OREGON CAPACITY BUILDING INSTITUTE INITIATIVE

BETH I. BAROL PHD, LSW, BCB, NADD-CC
BETHBAROL1@ME.COM

Table of Contents

Context for the Capacity Building Institute 2
Executive Summary 4
Mission & Vision 5
Program Design 6
- Core Components
- Regional Cohorts
- Impact of Cohorts

Training Curriculum 8
- Core Components of Training
- Training Elements Grid

Proposed Timeline 10
Evaluation & Impact Assessment 12
Budget and Financial Plan 15
Conclusion 16

Context for the Capacity Building Institute

The prevalence of individuals with intellectual and developmental disabilities (IDD) who have complex support needs, dual diagnoses, and challenging behaviors has been increasing across the United States (NCI Data Brief 2019). Pennsylvania recognized this growing need and initiated the Capacity Building Institute (CBI) eight years ago. Funded through a Money Follows the Person (MFP) grant, the CBI was established to bridge gaps between Intellectual and Developmental Disabilities/Autism (IDD/A) and Mental Health Services. This initiative fostered collaboration across departmental silos, enabling supporters to work collegially to address the needs of individuals with complex diagnoses. The CBI aims to reduce challenging behaviors and help individuals achieve meaningful, fulfilling lives by adopting person-centered, promising solutions.

While significant advancements have been made in neuroscience, psychology, and medicine—particularly in understanding trauma, stress effects, mental illness, and neurodiversity—these innovations often remain underutilized in practical settings. Treatments such as psychopharmacology and interpersonal therapies are frequently not fully integrated into broader practices within various states.

Moreover, evidence underscores the healing power of trustworthy, supportive environments. These environments emphasize healthy living practices, such as proper nutrition, adequate sleep, regular exercise, mindfulness, and fulfilling relationships. However, many caregivers and the individuals they support, particularly those with IDD/A, lack awareness or access to these life-affirming practices. Research reveals that regardless of the quality of traditional therapies, individuals rarely heal or thrive without consistent lifestyle support. Establishing restorative environments and promoting basic healthy living practices are therefore essential for fostering positive change, reducing challenging behaviors, and enabling individuals to engage fully with their surroundings.

Unfortunately, professional training often focuses on specific therapies, diagnoses, and medications without considering the whole person and their experience. While important, these interventions are seldom effective in isolation, emphasizing the need for a more holistic approach.

One-day conferences and training sessions can inspire practitioners and set new standards. However, these formats often fail to embed new practices and equip professionals to implement learning effectively in daily practice.

The CBI addresses this gap by offering a comprehensive, sustained approach to professional development. It combines inspiration and elevated practice standards with the practices of skill-building, testing intervention applicability,

and embedding learning over an extended period. Through individual work and cohort collaboration, participants explore the interconnected healing aspects, including personal history, systems dynamics, and therapeutic elements across home, school, and work life. The institute also deepens participants' understanding of neurodiversity, psychiatric interventions, mental health concerns, and overshadowing diagnoses.

At the program's conclusion, cohorts present their collective findings and recommendations to state leadership. This process provides cross-system education, validation, and evidence-based suggestions for evolving policies and practices statewide. Additionally, state leaders benefit from a trained cadre of professionals prepared to support complex individuals effectively.

Now in its eighth year, Pennsylvania's CBI has trained approximately 385 practitioners, with 55 individuals completing the nine-month program annually. Graduates have demonstrated significant impacts across the system—from state, regional, and county leadership to agency staff, clinicians, and direct supporters. Many alumni now lead efforts to support challenging individuals, deliver state conference presentations, and serve as guest presenters in subsequent CBIs. This continuity highlights the institute's effectiveness and role in fostering a culture of support for the most complex individuals. Initially contracted for four years, the CBI's continuation into its eighth year reflects its widespread benefits and systemic impact.

