach", individual budgets will be developed by each person's person-centered planning team. Budgets will be based on a clearly defined set of services and supports. Each service and support will have a funding "range" aligned with a new process for determining funding and support levels. Funding from ALL pertinent agencies will be integrated into one cohesive system.

- Goal #3: Services and supports will be individualized and aligned to the plan developed by each individual's team. New models for organizing individual services and supports will be developed and implemented.
- Goal #4: The new models for funding and for providing services and supports will be strategically implemented during a six year time frame Year I devoted to model development, Year 2 for beta-testing with 20% of the population, Years 3 6 for full implementation.

- Recommendation #1: "Level of Need" Determination based on multi-factor system.....preferably done by third party
- Recommendation #2: Funding by function
 - Clearly defined list of functions
 - Functions to include (I) planning and navigation, (2) discovery, (3) traditional e.g., housing, employment supports, (4) non-traditional array of community fees (organization dues, tickets to leisure/cultural events, etc.) (5) transportation, (6) technology et al
 - Five (or some other number) of funding ranges for each function
 - Identification of source one stop braided multi-agency process
- Recommendation #3: Individual "Person-Up" budget development
 - Comprehensive Person-Centered Plan all components of quality community living (Minnesota RTC) should/must be considered
 - Person and Team develop budget proposal
 - Reviewed by BHDDH Case Manager



- Recommendation #4: Define three service options
 - Self-Direct with fiscal intermediary
 - Contract with agency to manage
 - Custom self-direct some functions, agency manage some functions
- Recommendation #5: Make "conflict free case management" simple
 - Simple criteria does not provide direct service to the person
 - Provide training define criteria for being designated as a navigator
 - Application to be a Navigators
 - Maintain a list

- Recommendation #6: Person-Centered Plans to Include
 - Preparation of person communication, self-determination, meeting preparation
 - Community Mapping
 - Personal Profile
 - Consider all components of high quality community living
 - Support/Service Options
 - What can person do

- Recommendation #6: Person-Centered Plans to Include
 - What can family/friends do
 - What functions can be supported through applied technology
 - How can other community resources/organizations be used
 - What must be done by paid staff
 - Funding by Function per above
 - Simple outcome metrics
 - On line submission

- Recommendation #7: Person-centered plans, individual budget authorizations and agency contracts should be bi-annual (every two years). Eliminate quarterly and annual authorizations. Define criteria for review of allocations.
- Recommendation #8: Reorganize and simplify parts of the system
 - One time, one process application for all services/supports
 - Meld all employment funding (BHDDH, ORS, DLT)
 - BHDDH monitors funding and outcomes less focus on process indicators
 - BHDDH responsible for Data Management
 - Ongoing BHDDH responsibilities eligibility, QA

KATHLEEN SHERLOCK RI DISABILITY LAW CENTER

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... better than it is today. As an individual being served, I will have more and better options for my life. I will know what my options are. I will choose among the options. If I need help to choose, I will have the support I need. I can come up with my own options. I will live as independently as possible. I will choose whether to live by myself or with others. If I live with others, it will be because I chose to live with them. I will have a job that I like and earn a decent amount of money. I will be a part of my community. I will have activities I like. I will be active and fit. I will eat healthy foods. I will keep my friends but I will also have opportunities to make new friends. I will have time to spend with my friends and family. I will learn new things. I will have new experiences. I will go places, both places I have been and new places. I will be able to change my mind. It will be easy to make changes in my life. My staff will be my facilitators. I will use the system as little as possible.

- Goal #1: The system will include an array of options. Self Determination, Person Centered Planning and Informed Choice mean nothing without an array of options.
- Goal #2: Individuals who can express a decision will have the right to make their own decisions. Individuals who need it will have support to make decisions.
- Goal #3: Staff will be facilitators.

- Recommendation #1: The system must be more flexible and afford more options. This will take DD community research, brainstorming, planning, and possibly funding.
- Recommendation #2: Provide assistance to individuals regarding decision making: The legislature should pass the pending Supported Decision-Making Act legislation: 2019 -- S 0031to formalize individuals choosing a supporter or team of supporters to assist them with decision making. To assist individuals to know what their options are, their plans (such as IEPs, ISPs, IPEs) should include a goal to explore options and expose them to the array of options. Individuals' plans should also include expanding their decision making opportunities and enhancing their skills.
- Recommendation #3: Provide lots of training that includes role playing to fully effectuate this paradigm shift.

CHRIS SEMONELLI RI FORCE

Organized communication/education with legislators

Life Span – Life to Death – one DD System

Well trained, well paid DSP = better staffing

Safe place to live

Communication "vessel" for families

Advocate for legislation for licensing transparency

"Jerry McGuire" x3

Consumer to be heard and valued

Address communication services/technology

Daytime that is meaningful

Social media

- One system instead of many navigation would be so much easier
- Establish a Person Centered delivery system to include training, redesigning and how this will happen
- One system life to death
- Stability long term
- Seamless entry from school to life after
- Common sense regulation

- Safe place to live
- Central place for coordination
- We can educate our legislators just by telling our stories
- Lifespan-wide DD agency
- Organized communication with legislators
- Look at funding structures make it flexible and possible to get what people need and want

KEVIN NERNEY DEVELOPMENTAL DISABILITY COUNCIL

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... driven by the individual and their family. People will actively participate as members of the community and have connections that further their aspirations. When paid supports are necessary, people will have control of an individualized budget to meet their needs.