We will use the Pennsylvania CBI as a model to develop the following template recommended for the state of Oregon, tailored to its mission and unique attributes of the state system.

Executive Summary

The state of Oregon's Department of Human Services has the mission of "Empowering Oregonians with intellectual and developmental disabilities. We strive to support the choices of individuals with disabilities and their families within communities by promoting and providing services that are person-centered and directed, flexible, community-inclusive, and supportive of the discovery and development of each individual's unique gifts, talents, and abilities. We are committed to working toward service options to assure that people with developmental disabilities have the opportunity to have lives that are fulfilling and meaningful."
(https://www.oregon.gov/odhs/idd/pages/default.aspx)

The proposed Oregon Capacity Building Institute (CBI) seeks to address systemic gaps in supporting individuals with Intellectual and Developmental Disabilities, Autism (IDD/A), and co-occurring mental health challenges. Over the last two decades, advances in trauma-informed care, mental health practices, and holistic therapeutic approaches have reshaped how these individuals are supported. However, practitioners, caregivers, and direct support professionals often lack the training, resources, and systemic coordination needed to implement these advances.

The proposed institute will address these gaps by providing multidisciplinary training to leaders, clinicians, and direct service providers across Oregon. Through regional cohorts and experiential projects, the institute will foster collaboration and build capacity and available practices that can enable people with IDD/A and dual diagnosis to lead fulfilling lives in their communities.

Mission & Vision

Mission
The institute aims to elevate Oregon's capacity to deliver holistic, evidence-based support for individuals with IDD/A and co-occurring mental health needs. By fostering interdisciplinary collaboration and building a shared knowledge base, it will equip practitioners, caregivers, and system leaders with the tools needed to create a more inclusive and compassionate care system.

Vision
A unified Oregon where all individuals with IDD/A have equitable access to the resources, therapies, and environments they need to thrive. Through this institute, we envision a future where caregivers, clinicians, and communities work together to support healing, growth, and empowerment.

Program Design

Based on the State of Oregon's mission, the Oregon Capacity Building Institute (CBI) integrates a multifaceted approach to enhance the skills, knowledge, and collaboration of all stakeholders in the system of care. This design ensures that every participant—whether a direct supporter, clinician, manager, or system leader—understands their critical role in creating a positive, healing environment for individuals with IDD/A and co-occurring mental health needs. There is a specific focus on working with the most challenging individuals to support, with the understanding that these promising practices can then be generalized to help individuals with varying needs across the State.

Core Components

1. **Direct Support Enhancement**:
    - Recognizing that the direct supporters and the healing environment they create are the lynchpin for recovering and solving issues resulting in challenging behaviors.
    - Equip direct supporters with trauma-informed practices, therapeutic communication skills, and the understanding and tools for fostering restorative environments.
    - Teach about the efficacy of using oneself as a positive change agent to build trust, soothe, and calm the people one supports on an ongoing basis.
    - Train leaders, managers, and clinicians to effectively support, mentor, and empower direct supporters.
2. **Therapeutic and Mental Health Training**:
    - Provide participants with state-of-the-art knowledge on evidence-based therapeutic approaches for individuals with IDD/A.
    - Offer training on trauma-focused care, emphasizing strategies for recognizing and addressing the effects of trauma in individuals.
    - To enhance participants' therapeutic skill sets, introduce cutting-edge practices such as neurofeedback, EMDR (Eye Movement Desensitization and Reprocessing), and integrative therapies.
    - Training on enhancing a healthy lifestyle as an important scaffolding for all interventions.
3. **Holistic Care and Collaboration**:
    - Foster interdisciplinary relationships to ensure seamless care for individuals.
    - Create shared language and goals among all participants to bridge the gap between IDD/A and mental health systems.
4. **Systemic Transformation**:
    - Use promising practices and cross-system collaboration to raise the bar across systems regarding what can be gained for people with IDD/a.

- Dispel the myth that challenging behaviors are genetically ordained and inherent in the overshadowing IDD/A diagnosis using case studies, professional and personal experiences, and grounded in current research.
- Encourage participants to apply what they have learned to case studies, leading to actionable recommendations for systemic improvement.
- Focus on addressing inequities in access to care, particularly in rural and underserved regions.

Regional Cohorts

To ensure the program effectively addresses regional and systemic challenges, participants will be grouped into **regional cohorts** based on geography. These cohorts will:

- **Promote Collaboration**:
  - Build localized networks of support and shared problem-solving.
  - Foster cross-agency collaboration between mental health, IDD/A, and other service systems.
- **Focus on Complex Individuals**:
  - Each cohort will identify individuals with IDD/A complex needs (e.g., those frequently hospitalized or rejected by service providers due to highly challenging behaviors).
  - Teams will use tools presented throughout the months of CBI to perform comprehensive assessments and develop tailored interventions, tracking progress throughout the program.
- **Present Findings**:
  - At the end of the institute, each cohort will present their findings and recommendations to state leadership and the CBI participants. These presentations will highlight one case study, their assessments, treatment models, successes, and concerns regarding the case study, identify systemic barriers, and propose actionable solutions for statewide implementation.

Impact of Cohorts

The cohort model ensures:

- **Localized Relevance**: Solutions are developed with regional resources, cultural considerations, and systemic challenges in mind.
- **Scalable Change**: Insights and practices from one cohort can be adapted to other regions.
- **Participant Empowerment**: Cohort members gain confidence in applying advanced tools and collaborating to achieve meaningful results.

Training Curriculum

The Oregon Capacity Building Institute's curriculum is designed to provide participants with a deep understanding of therapeutic practices, systemic collaboration, and person-centered care endorsed by the State. The leadership team of the CBI should be composed of leaders in the field who represent IDD/A as well as the Mental Health system. At least one member of the leadership team should be part of the state system and have the ear of the leadership of the relevant departments, i.e., the clinical director for the department. Others may be experts/leaders in the IDD/A field outside the government leadership structure. Each member of the team should have rich experience in working successfully with individuals with dual diagnosis, IDD/A, and MH, especially individuals seen as being "complex cases". They may implement a large portion of the curriculum, depending on their expertise. They may also choose and invite additional trainers and guest speakers with specific areas of expertise that are congruent with the mission and values of the institute. While it is recommended that the invited guests, trainers, and speakers be from Oregon, there may be areas of expertise that are needed that don't have an identified champion in the state at this point. In these instances, choosing a compelling expert from outside of the state might be necessary to extend the capacity within the state.

Core Components of Training

1. **Direct Support Enhancement:**
    - Equip direct supporters with trauma-informed practices, therapeutic communication skills, and tools for fostering restorative environments, including self-regulation techniques to help them reduce their own stress on the jobs as well as the stress of the people around them.
    - Train leaders, managers, and clinicians to effectively support, mentor, and empower direct supporters.
2. **Therapeutic and Mental Health Training:**
    - Provide participants with state-of-the-art knowledge on evidence-based therapeutic approaches for individuals with IDD/A.
    - Offer training on trauma-focused care, emphasizing strategies for recognizing and addressing the effects of trauma in individuals.
    - Introduce cutting-edge practices, such as neurofeedback, EMDR (Eye Movement Desensitization and Reprocessing), and somatic and other integrative therapies, to enhance participants' therapeutic skill sets and help them knowledgeably refer the people they support for therapeutic services designed to address the root causes of challenging behaviors.