There are many goals and activities that we could implement to better the quality of life for people with intellectual and developmental disabilities. I believe that focusing on too many goals may result in little action, so I would focus on three main areas for immediate implementation.

- Goal #1: Ensure that people, with the assistance of trusted family and allies when requested, are in control of their lives. At a service level, this would mean driving their life plan and controlling their own budget.
- Goal #2: Implement supports that adequately meet the needs of the person.
- Goal #3: Support people and families in crisis.

- Recommendation #1: Any assessments used to determine needs are done independently.
- Recommendation #2: Life planning is driven by the individual (with assistance when requested) and in accordance with HCBS rules independent facilitators, not by the funder (state) or provider of service.
- Recommendation #3: The person (with assistance when requested) develops an individual budget and controls those funds.
- Recommendation #4: Ensure that planning focuses on family and community supports.
- Recommendation #5: Ensure that paid supports are provided by people that the individual receiving them wants.

- Recommendation #6: Ensure that individuals providing services are adequately compensated.
- Recommendation #7: Implement strategies to prevent crises, such as Trauma Informed Care.
- Recommendation #8: Provide emergency services and supports in home settings for people or families in crisis.
- Recommendation #9: Provide non hospital emergency supports to individuals in crisis or recovering from a crisis situation.

TOM KANE ACCESSPOINT

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual will ... be in control of and direct their support system so that they live the life they desire including employment, a secure place to live, access to quality health care, and a place in their community, supported by a system that is funded to appropriately meet their needs.

- Goal #1: Each person will have the supports they require to learn about employment options and have the supports they need to obtain and build a successful career.
- Goal #2: A variety of housing options will be available so that a person supported can choose the living situation that best suits their needs.
- Goal #3: There will be a statewide transportation network that is flexible and responsive to the needs of each person so they can readily access their community.

- Goal #4: A health care system, including mental health, that understands and is responsive to the needs of people with I/DD so they can live healthy, well balanced lives.
- Goal #5: A service system that is funded to cover the real cost of providing supports including sufficient funding to attract and retain talented employees.
- Goal #6: Each person will have access to technology, and the supports needed to best utilize that technology to gain the greatest independence possible.

- Recommendation #1: Convene a commission to assess the transportation needs of people with DD, assess the capacity of the current systems and devise recommendations on how to realign services to better meet the needs of people supported in the DD system.
- Recommendation #2: Eliminate rules, regulations and laws that inhibit the efficient and effective system of supports including, ratio requirement, 15 minute units of billing and quarterly authorizations
- Recommendation #3: The state departments/divisions that authorize spending to support employment will eliminate all barriers to braiding funding to increase opportunities for people to access the resources needed to discover job opportunities, obtain and maintain employment.
- Recommendation #4: BHDDH/State Legislature will ensure that the rate review committee takes the cost of the real of the system into account when doing their analysis and making their recommendations. The rate recommendations should be presented without edit to the legislature and used as the basis for funding the system.

- Recommendation #5: Develop a stakeholders group to research and create new living options.
- Recommendations #6: The state of RI will create, fund and implement a marketing strategy to inform and encourage the RI business community about the opportunity and benefits to hiring people with disabilities.
- Recommendation #7: Establish a committee to research technology available to be utilized as a part of the support system, write necessary appropriate guidance to establish how technology can be utilized and fund the development and maintenance of technology in support of people with I/DD.

PETER QUATTROMANI PROVIDERS COUNCIL OF RI

COMPLETE THE VISION -

In 2025, when viewed through the eyes of the individual being served, the Developmental Disability system of services, which is guided by the expectation of standards established through the ADA and the Consent Decree agreement to achieve the ADA requirements, the individual's experience will be ... truly based upon the needs of that individual from a whole life perspective. Every person supported in the system will have an annualized funding authorization that they may use to purchase an array of high quality, adequately staffed supports through a self-directed program or from any licensed and certified provider in Rhode Island.

- Goal #1: Achieve flexibility in the manner in which individuals are allowed to utilize her/his funding to purchase supports.
- Goal #2: Develop outcome measures to ensure that supports provided are high quality vs. meeting the criteria of the number of minutes or hours of support provided.
- Goal #3: Secure funds adequate to ensure that qualified staff are hired and retained so that true choice is available in the system.

- Recommendation #1: Replace SIS with a more appropriate tool that preserves the dignity of the individual and adequately addresses her/his support needs.
- Recommendation #2: Eliminate quarterly authorizations and tiered funding based on support category (residential vs. day vs. employment vs. transportation, etc.) Institute individual annual funding authorizations that are outcome-based (vs. time increment based) where monies are fungible across support areas. Recommendations I and 2 could mirror model presented by Bill Ashe from Vermont.
- Recommendation #3: Develop quality outcome measures. These measures should NOT reflect acute health care needs but should instead focus on the quality of life of the individual.
- Recommendation #4: Develop multi-year plan to adequately address wages and benefits for direct support staff.