3. **Holistic Care and Collaboration:**
    - Foster interdisciplinary relationships to ensure seamless care for individuals.
    - Create shared language and goals among all participants to bridge the gap between IDD/A and mental health systems.
4. **Systemic Transformation:**
    - Encourage participants to apply their learning to case studies, leading to actionable recommendations for systemic improvement.
    - Focus on addressing inequities in access to care, particularly in rural and underserved regions.
5. **Restorative Environments**
    - Understand how physical and social environments influence behavior and well-being.
    - Design individualized environmental interventions to reduce stress, increase health, and enhance comfort.
6. **Developmental Trauma and Healing**
    - Recognize the signs and impacts of trauma in individuals with IDD/A.
    - Learn how to use tools such as the Biographical Timeline to identify the root causes of a person's trauma and develop the team's capacity to design targeted responses, lifestyle adaptations, and therapies to address these root causes.
    - Exposure to various interventions that can be used as part of the restorative environment daily or as formal therapies, including music, drumming, art, movement-based therapy, yoga, mindfulness, equine therapy, nutrition, and healthy eating.
    - Apply trauma-informed strategies to create safe, supportive environments.
7. **Mental Health Collaboration**
    - Collaborate with psychiatrists to achieve accurate diagnoses and person-centered treatment plans.
    - Advocate for appropriate care through an informed understanding of psychiatric assessments.
8. **Integrating Physical and Mental Health**
    - Address the interplay between physical and mental health concerns to ensure holistic, person-centered care.
9. **Communication, Self-Advocacy, and Healthy Sexuality**
    - Equip participants to foster meaningful communication and empower individuals to express their needs.
    - Support healthy sexuality education to promote dignity and informed decision-making.

TRAINING ELEMENTS GRID		
Training Element	**Key Topics Covered**	**Expected Outcomes**
Restorative Environments	Healthy routines, sensory integration, environmental adjustments	Participants design environments promoting healing and stability.
Developmental Trauma	Identifying trauma, trauma-informed care practices	Improved ability to address trauma-related behaviors compassionately.
Biographical Timelines	Life history analysis, root cause identification	Tailored interventions informed by personal history and experiences.
Mental Health Collaboration	Psychiatric assessment, medication management, system navigation	Effective advocacy and collaboration with mental health professionals.
Physical and Mental Health Interplay	Integrating physical health concerns into mental health care plans	Comprehensive, person-centered care strategies.
Communication and Advocacy	Effective interpersonal communication, supporting self-advocacy	Participants foster a sense of being heard and valued in individuals.
Healthy Sexuality	Promoting rights, responsibilities, and informed choices	Empower individuals to live fulfilling lives with confidence and respect.

Proposed Timeline

Phase 1: Planning and Development (Months 1-2)

- Key Activities:
  - Arrange venue for the in-person sessions and choose dates for the monthly 2-day sessions. Generally speaking, you must have the venue lined up before the dates can be finalized. Decide if sessions will be held in-person or on a virtual platform such as Zoom. You may decide to do live sessions in the fall and spring, and virtual sessions in the winter. Having live in-person sessions is generally preferable for cohort engagement and to build rapport and comfort among participants. However, if cost-prohibitive or travel is challenging, you may opt for live virtual training. We have found, however, that while having live or virtual sessions can work, a simultaneous hybrid session (where some participants are on-site, and others are on Zoom) is not preferable. Agree upon the rules for engagement while on Zoom (i.e., cameras must be on for attendance to count, no recording of sessions, etc.).

- Arrange for hotel blocks if needed. The participants or their agencies pay for hotel rooms and dinners. A participation fee should also cover the expenses for lunch and two breaks per day for a live session.
- Decide who the stakeholders are in this project and if you need an advisory committee representing the "silos". Finalize curriculum content and structure, integrating input from stakeholders.
- Identify and confirm institute leadership and, through them, the guest presenters.
- Develop outreach strategies for participant recruitment.
- Agree on the number of participants accepted for the year. Suggest 60-70 to allow for inevitable attrition due to job changes, illness, and personal issues, causing a 10% dropout rate.
- Agree on participation and completion requirements (i.e., must attend all sessions or only miss one session to earn the certificate of completion).
- Establish evaluation metrics and tools to measure program success.
- Finalize presenter contracts.
- Launch recruitment campaign.

Phase 2: Recruitment and Selection (Months 2-3)

- Key Activities:
  - Conduct statewide outreach to attract participants from diverse sectors, including mental health, IDD/A services, education, and direct support.
  - Screen and select participants, ensuring representation from all regions and systems.
  - Accept all participants at least 30 days before the start of the institute to ensure that they can arrange their schedules for full attendance.
  - Finalize participant cohorts.
  - Distribute orientation materials.

Phase 3: Program Implementation (Months 4-13)

- Key Activities:
  - Deliver training sessions (two days per month for nine months).
  - Facilitate experiential learning activities, i.e., biographical timeline exercises and interdisciplinary collaboration.
  - Leadership conducts regular program reviews by analyzing participant session evaluations and continuously observing participants' knowledge levels to assess progress and make adjustments as needed.
  - Case-based learning projects launched for individuals identified by regional cohorts.

Evaluation & Impact Assessment

A robust evaluation framework will be implemented to measure the effectiveness and impact of the Oregon Capacity Building Institute (CBI). This framework will assess outcomes at the individual, organizational, and systemic levels, ensuring that the program meets its objectives and contributes to lasting improvements across the state.

Outcomes as reported by the participants through an ending survey

1. Individual-Level Outcomes

The institute will track how training impacts the lives of individuals with IDD/A by focusing on the following metrics:

- **Behavioral and Emotional Outcomes:**
  - Reduction in challenging behaviors through improved therapeutic and environmental interventions.
  - Increased engagement in meaningful activities and relationships**.**
- **Quality of Life Metrics:**
  - Enhanced emotional well-being, independence, and community inclusion.
  - Feedback from individuals and families about improvements in daily life.
- **Trauma and Healing:**
  - Progress in addressing trauma and unresolved life experiences through the application of biographical timelines and other therapeutic tools.

2. Participant-Level Outcomes

Evaluation will measure the impact of the institute on the knowledge, skills, and satisfaction of participants:

- **Knowledge Acquisition:**
  - Pre- and post-training assessments to evaluate participants' understanding of trauma-informed care, biographical timelines, and therapeutic interventions.
- **Skill Development:**
  - Participant self-assessments and instructor evaluations to gauge proficiency in applying new techniques.
- **Job Satisfaction and Retention:**
  - Surveys to measure improvements in direct support professionals' confidence, satisfaction, and likelihood of continuing in their roles.

3. Organizational and Systemic Outcomes

The institute's broader goal is to create a ripple effect across systems of care. Evaluation metrics will include:

- **Systemic Collaboration:**
  - Increased cross-agency collaboration between mental health, IDD/A, and other service systems.
  - Enhanced sharing of resources and best practices among participants and organizations.
- **Policy Influence:**
  - Recommendations from cohort presentations that lead to changes in local and state policies.
  - Adoption of trauma-informed and person-centered care practices across systems.
- **Service Utilization:**
  - Reductions in emergency department visits, hospitalizations, and reliance on restrictive care settings.
  - Improved access to therapies and resources for underserved communities.

4. Long-Term Sustainability Metrics
The program's long-term success will be measured by its ability to build capacity across Oregon:

- **Statewide Expertise:**
  - Growth in the number of "go-to" experts across regions who can support IDD/A and mental health challenges.
- **Direct Support Retention:**
  - Monitoring turnover rates and career satisfaction among direct supporters who participate in the program.
- **Equity in Access:**
  - Measurable reductions in disparities between rural and urban regions in terms of access to care.

5. Feedback Mechanisms
The institute incorporates a continuous feedback loop to refine and improve its offerings:

- **Participant Feedback:**
  - Surveys and focus groups conducted at regular intervals to assess the relevance and effectiveness of the curriculum.
- **Cohort Presentations:**
  - Final presentations deliver actionable recommendations and identify system gaps, ensuring that these insights are communicated to state leadership to support both immediate actions and long-term strategic improvements.
- **State Leadership Review:**
  - Oregon's state leaders will evaluate the outcomes and integrate findings into broader policies and initiatives.

6. Reporting and Dissemination

Evaluation findings will be shared with key stakeholders to ensure transparency and promote continuous improvement:

- **Annual Reports:**
  - A comprehensive report summarizing outcomes, successes, and areas for improvement will be shared with state leadership and partners.
- **Peer Sharing:**
  - Best practices and lessons learned will be presented at conferences and shared with similar initiatives in other states.

Budget and Financial Plan

A well-structured budget is essential to the success of the Oregon Capacity Building Institute (CBI), ensuring that all components of the program are adequately funded to meet its objectives. While the specifics of the budget will be developed in collaboration with key stakeholders, the following outlines the primary financial considerations:

Key Considerations

1. **Guest Presenter Stipends**
    - **Purpose**: To invite subject-matter experts from various fields to deliver high-quality, specialized training sessions.
    - **Recommendation**: Allocate stipends to ensure diverse and experienced presenters, including those with expertise in trauma-informed care, integrative therapies, and mental health therapies, as well as presentations by self-advocates.
2. **Institute Leadership and Support Staff Compensation**
    - **Purpose**: To compensate professionals responsible for directing and supporting the institute's activities, including planning, facilitation, and participant support.
    - **Recommendation**: Include competitive salaries for:
        - Institute directors and coordinators.
        - Administrative and logistical staff.
        - On-site and virtual facilitators.
3. **Operational Costs**
    - **Venue and Technology**:
        - Costs associated with in-person training spaces, such as meeting rooms and accommodations for participants.
        - Investment in technology platforms for virtual learning, as well as an online classroom model to allow communication within cohorts, communication from CBI Staff, and information and resource sharing.
    - **Materials**:
        - Development and distribution of training materials, including handouts, toolkits, and digital resources.
4. **Participant Support**
    - **Purpose**: To minimize barriers to participation for individuals traveling from rural or underserved areas.
    - **Recommendation**: Budget for travel stipends, accommodations, and meals as necessary to ensure equitable access.
5. **Miscellaneous Costs**
    - Marketing and outreach efforts to recruit participants and raise awareness about the institute.
    - Costs for evaluations and reporting, including tools to measure program outcomes.

Conclusion

The Oregon Capacity Building Institute represents a transformative opportunity to enhance the quality of care and support for individuals with Intellectual Disabilities, Autism (IDD/A), and co-occurring mental health challenges. The institute aims to bridge the gaps in equitable, effective, and person-centered care by offering interdisciplinary training and fostering collaboration across systems.

Through this initiative, Oregon will see:

1. **Improved Outcomes for Individuals:**
    - Individuals with IDD/A will benefit from enhanced therapeutic environments, trauma-informed care, and tailored interventions that address their unique needs.
    - Increased community inclusion and reduced reliance on restrictive placements will empower individuals to lead more fulfilling lives.
2. **Empowered and Knowledgeable Workforces:**
    - Direct supporters, clinicians, and leaders will gain the tools and confidence needed to collaborate effectively, advocate for holistic care, and address complex challenges.
    - A more resilient workforce with reduced turnover and burnout will strengthen the state's service infrastructure.
3. **Systemic Transformation:**
    - The institute will promote equity by addressing disparities in access to resources and care, particularly for underserved rural communities.
    - Policy recommendations emerging from cohort projects may inform statewide improvements, ensuring the long-term sustainability of Oregon's care systems.

This proposal goes beyond addressing current gaps—it envisions a forward-thinking, inclusive system that values collaboration, empowers caregivers, and, most importantly, uplifts the lives of individuals with IDD/A. By investing in this initiative, Oregon will set a new standard for care, ensuring that the state's most vulnerable residents are treated with dignity and provided the opportunities and support they deserve.

References

https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf