Building Oregon's Capacity to Serve Individuals with Complex Support Needs:

Recommendations for Action

OREGON
COUNCIL ON
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Executive Summary

The existing service system for people with developmental disabilities is facing a crisis. The number of people with complex support needs entering the system is growing. This growth includes individuals with autism, criminal backgrounds, mental health issues, mild and moderate mental retardation, medical conditions, and difficult behaviors. At the same time, the total number of people requiring services also is rising. Service provider organizations in the comprehensive service system are not adequately equipped to serve these individuals. The provider organizations—struggling with inadequate funding levels and serious workforce issues—need help to be able to provide effective, long term support for people in or entering the system who may present complex support needs.

Sponsored by the Seniors and People with Disabilities Division, Office of Developmental Disabilities Services, the Capacity Building Project was designed to gather input from stakeholders to develop a set of recommendations that could be implemented in the 2007-2009 biennium to support capacity-building in service provider organizations. The paper includes summaries of the participants' vision for the next few years, which can guide discussions across time, as well as practical steps that can be taken to enable 24-hour comprehensive system service providers to be able to say "Yes" to serving individuals with complex support needs in the very near future. The paper addresses issues such as:

- What are the most important capacity-building strategies for developmental disabilities services?
- How can we use training and technical assistance resources in different ways to ensure a greater level of success for the service system and those whom it serves?
- What policies would support success?
- What partnerships do we need to develop?

This paper summarizes the results of a survey, interviews and group discussions with service providers, a focus group with families/advocates, research into best practices, and Think Tanks that included individuals working in different aspects of the system. Through these research methods, the project work group developed a set of profiles representing the people being discussed, identified a set of barriers/issues related to serving persons with complex support needs, and worked with Think Tank participants to develop future visions, strategic directions, and short term action steps that would result in improving the ability of service providers to support individuals with complex support needs. The final set of recommendations addresses priorities for Workforce Development, System Development, and Partnerships. These recommendations include:

Workforce Development:
- Develop a master plan for providing support for workforce development over the next biennium that will establish a multi-pronged training and technical assistance approach to developing competencies in the service system to support people with complex support needs. This should include <u>competency-based training</u> for all roles in the service system, <u>quarterly forums</u> to support on-going learning and sharing of strategies; and <u>on-site technical assistance</u> for transferring learning to agency sites.

- While the planning process will be ongoing, it is important to immediately begin developing and offering regional, effective training and technical assistance related to serving individuals with complex needs, such as working with people with dual diagnosis, sex offending, or criminal histories, and workforce recruitment and selection strategies.

System Development
- Analyze existing data related to the system's experience with crisis services.
- Form a work group to begin the task of redefining and redesigning Oregon's systems for crisis, emergent crisis, and long-term intensive support.
- Continue to research effective models for crisis services, and for serving individuals with complex support needs.
- Develop a standardized assessment process for people with complex support needs and their environments to anticipate issues, to assist in creating proactive supports and to analyze crises. The process should include the Supports Intensity Scale, Functional Assessment of Behavior, and medical and medication reviews, as appropriate.
- Work with counties to plan and prepare for their service development needs.
- Revise contracting for crisis services to establish a pre-need system to allow for discussions, planning and capacity-development prior to crises, and contracts that include start-up time, sufficient funding, and reviews.
- Form a work group to develop clear guidance related to liability, risk and protection.

Partnerships:
- Support providers to develop Treatment Teams to coordinate services for individuals with complex needs.
- Build collaborations for training.
- Establish joint contracts (e.g., local or county cooperative) for mental health services
- Develop more behavior specialists.
- Develop a marketing and educational plan to identify ancillary providers and other specialized resources interested in working with people with developmental disabilities. For example, develop a presentation to enhance interests and knowledge base of community-based psychiatrists, primary care physicians, other medical specialists, dentists, etc. to serve people with developmental disabilities.
- Develop partner agency collaboration at the Executive/Administrative level to address service gaps. This collaboration should include the Office of Developmental Disability Services, Vocational Rehabilitation, Addictions and Mental Health, criminal justice groups, Child Welfare, and other involved state agencies.

Oregon service providers and service coordinators need new skills. Providing the types of support services that individuals need requires new partnerships at the state, regional, county and local levels. To be most effective, Oregon will need to redesign its system for providing crisis and crisis-diversion services to encourage prevention and stability rather than relying so heavily on reactive methods. The task now is to begin to implement these recommendations to provide both immediate relief and long-term fundamental improvements.

Building Oregon's Capacity to Serve
Individuals with Complex Support Needs:

Recommendations for Action

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Introduction and Background

The existing service system for people with developmental disabilities is facing a crisis. The crisis and crisis-diversion systems are already overburdened with the number and severity of individuals with complex issues requiring support. This, at least in part, reflects the changing profile of individuals entering into the developmental disability service system. A substantial portion of the individuals now served by the comprehensive services system have autism, criminal backgrounds, mental health issues, mild and moderate intellectual disabilities, serious medical conditions, and/or difficult behaviors, and, therefore, complex support needs. More children are coming from the Child Welfare system. Current biennial plans call for developing services for at least 26 people now in prison or in the Oregon State Hospital who are waiting to be released. Plans also call for serving at least 24 people identified as needing community services other than nursing homes. We know that 25% of people getting long-term diversion funding have autism and 48% have co-occurring intellectual and mental health conditions.

At the same time, the total number of people requiring services also is rising. The demand for comprehensive services for children and adults with developmental disabilities is growing. For example, approximately 1000 children and adults will become eligible for long term crisis/diversion services during the 2007-2009 biennium, almost twice the number from the previous biennium. Of these, about 400 will be new to our comprehensive service system. According to the terms of the Staley settlement agreement, comprehensive services for 130 individuals not in crisis must be developed during the next biennium. Furthermore, there are an estimated 235 young people all over the state who are turning 21, leaving school, and needing day services.

Oregon must develop specific, enhanced and relevant services for all of these people. Service Coordinators are struggling to find service provider organizations with the personnel, skills, and

resources to take on these increasing numbers that include Oregon's individuals who are. hardest-to-serve.

Project Purpose

This paper is the summary of a project that was designed to gather input from stakeholders to develop a set of capacity-building recommendations for the Seniors and People with Disabilities Division's (SPD) Office of Developmental Disabilities Services (ODDS) and for the service provider community that they could implement in the 2007-2009 biennium. As such, it includes summaries of the participants' vision for the future to guide discussions across time. However, the most important purpose of the paper is to describe practical steps that can be taken to enable 24-hour comprehensive system service providers to support individuals with complex support needs in the very near future. The paper addresses issues such as:

- What are the most important capacity-building strategies for developmental disabilities services?
- How can we use training and technical assistance resources in different ways to ensure a greater level of success for the service system and those whom it serves?
- What policies would support success?
- What partnerships do we need to develop?

This paper presents strategies for improving provider capacity to serve those people who are considered the most difficult to serve, including those who in the past have cycled in and out of crisis. Although this project is—in part—seeking short-term solutions, it is clear that real solutions to the situation in Oregon need to be long-term in nature, addressing the true root causes of the problems. Many of the crisis situations are the result of long-term system problems which have produced poor planning, untrained staff, insufficient wages, and inadequate and inconsistent interventions. Long term strategies—increasing funding and professionalism in the field—are needed, and must guide any short term actions that are taken.

The Changing Service Population

The challenges around serving a growing percentage of individuals within the Developmental Disabilities service system have expanded. Who are the people who are now challenging both the public and private service system with their support needs? Appendix A includes a set of profiles of 10 individuals drawn from real people described by Program Managers, Services Coordinators, and Regional Crisis Coordinators during early 2007. While the profiles reflect information across surveys compiled and adjusted to protect confidentiality, all pieces of the descriptions are about real people. These profiles include the following disabilities and histories:

   Mild Mental Retardation
   Moderate Mental Retardation
   Autistic Disorder
   Sex Offender
   Impulse Control Disorder
   Pervasive Developmental Disorder
   Pervasive Developmental Disorder—Not Otherwise Specified

Bipolar Disorder
Obsessive Compulsive Disorder
Schizophrenia
Dissociative Disorder
Schizoaffective Disorder, Bipolar Type
Adjustment Disorder with Anxiety and Depression
ADHD Combined Type
Post Traumatic Stress Disorder
Intermittent Explosive Disorder
Hearing Impairment

The profiles also include medical conditions: Diabetes (Type II), Hyperthyroidism, Insomnia, Seizure Disorder, Fetal Alcohol Effect, Irritable Bowel Syndrome. They also report stressors related to problems with their primary support group, problems with interaction with the legal system, and severe psychosocial stressors. The profiles reflect people who range in age from 11 years to 50. Each profile contains from two to five mental health diagnoses, along with mild to moderate mental retardation, and up to two medical conditions. Behaviors observed in these individuals include episodes of physical aggression, sexually inappropriate behavior, threatening injury, self-injurious behavior, property destruction, suicidal ideation, cruelty to animals, criminal behavior, drug and alcohol abuse, oppositional defiance, sexual promiscuity, cutting, and leaving supervised areas. The profiles represent all regions of the state, and include individuals living with a residential provider, in the family home, alone in a duplex of a residential program, with a foster provider, and in specially developed foster care.

The people—like those represented by the profiles—who are now in or entering the service system include people with widely varying disabilities and very complex support needs. Clearly, the challenges faced by these individuals, and the service providers who support them, are serious. These profiles represent the people that the developmental disabilities service system is trying to build capacity to serve.

Influences on Current System Issues

Oregon has been affected by many of the same factors that affect developmental disability services around the county. People with more complex medical issues are surviving and staying in the community. More drug and alcohol-affected babies are now aging into the adult service system. In the late 1980s, formal training approaches went out of vogue in favor of adherence to values related to individual choice and natural supports. So, the cadre of staff who were skilled in training technology is largely gone from the system. In Oregon there has been a history of low funding levels and low pay for direct service staff. One result of this has been an incredibly high turnover rate: 65% turnover across all developmental disabilities program contractors in the 24 hour system in 2006, increasing to a much higher level (130% in at least one agency that is attempting to serve the population) for programs that provide support for the challenging population that is the focus of this paper. While a few providers have found strategies that work to retain staff, and experience turnover in the 30-40% range, many are facing the issue of constantly finding new staff who can provide the needed supports and services to this population.

Methods

The Capacity Building Project was carried out by a group of consultants from the Oregon Council on Developmental Disabilities, Oregon Technical Assistance Corporation, Center for Continuous Improvement, Oregon Rehabilitation Association, and the University of Oregon through contracts from Oregon's Seniors and People with Disabilities Division. These individuals conducted surveys and interviews, led focus groups, facilitated two "Think Tank" meetings and analyzed the results leading to the development of this paper.

Survey of Selected Professionals

The project emailed surveys to a mixture of professionals: eight Developmental Disabilities Program Managers representative of the five geographic regions in Oregon, the five Regional Crisis Coordinators, and ten service providers who are representative of the variety of developmental disabilities services available. The Regional Crisis Coordinators were invited to forward the survey to other interested parties. The survey requested information on demographics, diagnoses or other labels used to describe the person, health and safety issues, the community partnerships needed for successful community living, staffing issues, the additional supports needed due to language or cultural barriers, and the skills that providers/staff need to support the person. Twenty-six surveys were returned from two counties, two providers, and two regions. Together, these results were representative of all of the regions. The project work group compiled the information from these surveys and then reorganized it into composite profiles to be representative of the information provided but protecting individual confidentiality. The survey, the ten profiles developed, and a summary matrix are provided in Appendix A.

Interviews of Directors of Selected Service Providers

The project interviewed 13 directors of service provider organizations that have been involved with providing services to individuals with challenging support needs. Three additional organizations were contacted but did not schedule an interview. Appendix B includes a list of the organizations and individuals interviewed. After describing the focus of the project, the interviewer asked each of the directors the same set of questions:
- What services do you find most effective in supporting these individuals?
- What is working in terms of structure, training, and support?
- What is difficult and/or makes you unable to serve people effectively?
- What does staff need in order to support these individuals?
- What does the agency need in order to build capacity to serve these individuals?
- What partnerships would enhance service to these individuals?

A summary of the results of these interviews also is provided in Appendix B.

Group Discussions

Two sets of group discussions were used for gathering input.

Service Providers. The project sponsored a meeting at the April Quarterly Meeting of the Oregon Rehabilitation Association (ORA). Approximately 35 people attended, including ORA members and others who had been invited to join the discussion. Facilitators asked small discussion groups to each review two of the ten profiles and discuss a set of questions. Facilitators recorded the results on newsprint and, in some groups, asked the group to prioritize recommendations. The questions that formed the basis of the discussion were the same as those used in individual interviews. The summaries of the small group discussions are provided in Appendix C.

Family Members. At least a dozen families participated in focus groups conducted in 2006 during the Strategic Planning stage of Oregon's System Transformation grant project referred to as "ReBAR". Information gathered at that time was found to be relevant to the current issue. A summary of findings from the focus groups are provided in Appendix D.

Research on Best and Emerging Practices

The project work group also gathered information on best and emerging practices implemented in Oregon and other states. After conducting internet research, reviewing literature, and interviewing nationally recognized consultants and experts from The American Association on Intellectual and Developmental Disabilities (AAIDD), Oregon Health Sciences University (OHSU), the Association of Positive Behavioral Supports, and elsewhere, the project identified nearly 800 programs serving individuals who present significant support challenges. This number was narrowed using criteria to review only regional or statewide programs that address this population.

Think Tanks

The project work group presented the results of the interviews, surveys, group discussions and best practice research to a group of approximately 25 individuals. These participants were representative of the service systems for children and adults with developmental disabilities, including family members, regional crisis coordinators, technical assistance providers, county program directors, service providers, ODDS, Child Welfare and the project work group. At the first meeting of the group, participants reviewed information gathered by the project work group and came to consensus on vision statements and strategic directions related to capacity building. A second convening of the group focused on selecting and prioritizing short-term action steps related to the vision statements and strategic directions.

Results: Barriers and Issues, Visions for the Future, Strategic Directions, and Action Steps

Barriers and Issues

Throughout the interviews and group discussions, a pattern of barriers emerged that service providers are facing. These barriers reduce their ability to provide effective support in the

community to individuals with complex support needs. The most commonly identified barriers and issues are listed here.

Personnel

1. There is a huge gap between what is needed in staff skills and the applicants provider organizations attract.

Providers again and again discussed the poor pool of applicants that apply for direct service positions. Many of these applicants have little education, have a criminal history, use drugs, have poor math and literacy skills, have poor problem-solving skills, and/or lack ambition. Providers described the set of applicants they see, and compared them against the high level of demands when supporting individuals with complex support needs. Providers feel that their difficulties in attracting high-quality staff are related to the poor pay levels and low level qualifications for the direct service positions. Providers indicate the employees they have to hire don't have the skills needed to support people with mental health or other complex needs, and that their agencies don't receive enough funding to train them appropriately. Providers need to be able to attract higher quality staff as well as train promising applicants with fewer skills so they are able to implement support plans and protocols. They also need to be able to provide the ongoing training staff need, and have information systems that help their agency to assure quality services.

2. Providers don't have enough staff to do the work.

Closely related to the first issue on the quality of the applicant pool, is that providers are having difficulty maintaining enough quality staff. Staff handling crises have been physically assaulted and emotionally drained, and managers don't have the capacity to support them. Service providers are experiencing high turnover rates, especially in direct service positions. However, managers also are leaving after having to cover more shifts and burning out. Service providers need to be able to hire more quality direct support staff and provide them with the support they need to do their jobs well.

3. Some service coordinators are poorly informed or poorly trained.

Service providers are frustrated by service coordinators who don't appear to understand what agencies do, have unrealistic expectations, don't act as part of the team nor provide needed backup support for what providers are trying to do.

Crisis Services, Placement Process, and Ongoing Services

1. The placement process is crisis-driven with little opportunity for planning and little to no training for provider staff. As a result, placements are driven by vacancies and are not person-centered.

Because the placements are often crisis-driven, service coordinators tend to request services from the same organizations, or organizations where they know there is a vacancy. With no request for proposals process, not all providers are offered an opportunity to build capacity to serve this

population. Individuals are placed into group homes and group work settings, even though some providers contend they help escalate behaviors, victimize others and build on deficits. Some providers simply say, "Five-person homes don't work for this population." Others said, "You need the right house, right roommate, and right staff. If not, nothing works." The placement process itself is either too fast or too long, and may occur without really understanding what is at the root of the crisis.

2.   When an individual is moved to a new provider, information packets are often incomplete, out of date and even misleading, and arrivals are not well-planned and coordinated.

Service providers feel that there is a conscious effort to put a positive spin on the information provided about the individual, omitting vital information about the individual's history, challenges, and what has worked and not worked with them. In addition, the moving-in process sometimes occurs during "medication holidays"—when the person is not taking their medications—or even without things as important as their medications. Service providers complain that they sometimes are not made aware of special situations and needs, even something as important as an individual's suicidal tendencies.

3.   Service provider organizations are not funded to deliver the level of support that is needed.

Service providers find it difficult to negotiate rates and, are provided no funds for start-up. They feel that the rates don't cover the individual's needs, nor allow support providers to assign the most skilled and highest paid staff, although they are the ones best equipped to provide crisis services. People with complex support needs require an inordinate amount of support, depleting staff resources needed to serve the majority of people in services. Budgets don't include staff travel time and transportation, and payments are cut if the providers don't use all of the hours each month. As a result, some providers say that they lose money as they serve these people.

4.   Some service provider organizations are not skilled in providing services to people with developmental disabilities who are sex offenders, drug users, or have a dual diagnosis of mental health issues.

With the changes in the service population, service providers have not been able to identify and implement proven models for serving people with these histories and disabilities. Service providers are taking on individuals who need highly skilled support providers without adequate start-up time to identify methods that will work and obtain needed training in those approaches. Often our service providers just barely keep individuals with serious challenges from a "full-blown crisis", but at a serious cost to the agency and support providers.

5. OARs conflict with what is needed or required.

There is a conflict between the overriding philosophy of developmental disability services (e.g., rights, choice, person-centered services) and what is required for working with sex offenders or others who are involved with the criminal justice system (e.g., restrictions, consequences). Providers feel the variance system results in strategies that are too patchwork. In addition, service providers are concerned about excess liability related to serving this population.

Specialized Resources and Ancillary Services

1. Public systems don't work together.

Serving individuals with complex support needs usually requires working together with other public systems, such as the Psychiatric Security Review Board (PSRB); Vocational Rehabilitation; Criminal Justice including courts, Oregon Youth Authority, probation and parole officers; police; health care; Department of Human Services Child Welfare; and services funded by Addictions and Mental Health Services. Professionals in these other systems do not understand developmental disabilities, nor our philosophy of service. There are arguments over diagnosis as a result of conflicts over which agency is required to fund services. Overall, the system for serving people with complex support needs is fragmented. As one service provider interviewed said, "Services should be a woven whole, not a crazy patchwork."

2. Insufficient access to professionals in other fields.

Service providers—especially those outside of the main metropolitan areas—often cannot find mental health providers, and have insufficient access to good psychiatric care, health care, and medication management. Many professionals that are available do not understand and/or are unwilling to serve people with developmental disabilities. Providers have insufficient access to good, flexible nursing staff. It is difficult to get individuals from rural areas to specialists in the city as there often is poor or no public transportation. When they can find the resources, service providers report there is little communication among these professionals in other disciplines, reducing the effectiveness of the overall treatment team.

3. Access to qualified behavior specialists is too limited.

Service providers have limited access to behavior specialists, particularly after the behavior is improving. They need behavior consultants who can continue to work with them to assess the effectiveness of behavior support plans, update the plan and protocols, provide ongoing staff training and feedback, and offer positive mental health support to staff. Providers would like behavior specialists to help them to build competency within their own agencies. However, the providers seldom receive enough funding to allow them to use a behavior specialist in these ways.

Visions for the Future

At the Think Tanks, stakeholders achieved consensus on a set of vision statements for the next 3-5 years, to use in guiding the changes that are implemented. These statements are presented here in the themes: Personnel; Placement Process, Crisis Services, Ongoing Services; and Specialized Resources and Ancillary Services. Because so many of the issues identified could be addressed by Training and Technical Assistance, a vision for the future also is included for that area.

Personnel Vision

We envision a system that supports:
- Professionally diverse, specialized and stable workforce in desirable, well-defined, manageable positions.
- Livable wages that are commensurate with demonstrated competencies.
- Compassionate and passionate leadership
- Information systems to support quality in our work (including use for quality planning, quality assurance and quality improvement)

Placement Process, Crisis Services, Ongoing Services Vision

We envision a system that uses:
- An interdisciplinary, standardized, person-centered, and holistic approach to services—including helping people stay or become connected with family members—where money from different funding streams is blended, and follows and is directed by the person
- A proactive timely response to emerging consumer needs to stabilize placements before going into crisis
- Partnerships that are cooperative, contractual, inclusive of and equally value the expertise of all key stakeholders, based on shared values, use of emerging/shared technology, and creativity—not bound by tradition—and result in win-wins

Specialized Resources and Ancillary Services Vision

We envision a system that has:
- Developed specialized resources/ancillary services that are individualized, portable, flexible, and outcome-based all across Oregon.
- Professionals in other disciplines who are well-trained to work with people with developmental disabilities in a holistic manner that supports self-determination.

Training and Technical Assistance Vision

We envision training and technical assistance system that:
- Is adequately funded, responsive, coordinated, valued, and strategically planned based on the principles of Continuous Quality Improvement.
- Is built on collaboration and partnerships and increases the expertise and marketability of all participants.
- Includes an array of education, training and support for generalists and specialists both in agencies and for families/friends in non-traditional models.
- Is so effective that the field and all stakeholders (families, individuals with disability, community partners) are internally motivated to seek Training & Technical Assistance rather than it being externally imposed.

Strategic Directions

Based on these visions for the future, participants identified a series of strategic directions. These long-term strategies reflect which of the many options available would be the best overall approach to get Oregon closer to the vision. It is these strategies that should guide decisions in the next few years about how to best build provider capacity in Oregon's comprehensive system. These strategic directions are summarized here.

Personnel

Participants believe that additional organizations in Oregon need to create a new tier of direct service staff persons who are better paid, better trained. Accomplishing this will require:
- Increasing the level of qualifications required for direct support workers, increasing their status and pay to attract better qualified applicants with higher skills, greater cognitive capacity, and a higher educational level (e.g., bachelor's degree required)
- Creating structured opportunities for growth and development in the field (career ladder)
- Considering instituting certification programs for direct service staff
- Establishing a training program for direct service professionals
- Investing long-term in the development of staff

Accomplishing improvements in the nature of direct service personnel will require establishing partnerships and shared resources, including:
- Establishing partnerships for jointly recruiting and training
- Investigating ways to work together to ensure that all staff are adequately supported
- Exploring "naturals" for partnership, e.g., ethnic/cultural groups that can help us improve our cultural sensitivity, faith-based groups and other organizations

Service provider organizations and public agencies also need to improve their personnel management practices. They can do this by:
- Creating clear job descriptions for manageable work loads (# of caseload; # of hours) for direct service professionals, managers and case managers
- Implementing best practices around recruitment and selection of staff, including developing organizational marketing programs for attracting high quality staff
- Implementing best practices around staff retention
- Establishing mentoring programs for direct support professionals and supervisors
- Providing strong supervision and support at all levels of the organization
- Developing leadership skills at the mid-management level to build knowledge and skills as senior managers are retiring
- Developing/identifying staff management models that provide high levels of support
- Considering flexible staffing model, and alternatives to staffing in shifts.

Although not a primary focus of the project, participants believe it is important to develop strategies for better supporting families to be successful in supporting their children/adult children. They suggested reviewing the information from this Capacity-Building project to determine which strategies and actions could include providing resources to families.

Participants also want to improve how service coordinators work with people and programs in crisis. This would be accomplished by developing service coordinators who understand what agencies do, have realistic expectations, are part of the team, and provide good back up to providers. Achieving these would require identifying core competencies for service coordinators, providing competency-based training, and informing the county management structure about developmental disabilities issues.

Placement Process, Crisis Services, Ongoing Services

Participants believe that improving the capacity of Oregon's service providers to serve individuals with complex needs will ultimately require decoupling the delivery of crisis services from "crisis-diversion" funding. Therefore they recommend establishing and piloting a new design for dealing with crisis and emerging problems, as well as for delivering long-term intensive services. The system should be premised on:
- Identifying individuals with a high probability of requiring short-term crisis services and long-term intensive services
- Careful matching for the individual's (initial) placement
- Designing environments to support success
- Delivering enhanced technical assistance and training to support maximum opportunity for success in their (initial) current environments
- Providing a team of expert support to provide quick response, relief and planning during a period of crisis (both an internal team and external county/regional team)
- Using creativity and person-centered approaches
- Establishing regional acute crisis programs for short-term stays
- Developing strategies for supporting individuals who have infrequent high-level support needs
- Addressing the needs of families as well as providers, and engaging families as resources for support

Participants indicate that service providers would be able to do a better job if contracting for crisis services were improved. This includes:
- Issuing "requests for qualifications" to allow developing contracts and in-depth planning discussions before they are needed. With these "pre-need" awards, providers could determine which specialty services they wish to provide and build their capacity to do so.
- Issuing these requests with the potential of serving several individuals, to give providers sufficient resources to develop capacity.
- Including six-month reviews of contracts and placements, to ensure that funding and supports are effective.

Participants in the Capacity Building Project interviews and discussions firmly believe that we need to do a better job of developing person-centered environments for people with complex support needs. Strategies that could assist with that would be to:

- Develop affordable housing projects in various regions around the state (smaller units, duplexes) for providing supported living or very small living situations (alone or with one other person)
- Develop individual work environments that match the needs of the person who presents challenges
- Consider various housing models, including, for example, an apartment complex with 24-hour support for transition-age young adults

Service providers recognize an important need to improve information and coordination between service coordinators and providers when a crisis placement needs to occur. This would include:

- Developing an expectation of complete and accurate information about the individual and their challenges, history, what has worked and not worked.
- Providing accurate and complete information for all placements

A large barrier for providers is the funding level for serving people with complex needs. Improving funding for people with complex needs would include:

- Building capacity for providers to serve several people, in individualized settings, rather than addressing the issue one person at a time
- Developing rates that are sufficient to support people
- Developing funding models that include staff training and back-up
- Facilitating more flexible use of resources across counties and providers based on specific individual's needs
- Reassessing the present model for crisis budgeting

Many service providers are not experienced in supporting some of the complex needs of people now entering the system. Therefore, they need:

- Support for implementing proven models for serving people with developmental disabilities who are sex offenders, drug users, or have dual diagnoses
- Information regarding future service needs so that they can incorporate that into future planning
- Help for understanding how to provide services to this population within the existing OARs
- Review, revise or develop OARs, statutes, contracts, waivers needed to support the vision, including those associated with Foster Care. Look for opportunities to mesh OARs, definitions, eligibility standards, etc.

Specialized Resources and Ancillary Services

An important strategy for improving access to specialized resources and ancillary services involves developing partnerships:

- Establish partnerships across disciplines at the state and local levels**,** e.g., mental health practitioners, regional behavioral consultants, probation/parole officers, crisis units, police, school, hospital staff, hospice, psychiatric medication management, Voc Rehab.,

transportation, dentists, physicians (neurologists, primary care physicians), dietitians, Southern Oregon Regional Crisis Unit, Child Welfare, Oregon Youth Authority, domestic violence groups, residential and employment providers, PCC in Salem, shelters, recreation programs
- Identify or develop new models that promote different services, respond to different needs, and expand partnerships
- Create incentives for specialists to partner with us

Service providers also are concerned that they maintain "knowledge learned" and best practices:
- Provide incentives to providers for achieving desired outcomes
- Move beyond "Care Model," so all settings are viewed as teaching/learning environments
- Explore risk in light of changing demographics
- Clarify risk and liability issues and strategies for reducing liability and risk

Service providers need help to improve access to high quality mental health services: The participants suggested:
- Hiring psychiatrists on staff or on retainer to provide consistent care and to support better medical care and better medication management by others
- Hiring in-house mental health counselors
- Developing fee for service agreements for counselors with mental health funders so that they are paid by the hour, rather than a case rate. (People with DD often require more time and therapists can't afford to see many of them)

Participants believe that making better use of technology, such as developing or enhancing resource guides, websites (e.g., Disability Compass) would help service providers to improve their ability to serve.

It will be important to improve teamwork when providers must work with a variety of ancillary services and specialized resources. Therefore they need help with:
- Establishing a treatment team model that includes direct service professionals, counselor, psychiatrist, staff, family, service coordinator, all working together with frequent contact (e.g., monthly staffing). The team needs to include an administrator who can change assignments and budgets.
- Developing cooperative training agreements for pre-service and in-service training across disciplines. This includes improving pre-service and in-service training for professionals in other related fields: Work with university training programs for professionals from other fields to build information about people with developmental disabilities into their pre-service and in-service training curricula.

Service providers also need improved funding for and improved use of behavior consultants. They would like to:
- Have funding for behavior consultants to attend staff meetings (4-6 hours/month) to assess effectiveness of the behavior support plan (BSP), review/update BSP and protocols, provide ongoing staff training and feedback, and offer positive mental health support to staff.
- Increase the number of qualified behavior specialists available

Action Steps

For many of these strategic directions, participants were able to identify specific action steps that could be implemented within the next six months to make it easier for service providers to say "Yes" when asked to take on supporting a person with complex needs. These action steps have been grouped into the categories of Systems Development, Workforce Development, and Partnerships.

Systems Development

Placement Process, Crisis Services, Ongoing Services
- Clearly define what we mean when we say "crisis"
- Develop a standardized assessment process for people with complex support needs and their environments to anticipate issues, to assist in creating proactive supports and to analyze crises. The process should include the Supports Intensity Scale, Functional Assessment of Behavior, and medical and medication reviews, as appropriate.
- Complete a critical analysis of what is happening now and why, such as the number and types of crises, number and percent who move due to their crisis.
- Form a work group to begin the task of redefining and redesigning Oregon's systems for crisis, emergent crisis, and long-term intensive support.
- Ensure that each region has the ability to provide services to people with high needs
- Standardize use of guidelines for information packets across regions
- Develop guidelines/checklists for moving
- Conduct research to identify effective models for serving people with complex needs
- Develop strategies to support individuals who have infrequent high-level support needs
- Establish a pre-need Request for Qualifications or similar system and contracts that include start-up time, sufficient funding, and reviews, allowing proactive capacity-building; improve flow of information for planning purposes
- Meet with providers to discuss future development needs, so that they can build the appropriate services and supports into their long-term planning
- At the start of each biennium, earmark part of the budget for start-up funds (Counties or Regions)
- Review how we are managing vacancies, how they are used for crises
- Support developing overall county vision and planning for serving people with complex needs
- Develop a work group to establish clear guidelines related to liability, rights, risks, protection, county/state/provider liability

Workforce Development

Personnel
- Provide training and technical assistance for managers and families on recruitment and selection strategies to get the right staff
- Develop core competencies that go beyond initial training (agencies & foster)
- Provide training and technical assistance on best practices in orientation and training

- Provide training on effective quality systems
- Provide training from the OIS.08 manual module on how to support staff during and after crises
- Provide training and technical assistance on mentoring and coaching, and other methods for retaining staff
- Develop and implement core competencies for managers and supervisors
- Identify core competencies for service coordinators, including rights v. liability, maximizing independence, developmental disabilities issues
- Provide competency-based training for service coordinators
- Provide training on basic therapeutic interactions and creating & maintaining therapeutic environments
- Provide training to managers and supervisors on skills needed by direct service staff so they can mentor staff in skills needed

Placement Process, Crisis Services, Ongoing Services
- Provide training on contents of information packet and coordinating moves
- Provide training on effective approaches for providing services to people who are sex offenders, have dual diagnoses, or other histories or disabilities that present complex support needs
- Provide training on how to work with the conflicts between developmental disabilities services and other systems
- Explore establishing rules specific to services to sex offenders, kids v. adults
- Provide support for agencies placing people in the community, to help overcome "not in my backyard" response
- Help providers to understand how to provide services to specific populations, such as sex offenders, within the OARs

Specialized Resources and Ancillary Services
- Sponsor local or regional forums for people from across disciplines to begin to form relationships, determine common ground, and share solutions and approaches
- Explore models such as "Community Works"—a combined human services group in Medford with domestic violence and people with developmental disabilities to develop curriculum to help people prevent sexual abuse
- Develop a presentation to enhance interests and knowledge base of community-based psychiatrists, primary care physicians, other medical specialists, dentists, police, etc. to serve the DD population; provide to service providers and others for dissemination
- Provide support to providers to help them to develop these treatment teams or create regional teams.
- Train more behavior support specialists

Training and Technical Assistance: General
- Provide training regionally
- Increase the use of technology—videos, telecasts to minimize impact on staff scheduling
- Provide training on basic computer skills

- Improve training strategies and materials so they are most effective for those we are trying to train
- Evaluate the effectiveness of training
- Proactively invite families to participate in any appropriate training

A more complete summary of training and technical assistance needs and recommendations is provided in Appendix E.

Service Provider Actions
- Seek ways to pool some recruitment or share applicants; develop marketing plan
- Create tiers of direct care staff, with different titles, with more advanced staff acting as mentors and providing support during crises
- Use flexible staffing models to make best use of resources; creative scheduling
- Use a person-centered plan to develop a vision for person's preferred living situation so they do not stagnate in a program
- Include direct service personnel in regular data review and monitoring of plan implementation

Partnerships

Personnel
- Develop partnerships with community colleges to explore strategies for recruitment and certification programs for direct service personnel

Placement Process, Crisis Services, Ongoing Services
- Develop a relationship with a county housing authority to explore possible partnerships for developing affordable housing projects
- Develop partnerships with schools, mental health, criminal justice system and others
- Work in partnership with other organizations to ensure individuals get the support they need

Specialized Resources and Ancillary Services
- Establish local, county, or regional contracts with psychiatrists and mental health counselors so they may become familiarized with individuals, agency and staff (e.g., develop "time shares" with provider organizations pooling resources to hire specialists)
- Develop local and regional partnerships with criminal justice, schools, mental health and other relevant systems
- Develop partner agency collaboration at the Executive/ Administrative level to address service gaps. This collaboration should include the Office of Developmental Disability Services, Vocational Rehabilitation, Addictions and Mental Health, criminal justice groups, Child Welfare, and other involved state agencies.
- Develop formal partnership agreements as appropriate
- Support on-going systems change efforts (ReBAR, Mental Health, Children's Programs)

- Work with local behavioral health organizations to include more therapists who will work with people with developmental disabilities
- Offer technical assistance to community partners

A more complete summary of the barriers/issues, long-term strategies, and short-term actions that were derived from the individual provider interviews, group discussions, and Think Tanks is presented in Appendix F.

Nationally Recognized Models of
Effective Partnership and Workforce Development

An important part of the Capacity-Building project has been research to identify national best and emerging practices. After reviewing nearly 800 programs, research identified a few that served a region or statewide, and focused on serving individuals with complex support needs similar to those we are supporting in Oregon. Overall, the people that these programs supported who were "a challenge to support" were individuals with dual diagnosis, individuals with severe behavioral challenges, or individuals on the Autism spectrum. A summary of the best of these programs—and ones that have the greatest relevance to Oregon—is included in Appendix G.

Results of Research into Best Practices

The following common program elements were identified from the research into best practices conducted by the project:
- Person-centered case management
- Staff competency in person-centered and positive behavioral support values
- Expert inter-disciplinary team of professionals with 24/7 availability
- Systems coordination to facilitate transition to community
- Residential and respite (emergency and planned) services
- Acute in-patient psychiatric services
- Stabilization
- Specialized mental retardation and mental illness out-patient clinic
- Medication management
- Comprehensive assessments, including diagnostic work-up
- Pervasive training and technical assistance for community staff and programs

It is important that these common elements be incorporated in designing responses to the current issue in Oregon.

Overview of Project Recommendations

The Capacity Building Project included service providers and other stakeholders in identifying barriers and issues, visions for the future, strategic directions, and action steps related to improving the capacity of service providers to support people with complex support needs. Few of the recommendations of the groups involved are simple, some are inter-related, and many will affect services beyond those for the population targeted by this project. However, there are steps

that can be taken in the next six months to help service providers in their efforts to support people with complex support needs.

At the end of the second Think Tank, participants identified the strategies that they believed would be most important for building the system's capacity for serving individuals with complex needs. The prioritized strategies were:

- System Development: Redefine and redesign the systems for crisis, emergent crisis, and long term intensive support. Change from a "care" model to a treatment/ teaching/learning model in how we approach services. Work with counties to plan and prepare for the needs for development. Issue Requests for Qualifications (or other format) to allow for discussions, planning and capacity-development prior to crises.

- Workforce Development: Prioritize workforce development, including recruitment, selection, mentoring and training for direct service staff to improve their capacity to serve individuals with complex needs and for mid-managers to develop their leadership capacity. Professionalize the field. Improve how and where training is provided to increase its effectiveness for its target audience. Develop and implement core competencies for service coordinators.

- Partnerships: Establish better relationships with ancillary providers to improve access to these services. Develop partnerships. Plan with partners.

These strategies and actions, summarized in Table 1, should form the basis of an action plan for the next several months.

Summary and Conclusion

Oregon has a well-established system of committed service providers, services coordinators, families and advocates who all agree that changes are needed. People with complex service needs are placing great stress on the existing service organizations. Providers are struggling with finding and retaining staff competent for serving these individuals. People with complex support needs require an inordinate amount of support, depleting staff resources needed to support the majority of people being served. The service providers organizations; families; county, regional, and state staff members; and consultants involved with this phase of the Capacity-Building project have identified the barriers and issues facing the system and developed strategies and specific action steps for addressing them. Oregon service providers and service coordinators need additional resources and new skills. Providing the types of support services that these individuals need requires new partnerships at the state, regional, county and local levels. To be most effective, Oregon will need to redefine and redesign its system for providing crisis, emergent, and long-term intensive services to encourage prevention and stability rather than relying so heavily on reactive methods. The task now is to begin to implement these recommendations to provide both immediate relief and long-term fundamental improvements.

	Table 1. Prioritized Short-Term Actions
System Development	• Form a work group to begin the task of redefining and redesigning the systems for crisis, emergent crisis, and long term intensive support. • Continue to research effective models for crisis services, and for serving individuals with complex support needs. • Develop a standardized <u>assessment process</u> for people with complex support needs and their environments to anticipate issues and create proactive supports and to analyze crises. • Analyze existing data related to the system's experience with crisis services. • Work with counties to plan and prepare for their service development needs. • Revise contracting for crisis services to establish a pre-need system to allow for discussions, planning and capacity-development prior to crises, and contracts that include start-up time, sufficient funding, and reviews. • Address liability concerns by forming a work group to develop clear guidance related to liability, risk and protection.
Workforce Development	• Develop a master plan for providing workforce development over the next biennium to establish a multi-pronged training and technical assistance approach to developing competencies in the service system to support people with complex support needs. This should include <u>competency-based training</u> for all roles in the service system, <u>quarterly forums</u> to support on-going learning and sharing of strategies; and <u>on-site technical assistance</u> for transferring learning to agency sites. • Immediately begin developing and offering regional, effective training related to serving individuals with complex needs, such as dual diagnosis, criminal histories, and workforce recruitment and selection strategies. • Immediately begin offering regional, effective training and technical assistance on workforce recruitment and selection strategies.
Partnerships	• Support providers to develop Treatment Teams to coordinate services for individuals with complex needs. • Build collaborations for recruitment and training with entities such as Workforce Investment Boards, community colleges, and Oregon Worksource. • Establish joint contracts (e.g., local or county cooperative) for mental health services. • Develop more behavior specialists. • Develop a marketing and educational plan to identify ancillary providers and other specialized resources interested in working with people with developmental disabilities. For example, develop a presentation to enhance interests and knowledge base of community-based psychiatrists, primary care physicians, other medical specialists, dentists, etc. • Develop partner agency collaboration at the Executive/Administrative level to address service gaps. This collaboration should include the Office of Developmental Disability Services, Vocational Rehabilitation, Addictions and Mental Health, criminal justice groups, Child Welfare, and other involved state agencies.

Author's Biography

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Joyce Dean, M.Ed., has been a Senior Research Assistant at the University of Oregon's College of Education since 1985, and Senior Partner of the consulting firm, Dean-Ross Associates, since 1993. She also was the Program Director for Eugene Precision Manufacturing Services, a model program for providing employment support to people with severe and profound mental retardation from 1980-1984. Her emphasis in her more recent positions has been on researching and applying the principles and practices of Quality Management to not-for-profit and government agencies. Her role at the university has included planning, directing, coordinating, and/or evaluating numerous federal and state projects related to designing and improving organizations providing human services. She has served as a consultant and trainer in more than a dozen states, in several Pacific Islands, and in Australia. In her role as an evaluator, she has designed project evaluation plans, developed performance measures and instruments, compiled and analyzed data for determining the effectiveness of project methods. Her expertise in the field of quality derives from both formal training—including training by W. Edwards Deming, Peter Scholtes, and Donald Wheeler—and experience working with a wide variety of community organizations across the country. Ms. Dean is the author of the book *Quality Improvement in Employment and Other Human Services*, published by Paul H. Brookes Publishing as well as numerous individual chapters, articles and manuals.

Appendices

Appendix A: Profiles

    1.   Matrix summarizing the 10 profiles of individuals with complex support needs

    2.   10 Profiles of individuals representative of those with complex support needs

Appendix B: Interview Summary

    1.   Individuals interviewed for the Capacity-Building Project

    2.   Summary of interview results

Appendix C: Small Group Discussion Summaries

    1.   Organizations participating in small group discussions held at the April 2007 ORA Quarterly meeting

    2.   Summaries of small group discussions held at the April 2007 ORA Quarterly meeting

Appendix D: Family Focus Groups Summary

    1.   Summary of focus groups of family members and significant others

Appendix E: Training and Technical Assistance Recommendations

    1.   Summary of training and technical assistance recommendations from interviews, group discussions and Think Tanks

Appendix F: Summary of Barriers, Strategies and Actions

    1   Summary of Barriers/Issues, Long-Term Strategies and Short-Term Actions derived from individual provider interviews, group discussions, and the Think Tanks

Appendix G: Nationally Recognized Models

    1.   Review of nationally recognized models of effective partnership and workforce development

Appendix A: Profiles

1. Matrix summarizing the 10 profiles of individuals with complex support needs
2. Ten Profiles of individuals representative of those with complex support needs

Person	Disability	Age	Location	Living Situation
Dylan	Fetal Alcohol Effects, MRDD	20	Mid-Valley	Family Home
Richard	MRDD, Sex Offender	18 -50	Mid-Valley	Residential Provider
Freddy	Axis I: Bipolar, Obsessive Compulsive Axis II: Moderate Mental Retardation, Axis III: Diabetes (type II), hyperthyroidism.	43	Eastern Oregon	Residential Provider
Peter	Axis I: Schizophrenia, Depression Axis II: Mild Mental Retardation and Axis III: Insomnia.	32	Southern Oregon	Residential Provider
Rachael	Autistic Disorder, Impulse control disorder, PDD-NOS, moderate MR and hearing impaired	26	North Coast	Family Home
Susan	Bi-Polar, Borderline Personality Disorder (BPD), Depression MRDD, Diabetes II	50	Mid-Valley	Residential Provider
Matthew	MRDD, Dissociative Disorder, NOS	42	Mid-Valley	Alone/Duplex Residential Prog.
Maria	Axis I: Schizoaffective Disorder, Bipolar type Axis II: Mild Mental Retardation. Axis III: Seizure Disorder, Axis IV: Stressors related to problems with primary support group, problems with interaction with the legal system.	27	Eastern Oregon	Foster Home
John	Axis I: Adjustment Disorder with anxiety and Depression, Pervasive Developmental Disorder. Axis II: Mild Mental Retardation	32	Portland	Residential Provider
Jamie	Axis I: ADHD Combined Type, Bipolar Disorder, Obsessive Compulsive Disorder, PTSD, Intermittent Explosive Disorder. Axis II: Mild Mental Retardation. Axis III: Fetal Alcohol Effect, irritable bowel syndrome, post tonsillectomy and adenoidectomy. Axis IV: Severe psychosocial stressors.	11	Cascade	Specially developed foster care

Profile: DYLAN

Dylan is a young man, age 20, who lives at home. He is still enrolled in his local high school but has a history of truancy and the school wants to exit him from their Special Education class.

His disability is MR/DD and Fetal Alcohol Effects.

His behavior includes:
1. Episodes of physical aggression
2. Sexually inappropriate behavior
3. Threatening injury to family members

Dylan cannot be staffed by young females due to previous sexually inappropriate behavior.

The supports needed to successfully live in the community include:
1. 24 hour staffing
2. 1:1 counseling
3. Monthly treatment team meetings
4. Psychiatric services

Staff skills required:
1. OIS trained
2. Knowledge of behavioral support plans
3. Knowledgeable about Fetal Alcohol Effects

Profile: FREDDY

Freddy lives in a group home and is 43 years old. It's important to know that Freddy was a long time institutional resident.

He has been diagnosed with: Axis I: Bipolar, Obsessive Compulsive
Axis II: Moderate Mental Retardation, Axis III: Diabetes (type II), hyperthyroidism.

Freddy enjoys hands-on outdoor activities and working with tools. He does not like to be alone and he requires a diabetic special diet.

His behaviors in the home and community are:
1. Aggression – will hit (with a closed fist), kick, grab, shove, uses various weapons in order to inflict harm on others, verbally threatens others health and/or safety and approaches/threatens others. Multiple assault charges but based upon cognitive ability no formal charges.
2. Self Injurious Behavior – picks at his skin, pinches self, runs into dangerous areas, drinks excessive fluids resulting in an electrolyte imbalance, refuses medication
3. Property Destruction – throws, kicks, hits and tears various items
4. Suicidal ideation/False reporting/AWOL – has a history of threatening to harm himself in order to end his life, refers to himself as "worthless", reports to authorities that he has been harmed and/or neglected and leave unsafe areas to go to jail, the hospital, etc.

His support team is comprised of rotating staff, mental health professionals and a dietician. Freddy needs clear boundaries and he feels safest in a locked facility. He will seek out emergency personnel. His environment requires structure and predictability (accessible calendar of events but not more than a week); requires monitoring of diet and fluid intake and requires awake staff at night.

Staff skills needed:
1. Understanding of psychiatric diagnoses
2. OIS trained
3. Knowledge to implement PPI

Profile: JAMIE

Jamie is 11 years old and currently lives with her family.

She has been diagnosed with multiple complex disabilities: Axis I: ADHD
Combined Type, Bipolar Disorder, Obsessive Compulsive Disorder, PTSD,
Intermittent Explosive Disorder. Axis II: Mild Mental Retardation. Axis III: Fetal
Alcohol Effect, irritable bowel syndrome, post tonsillectomy and adenoidectomy.
Axis IV: Severe psychosocial stressors.

Her behavior at home and in the community includes:
1. Physical Aggression – including but not limited to spitting,
    blowing/throwing mucus, throwing objects, hitting with open or closed
    hand, kicking, pinching, and head butting. All of these behaviors occur at
    any time of day in all environments and may be directed at those both
    familiar and unfamiliar. This behavior occurs anywhere between 1-3
    times per day and rarely stops without intervention.
2. Cruelty to animals – including but not limited to pulling ears, choking
    with leash, pushing, and grabbing. Incidents have occurred with a variety
    of domesticated animals. Frequency of these events is unknown and close
    adult supervision has been applied in the presence of animals.
3. Self-injury – including hair pulling, poking/gauging eyes, head banging,
    refusing to eat, hitting self with open or closed hand, swinging arms and
    legs around and hitting wall or furniture. This occurs 0-5 times a day and
    will rarely stop without intervention
4. Property destruction – including but not limited to throwing of objects
    towards walls, floor, and furniture, taking items apart, pushing items off of
    furniture, kicking walls and objects, punching of walls, objects, and
    windows. This behavior can occur in any setting 0-5 times per day and
    rarely stops without intervention
5. Medical Concerns – struggles with lack of appetite and maintaining
    weights. Has a protruding overbite which causes discomfort, is
    incontinent, and is in need of specialized medical evaluations and
    monitoring to determine the reason for sudden skill loss as well as medical
    stability.

6. Early childhood includes abandonment, parental drug use, familial history of chronic mental illness, possible sexual abuse, possible over-medication, and frequent bouts of malnourishment.
7. Needs assistance to evacuate for fire and assistance in regards to water temperature adjustment.
8. Needs full assistance with ADL's and often has behavioral outburst surrounding personal care.
9. Has demonstrated inappropriate sexual behavior and should be monitored around other children that are sexually reactive.
10. Has no since of danger and runs into unsafe situations to include traffic.

Based upon severity of behavior support needs and multiple MED diagnoses Jamie would best be served in a 24 hour group home with access to trained, rotating staff and wrap-around medical and mental health services. Staff would need to be trained on: OIS interventions based upon Behavior Support Plan; knowledge of psychiatric diagnosis; understanding of medications and side effects and experience or training in regards to mental health issues.

Profile: JOHN

John lives in a 5-person group home and is 32 years old.

He has been diagnosed with: Axis I: Adjustment Disorder with anxiety and Depression, Pervasive Developmental Disorder. Axis II: Mild Mental Retardation

John is very street smart and will need to be supported effectively in order to curve propensity to get into trouble with the law.
John's behavior in the community includes:
1. Extensive criminal history- multiple incarcerations
    a. Theft
    b. Criminal Mischief
    c. Assault
    d. Carrying a concealed weapon; felony possession of a weapon
    e. Criminal Trespass
    f. Burglary
    g. Unauthorized Use of a Motor Vehicle
2. Inappropriate Sexual Behavior
3. Drug and Alcohol Abuse

Supports that John would need to be successful in a community setting would be: 1:1 staffing in community setting; partnership with Parole and Probation board; mandatory anger management counseling; drug and alcohol counseling; and psychiatric monitoring. John requires a behavior support plan and OIS interventions (not necessarily PPI.)

Staff need:
1. To have an understanding of psychotropic medications
2. To effectively monitor him in the community without causing conflict with him
3. To work with multiple agencies to support John's needs

Profile: MARIA

Maria, age 27, lives in a foster care setting.

Her disability diagnoses include: Axis I: Schizoaffective Disorder, Bipolar type
Axis II: Mild Mental Retardation. Axis III: Seizure Disorder, Axis IV: Stressors
related to problems with primary support group, problems with interaction with the
legal system.

Her behavior at home and in the community includes:
1. Oppositional Defiant – will have screaming temper tantrums regardless of
   setting
2. Lack of Social Skills – unable to maintain social relationships
3. Sexual Promiscuity- no relationship boundaries
4. Physical Aggression – stabbed previous boyfriend, will punch, kick, pinch,
   bite, and choke
5. Irrational thinking – will not weigh consequences of decisions
6. Thinking Errors – refuses to take responsibility for actions
7. Sleep issues – does not consistently sleep through the night
8. Theft – has a history of shoplifting
9. Financial Issues – has no concept of the value of money, is materialistic and
   will spend impulsively without regard to need for funds for current or future
   required expenditures
10. Lack of impulse control
11. Vocational – unable to maintain in traditional vocational placements

Her support team includes her staff, PSRB and a psychiatrist. The staffing pattern
requires structure and predictability and but also needs rotating staff to avoid
burnout. She requires awake staff at night.

Staff would need to be trained on:
1. OIS Training/ behavior support and protective physical interventions
2. Knowledge of mental health diagnosis and related behavioral concerns
3. Medical knowledge – training in regards to seizure interventions
4. Ability to provide absolute boundaries
5. Financial Management skills

Profile: MATTHEW

Matthew is 42 and lives by himself with 1:1 staffing at all time. The services coordinator and residential agency are trying to find an employment agency that will support Matthew 25 hours a week in a community job in a closely supervised environment.

His diagnoses are: MRDD, dissociative disorder, NOS. He has poor speech and poor receptive communicative skills. Matthew left Fairview 15 years ago and has no family.

He engages in:
1. Severely self-injurious behavior
2. Physical aggression
3. Potential suicidal risk behavior

Matthew works best with males. He requires:
1. Daily clothing checks for small items that could be swallowed
2. A Pica free environment

His support currently includes agency staff, mental health therapist, psychiatrist, neurologist and a primary care provider.

Profile: PETER

Peter is 32 years old male living in a group home with two other men.

His disability diagnoses include: Axis I: Schizophrenia, Depression
Axis II: Mild Mental Retardation and Axis III: Insomnia.

Peter is a large gentleman who can become physically aggressive and requires OIS PPI. He also becomes delusional so all staff must be aware and deal with his perceived reality. He takes long (3+ miles) walks daily and requires staff accompaniment.

Peter's health and safety issues are:
1. AWOL – leaves home and areas in which supervision is present
2. Delusions – takes on the thoughts and feelings of a fictional self, believing that he is in danger, involved in an activity that is not perceived by others.
3. Depression – is tearful, experiences sleep disturbances (insomnia), lacks personal hygiene and refuses to participate in daily activities
4. Physical Aggression – hits (slaps and punches), kicks, grabs, and throws objects at others (primarily peers and those he perceives as weak)

Peter's support team includes 1:1 staffing, mental health professionals because he takes a number of psychotropic medications and a behavior support specialist.

Peter's supports require absolute structure and predictability. His housing requires consistent house rules, a fenced/locked yard and relaxation soothing techniques.

Profile: RACHAEL

Rachael, age 26, lives at home with her parents (guardians.) Her parents want her supported outside the home. Family choices, expectation and follow-through will greatly impact the success of her future supports. She is very mobile and active and would create potential safety issues for other residents of a group home and day program participants.

Over time her file came to include the following disabilities: autistic disorder, impulse control disorder, PDD-NOS (pervasive developmental disorder, not otherwise specified), moderate MR and hearing impaired.

Rachael engages in:
1. Self-injurious behavior, hitting her face, banging her head on walls
2. Property destruction
3. Aggressive behavior to others including hitting and kicking

There is alleged history of domestic violence in the home. She lacks stranger awareness or understanding of social vs. intimate relationships.

Supports needed are:
1. Family counseling
2. Individual counseling with therapist skilled in ASL and DD Deaf counseling experience
3. Home respite or full time residential program funding
   o 1:1 staffing with ASL
   o Large enough area for "safe space"
   o Female staff trained in working with victims of violence, self-abuse and aggressive behaviors

Profile: RICHARD

Richard lives in group home with four other men whose diagnoses include: mild MRDD, anti-social personality, PTSD and a history of sex abuse, both victim and perpetrator. He is a known sex offender.

The issues faced by Richard and his roommates are around:
1. Interpersonal boundaries
2. Medication needs
3. Community safety (the ability to travel and be in the community safely)

Staff skills needed:
1. Understand how to address his needs in an ISP
2. Knowledge of working with the courts
3. Understanding how to balance rights of the individual and the community
4. Sex offender treatment
5. Consistent communication strategies to keep everyone on his team, especially parole and probation officers

One community's perspective: In the next two years the state of Oregon will mandate all Sex Offenders be placed on the internet for "notification" purposes. Currently only predatory sex offenders are listed on-line and even their on-line notifications are, to some degree, at the discretion of their Probation Officer. We will go from no on-line notification of the dozen plus sex offenders we serve in comprehensive services to all being on-line. This will create community outrage and lead to highly visible criticism of our comp services. We currently have two group homes with a combined capacity to serve nine such individuals. We already are facing neighborhood pressure and questioning re: these two homes. This occurred when just one resident absconded and was hence placed on the internet notification site. That one notification sparked an angry reaction that may still not be resolved and could result in the Group Home's disruption from its current location.

Profile: SUSAN

Susan is 50 years old and lives in a group home with three other individuals.

The current provider is asking the county to find someone else to serve her due to the high turnover rate and unsuccessful attempts at keeping her staff trained and knowledgeable about her mental health supports as well as her cognitive and behavior issues.

Over the years she has been diagnosed with: Bi Polar I, Borderline Personality Disorder, Depression, MRDD and Diabetes II.

Her family lives in another part of state and comes into town for the annual ISP meeting and for her birthday. Susan has a history of legal concerns and is currently on parole for theft. She is at high risk for suicide. She lost her employment services and is now served through community inclusion services. There is difficulty in maintaining a consistent team due to high burnout.

Susan engages in:
1. Self-injurious behavior
2. Physical aggression
3. Property destruction
4. Cutting
5. LSA

Her support team includes agency staff, a mental health therapist, behavioral specialist, treatment team, primary care provider and her parole officer. Her current residential staffing is 1:1 and 2:1 in the community.

Staff would need to be trained on:
1. OIS Training/ behavior support and protective physical interventions
2. Knowledge of mental health diagnosis and related behavioral concerns
3. Working with the judicial system

Appendix B: Summary of Interviews

1.   Individuals interviewed for the Capacity-Building Project

2.   Summary of interview results

Individuals Interviewed for the Capacity-Building Project

Pat Allen-Sleeman, ASI

Dennis Billingsley, CCI

Jake Carls, Coast Rehabilitation

Joanne Fuhrman, PCL

Roger Hassenpflug, Living Opportunities

Zee Koza, New Day

Chris Krenk, Albertina Kerr

Mindy Mitchell-Goin, Rise

Gary Ostrom, CCTH

Kelly Thran, Good Shepard

Brett Turner, ALSO

Tom Wysuph, Eastco

Capacity Building Project
Interview summaries

III = item was stated in multiple interviews

1.   What services do you find are most effective in supporting these individuals?

IIIIIIII
- Supported living or very small living situations – alone or with at most 1 other person. Don't group them together!! 5 person home never works! Don't put them with other vulnerable people. (Cost for 1:1 staff & own apt. = @ $12,000/mo)

IIII I
- Contracted psychiatric services (at adolescent crisis center) or psychiatrist on staff – psychiatrist really knows organization, staff, and clients. Allows for better delivery of medical care by others (neurologists, PCPs) and better coordination with schools. Knows med management is an adjunct to behavioral programming rather than the other way around.

IIIII
- Proctor care model for kids - assuming right match – also for adults, TBI, severe mental illness.

III
- Individualized, person centered planning

II
- Structured Teach Program (for autism and others as well)
- Small environments for work also OIS
- Good supervision – at all levels of the organization
- Teamwork with residential coordinators, clinical staff, ISP team, family, etc.
- Registered dietitian
- School or vocational program for all individuals
- BSPs that are consistently implemented
- Quality health care providers who agree with philosophy of agency
- Secure locked homes (for some kids)
- Strong behavioral training
- Psychiatric team services
- Visual systems & alternative communication systems
- Applied Behavioral Analysis (but don't have the # and quality of staff to really do it)

2.   What is working in terms of structure, training and support?

IIIIIII
- Living in own place or smaller setting

IIIIII
- Predictability & consistency

IIIII
- Lots of Structure

IIII
- Well trained, well paid, mature staff (who stick around after being hit)

IIII
- 1:1 staffing to be able to do things without a whole group

II
- Internal information/data gathering processes – shift change, 2x CQI checks, month end reports, annual self assessments

II
- Treatment team model separate from IDT (counselor, service coordinator, case manager, psychiatrist, staff, family)
- Consistent staff with few changes

- Behavior consultant who goes to monthly staff meeting to review protocols and offer positive mental health support to staff (5-6 hours/month)
- Individual allowed to have personal and sexual relationships with others
- Screen staff for own sex abuse
- In-house OIS trainer
- Random drop ins by different management staff
- Cameras in common areas that are randomly monitored elsewhere
- Involvement in activities outside the home
- Proctor homes. Staff are trained to work with 1 kid rather than overall group with disabilities
- Matching of clients & care givers
- Positive behavior support training
- Monthly IDT staffing including admin person who can change assignments & budgets
- Involve dsp in regular data review
- Close monitoring of plan implementation
- Faster replacement of toxic staff
- Team must agree to pre-crisis plan & not just react to crisis
- Good BSP with the ability to re-tool
- Clear expectations of staff
- Locked kitchen, regular sweeps of house for sharps, never letting guard down
- For sex offenders & parolees – Different mentality, (more like police) with strict house rules, alarm systems on doors, windows, BSPs with reward points & contract
- Need right house, right roommates, right staff
- Staff in sex offender program are hand picked and paid at the highest level ($.25/hr more)
- Need lots of good background materials. Know history & what worked & didn't
- Team working together
- Psychiatrist who really knows the meds.
- Quick response team – people trained around strong aggressive behavior (more than OIS)
- Protocols in place around hospitalization
- Counseling
- Treatment team or trainer debriefs after incident
- Formal treatment in groups and/or individuals, esp for sex offenders
- Include dsp in treatment team
- In-house counselors
- Job assessments in 5 or 6 jobs for several days each
- Have people in highly integrated environments doing stuff they really like

3. What is difficult and/or makes you unable to serve people effectively?

IIIIIIIII • Don't have enough staff & hard to attract good staff (Risk factors of behavior make hiring even more selective)

IIIIII • High turnover (& need for constant training)

IIII • Poor wages for staff

IIII • Poor pool of applicants – less education, less ambitious, criminal histories, can't pass drug screen, poor math & literacy skills

IIII • Inaccurate information in referral. Info is old or missing

III • Poorly informed case managers.

III • Poor placement process i.e. arriving during med holiday, arriving w. no meds, no transition planning, disregard for established relationships, unaware of suicidal tendencies, Info is sometimes removed from file to make placement look better.

II I • No funding for level of training needed

III • OARs conflict with what's needed w. sex offenders i.e. rights & freedoms vs. restrictions

II • Huge gap between what we need in staff and what we pay for

II • Rates don't cover people's needs

II • Poor school supports – kids sent home or suspended or out of school for months but no $$ to pay staff. If teacher doesn't want kid in class, union supports that

II • Placement is too fast & usually in crisis. They want placement NOW!

I • Finding qualified therapists

• Recruiting crisis – not enough people to cover shifts & not able to fire people who should be fired.

• Hard to find live-in staff

• High level of physical needs

• Not understanding what's going on with individuals and why

• System barriers – DD system is committed to permancy vs. the fact that kids change and get better & need changing supports

• Lack of nursing staff

• Poor level of care from physicians

• Families who also have psychiatric problems

• Systems don't work together: With sex offenders, the juvenile department and probation officers don't buy into agency services and philosophy. They want consequences

• Lack of resources & mental health services – especially in rural areas

• Lack of training and resources, i.e. TBI, personality disorder, FAS

•

• No funding for ongoing behavior consultant once things are going well. You can't back off just because things are going well.

• Rates are cut if you don't use the hours

• Poor quality med reviews

• Matching is supposed to matter but doesn't when county wants a placement right away.

- Lousy crisis rates (where the most skilled and highest paid staff are needed)
- Need capacity & flexibility with behavior consultants & nursing staff
- 5 person group homes do not work. They teach each other bad habits
- People come with certain rates and agency is told to "make it work"
- Would need to start program for 1 or 2 people at a time
- If house, roommates & staff aren't all good matches, nothing works
- People refusing to take meds or follow treatment plan
- We end up serving people at a loss of $$
- Can't add counseling in budget
- Can't add extra training time in budget (2 hr/we for staff mtg is all that's allowed but staff need more time for initial shadowing and ongoing training.
- No backup options for kids who blow out except a lockup in Roseburg
- No backup options
- No MH resources esp for dual diagnosis
- Med management is guessing
- School District discipline policy conflicts with what kids needs
- Teachers and behavior specialists at the school can't do functional assessment or write decent BSP
- Conflicting rules between child welfare, SPD. (rules don't necessarily match what is best for kid. & what is reinforcing. Leads to escalation o behaviors.
- Little access to behavior specialists
- MH & DD don't work together. They argue over diagnosis (This one's yours)
- Staff in house aren't skilled to deal with kids behaviors. They need therapists
- Simple behavior modification doesn't work w mentally ill kids. Much deeper need
- Case managers don't know how to do transition to adult program & may never meet kids. Kids turn 18 and have nowhere to go.
- Staff have poor work ethic
- Staff are emotionally, spiritually & financially impoverished.
- Slots are left open & can't have fewer staff so either loose money or end up putting mis-matched person in the slot. Kids go where the opening is.
- Mixing adolescent boys and girls doesn't work.
- Procedures for placement aren't followed & check lists aren't used. i.e. no medical checks done on kids prior to placement.
- No accountability at county level

4. What does staff need in order to support these individuals?
IIIIIII
- Living wage for staff ($13-15/hr) ($2 over minimum wage)

IIIII
- Good supervision and coaching (really watch out & care for them or they will burn out & do something stupid) Build support into weekly staff meeting. Could use coach or supervisor at all times.

II • Forum to check in and get emotional support. Learn how to not own the clients' issues. Debriefing & review of incident reports & protocols.

II • Support to deal with abuse (emotionally & verbally)

II • Good staff training (in simple language):
- Medical protocols
- ISPs
- Client rights & rights restrictions
- Avoiding power struggles
- Impact of modeling behavior
- How to help families in proctor situation
- TBI, personality disorders, FAS
- Dual diagnosis
- Sexually abused
- Problem solving
- Precursors and patterns of behavior
- Positive behavior support
- Escalation
- Mental health issues
- Family dynamics
- Group dynamics
- Psychotropic medications
- Autism
- Structured routines
- Sex offender training (Gerry Newton, Sandra Potter)
- Different philosophy around supports for sex offenders and parolees than DD
- BSP – need techniques that are more sophisticated than OIS
- OIS
- Burnout prevention
- Reinforcement
- Staff need to be physically able & mentally stable
- Frequent staff meetings for venting (well facilitated)
- Systems & ways to further formal education (MH side requires bachelor degree)
- Recognition
- Need to be able to separate themselves from emotional turmoil of the kids & not take things personally
- Need good coping skills

5. What does the agency need in order to build capacity to serve these individuals?

IIIIIIII • Decent rates

IIIIII • Need higher skill level of dsp. Centered, mature, with understanding of MH issues, greater cognitive capacity, more professional, strong personality, bachelors degree

IIIII • Better case managers who understand what agencies do and have realistic expectations. They need core competencies.

IIII • Access to good supports (psychiatric, medical services, behavior specialists, dentists)
II • Good med management
II • Good psychiatrist who understands DD, preferably on contract with agency
II • Start up $$ (training, time to ramp up, capacity to serve several people not just 1 or 2 at a time)
• Management training on how to deal with scenarios and staff support (therapist)
• Core competencies for managers
• Good behavior specialist – with follow up and a feedback loop
• Replicate Rise's model in Utah – team of therapist, psychiatrist & behaviorist that work together and don't have competing efforts. This helps keep people out of the hospital
• More choice in therapists and MH professionals
• "We're fishing in the wrong pond."
• Predictable funding
• Compassionate & passionate leadership
• Good QA system
• Dedicated & consistent staff
• Community support
• Lots of training
• Good therapists locally
• Better planning time prior to placement
• More accurate info about what others have done
• Clear expectations from state on liability
• Better referrals (clear & complete information) and better matching of referrals. (Organization gets 15 referrals when they are full and then none when they have vacancies)

6. What partnerships would enhance service to these individuals?
IIIIIII • Access to good psychiatric care (Dr. Green)
IIIIIII • Access to med management,
IIIIIII • Access to behavior specialists
IIIIIII • Access to therapists
III • transportation:
II • Psychiatrists have little or no experience with or interest in DD client. SPD should develop program to enhance the interest & knowledge base of community based psychiatrists to serve DD population. Same is true of PCPs, medical specialists and dentists. Perhaps go to med school & ask for required classes in DD.
II • Other partners are uninformed about DD population – hospitals, law enforcement, hospice, OHSU, SORPU (S. OR. Regional Psychiatric Unit). We need increased cooperation among providers to share solutions & approaches.
• poor or no public transportation.

- Difficult to get individuals from rural areas to specialists in the city.
- Staff travel time and transportation aren't included in budgets
- Voc Rehab is not eager to serve these folks
- Access to psychiatric help is slow (sometimes months) Screening is through mental health therapists with referrals then to Dr.
- Child welfare system depends on who you get.
- Proctor could work for sex offenders if the systems could work together - Oregon Youth Authority
- "We need a woven piece rather than crazy patchwork quilt of services"
- Partnership w. community colleges to professionalize field
- Partnerships for jointly recruiting & training foster parents (Morrison Center)
- sex offender therapists & probation officers & case managers all must be in line
- Therapists on the coast, especially sex offense & DD (in Portland – Henry Miller)
- Emergency supports – They use the hospital but the level of expertise is not there.
- Supports from schools, psych services, medical community (In Astoria there are good people in place but no network or organized effort to pull them together.
- Housing. Duplexes are hard to find
- County is not equipped to do counseling but agency is supposed to go there.
- MH side pays for staff at higher rates & requires BA degree
- Look at people holistically.
- Pay therapists by the hour not the case. DD folks take more time and therapists can't afford to see many of them.
- Community Works – combined human services group with domestic violence & people with DD to develop curriculum to help people prevent sexual abuse.
- Rules need to make sense for kids. Ludicrous interpretation of OARs that result in kids having to leave homes at 18 because they can't be with younger kid even though they are like brothers.
- DHS, Child Welfare, Counties, SPD need to work together.
- Law enforcement – director will prepare briefing and guidelines for all shifts to tell them about the organization and what kind of kids they support.

Appendix C: Small Group Discussion Summaries

1.   Organizations participating in small group discussions held at the
        April 2007 ORA Quarterly meeting

2.   Summaries of small group discussions held at the April 2007 ORA
        Quarterly meeting

Organizations Participating in Small Group Discussions Held at the April 2007 ORA Quarterly Meeting

Albertina Kerr
ALSO
Alternative Services, Inc.
Alvord-Taylor
CCI
Chamberlain House
Coast Rehabilitation
Columbia Gorge Center
Community Access Services
Cornerstone
Douglas Residential Training Center
Dungarvin
Edwards Center
Galt Foundation
Garten Services
Independent Environments
Living Opportunities
LCC—Specialized Employment
OFCO
OSLP
Pathway Enterprises
PCL
Rise
Riverside Training Centers
Shangri-La
Umpqua Homes for Handicapped
Witco

ORA Quarterly: Capacity Building
Dianne
Susan/Matthew

*** Indicates items prioritized by group

#1 What is or would be effective in supporting these individuals if your agency was new to serving her?? (Susan and Matthew)
- *** Give providers start-up time of 30/60 days to adequately prepare the site and staff to be successful; create contract with county that the placement will be reviewed at six months to judge success and the provider can state if it is working or not.
- Bring former agency trained staff in to train new agency staff if applicable
- Bring people who know her into the early discussion about her supports so that the larger picture of what works and doesn't work becomes clear
- Receive adequate, up-to-date and pertinent information from the county, the previous provider and their circle of support
- Allow for the crossover of information to be given in meetings that are face-to-face rather than just sending files.

Issues to look at before transitioning her to another agency:
- *** Work with current provider: Provide organizational support
- Look at the staffing patterns in the home
- Look at the roommates and is this working or causing problems
- Look at the configuration (environment) of the current placement
- Look at the training provided the current staff

What is the culture of the staff and of the organization? Is it a good fit with the person?

With either a new agency or within the same agency if a crisis occurs:
- Do a up-to-date medical/mental assessment
- *** Require a face-to-face team meeting w/all stakeholders
- The system needs to look at A&D and Mental Health models for wrap around concepts rather than reinventing the wheel
- Constant analysis of Susan and building trust

#2 How does the Placement Process work now?
- Placement process is driven by vacancies which is not a person centered approach
- Providers don't have flexibility in changing individuals they support except in cases of "Death or Dissatisfaction"
- Creative emerging programs are asked by state/county/region to take more and more individuals before they have really immersed themselves in learning what works and does not work with their emerging practices

What issues arise from the current placement process? What can be done differently?
- *** Educating providers about the emerging needs of the system and then helping them build expertise
- Forming provider support groups
- Support services funded systems for less complex individuals
- Rate system inadequate

- <u>Providers</u> are the proactive change agent not the state or the county
- How about the system creating opportunities for change rather than always operating out of a crisis mindset.
- Placements are driven by service coord/provider personality and who knows what about whom in the county rather than a fair open process to allow all interested providers to respond (There are no more rfps as was the practice in the past)

#3 What's difficult and/or makes you unable to serve people effectively?
- *** There has not been clear information about the system's needs to providers
- The person's paper trail (files) is intentionally minimized to avoid pre-conceived notions/judgment by potential providers
- The presumed fear is that if providers where given all the details/facts providers couldn't/wouldn't handle the truth
- Getting good supports to provide good service providers
- Not adequate resources (clinical staff) or array of training staff
- Providers are not prepared to support these individuals
- *** The system needs to allow for cross over of DD & MH funds and services
- System needs to start thinking in person centered ways
- On the profile the examples of what staff need there wasn't anything about PCP and learning about Susan
- Provider cooperation between residential and voc.

#4 What does staff need in order to support these individuals?
- Create a culture of support for staff
- Go back to agency mission and vision to provide direction
- *** Use creativity & person centered approaches
- All supports need to be driven by the individual
- *** Look at ways to build "Support Circles" for staff. Support looks like:
  - Counseling services
  - Positive R+
  - Recognition
  - Use yearly evaluation process to identify staff goals
  - Lottery and awards for retention incentive building
- Statewide curriculum (look at North Dakota) and staff training
- UAP
- "Certified" Staff with pay increased as they receive more training
- Required and funded by the state

#5 What does the provider organization need in order to build capacity to serve these individuals?
- *** Creating solution-based regional teams which become regional clearinghouse of resources: Behavioral specialist, MH Staff
- *** Revive supported living

- Encourage billiard effect of more & more inclusive services which allow individuals currently in group homes to move into supported living and that will open up more space for complex needs individuals to be served.
- T & TA from other disciplines around support needs – mental health

#6 What partnerships would enhance service to these individuals?
- Head of these state departments get together and work together
- *** Build partnerships across disciplines – MH nurse practitioner, parole officer
- Develop support systems for all people involved in serving Susan

ORA Quarterly: Capacity Building
Tim
Effective Supports (Richard & Dylan)

#1 What is or would be effective in supporting these individuals?
- Organize your team-agreements, authority, communication
- ***Recognize that "DD philosophy" may not apply to sex-offender groups—they may different training approaches
- Review rules, look for variances – but a better approach is to develop rules specific to this group (or to all groups who need consequating for serious issues)
- ***Person centered response needed but differently from standard system
- Sex offender unique
- Holistic approach – lots of treatment types needed in support/planning
- Recognize you may be using different approaches
- Don't mix 2 approaches in one home – hard to treat one person differently. However, don't create sex-offender ghettos either.

#2 How does the placement process work now?
- Case Managers Need a lower Case load to know person
- Provider Dilemma – Should we serve sex-offender types at a loss? Present support often insufficient for their real needs, and those needs are often glossed over in referral packets
- Go through referral packet with fine toothed comb – people don't want to label individuals with this "forever dangerous" tag and tend to downplay or not fully disclose sex-offending incidents.
- ***We need New training/treatment models for dual diagnosis
- 18-21 schools want to exit and providers don't want to serve unless there's sufficient funding

#3 &4 What is difficult and or makes you unable to serve people effectively?
What does staff need in order to support these people?
- Specified training
- Formal behavior program training geared towards the SO population
- ***Treatment team proactive, united front, frequent communication and support

#1 What is effective in supporting these people?
- Pay attention to community concerns-communication system

#2 How does the placement process work now?
- County approach often "Anyone who will take them" vs. planned placements
- ***Not full disclosure by county – and, worse, low-balling costs because of it
- Provider needs to interview referral sources outside formal channels, e.g. direct care where they were, etc. to ferret out "real" information

- ***Difficult to negotiate rates, e.g. FTE – County will try to low ball because of other budget pressures
- Placement out of crisis done in a hurry

#3 What **is difficult and or makes you unable to serve people effectively?**
- Important for providers to have an economy of scale—to deal with special populations and have specialist trained up and on staff (i.e. taking one "hard" person who needs special supports usually doesn't pay for itself)
- Providers paying more to work with hard people – differing opiniont—may not be perceived as fair – slippery slope. However, there is higher turnover in houses with harder people – how to fix this?
- ***Need strong buy-in by case management to support hard people: they must be a part of the team and provide good back up to providers
- ***Ancillary supports not always available in community, e.g. for sexual issues
- Structural changes often needed, technology may help (e.g. using phone GPS). We need to have serious discussion about role of tech.
- Opportunity to debrief with professionals on a regular basis

#5 What does the provider organization need in order to build capacity to serve these individuals?
- ***Need rates that support people
- Critical mass of people with similar issues vs segregation, but don't want to "form gangs"
- ***Consider administrative rule specific to sex offenders
- Variance approach doesn't work – too patchwork, too many necessary
- Non-adjudicated sex offenders, etc, often underreported in referral, staff protect and underreport too
- More $ to county to hire psychiatrists
- OIS does not always work for this population– may need add ons
- If authorized for restraint must staff up and wait for need – so be careful what gets authorized or it can present over-staffing
- Sometimes people need to live on their own – not mix with similar or other people
- Perceived risk/liability of professional to treat sex offenders, many don't want to
- Group therapy – mixing kids and adults doesn't work, most group therapy not geared to cognitive disabilities anyway
- Drug use/sex offenders an even harder population – drug use dd also
- **No SO or drug treatment models specific for people with DD

#6 What partnerships would enhance service to these individuals?
- Look to Attorney General Sexual Assault task force – anything there for us?
- ***Criminal system needs to be trained to work with PWDD
- People jailed then released because system can't serve people learn there are no consequences – what can we do?
- System and Providers good at teaching rights, not responsibilities

- ***System should have Core Competencies for case managers. Or managing/monitoring training. Avoid the "gotch ya" approach – we're all in this together and the person should be at the center.
- ***Case managers need to build relationships with providers (see kids case managers as good models) Need lower case loads
- Open, timely communication between case manager—provider
- Need specific trainings for Case Managers – see Res. Coordinator for kids proctor care

ORA Quarterly: Capacity Building
KC
Maria/Susan

(*** indicates items prioritized by group)

#1 What's effective in supporting these individuals?
- Staff consistency
- Routine
- Financial supports are not on-site (no immediate access to $) Susan
- Crisis support for staff
- Immediate access to MH supports
- Crisis line for the indiv
- Very responsive grievance policy
- ***Empowerment of the indiv. i.e.. Calling police
- ***Cognitive behavioral therapy i.e. Personal choice card/tree
- ***Removing potential victims/audience
- 1:1 staffing
- ***Have right staff, therapist, counselor
- Flexibility w/housing-able to move frequently if needed
- Correct medication
- Flexibility – opportunities to experience different employment
- Rotate 1:1 staff
- All the above

#2 How does the placement process work now?
- ***Crisis driven, little planning, no training (you put them where there is space)
- ***Poor informational packets for planning or budgeting
- If desperate will negotiate
- Sometimes turn people down
- No-one wanting to take responsibility for actual move
- ***Process is long and staff are already overworked
- Current systems already stressed

#3 Difficult/Unable to Serve
- Limited psychiatric services (avail. M-F days)
- Staff (not enough)
- County does not support police involvement (some counties)
- Police poorly equipped to work w/people with disabilities
- Development of BSP's very slow
- Staff turnover
- ***Not enough $ to provide supports
- ***Budgets are "set in stone", can't negotiate when needs change
- Inappropriate actions by guardians & family (poor advocates)

- People don't want the service
- Case manager lack of understanding
- ***Poor diagnosis

#4 Staff Needs
- ***Crisis counseling support for staff
- Ongoing counseling & Supports
- More $ so that they are not so stressed about their own lives
- ***Well trained relief staff to prevent burnout
- ***More training (diagnosis specific-ongoing, training and practice before they mess up, BSP, "how to not take it personally" – condition specific, observe success w/mentor)
- Management understanding of staff personal issues
- Better trained managers
- Overlap staff between organizations
- $financial planning/training

#5 What does agency need to build capacity?
- Affordable housing & apts.
- ***Pay decent wages to attract/keep staff ($17 hr)
- Teams that are creative about finding solutions (case manager) work together
- ***Ability to negotiate & renegotiate rates
- Quick and accurate referrals
- Appropriate housing
- ***Streamline bureaucracy
- ***Rules/regulations (delegated nursing, reaffirming diagnosis) mand. Work hours

#6 Partnerships?
- Police dept.
- ***Psych. Crisis (Salem Hosp. PCC)
- Other non-profits esp. around funding services
- Transportation
- Improve working relationship w/county
- Salem Hosp.
- Bus station
- ***Shelters (women's Crisis, Mission)
- Day recreation programs
- Colleges
- Subsidized housing
- DSO
- Social Security
- Cruises
- Press

ORA Quarterly: Capacity Building
Kelly G
Peter /Freddy

#1 Supports
- Individual person – centered
- Knowledgeable psychiatrist
- Consistency in funding coordination
- Flexibility in Budget

#2 Placement Process
- Placement in home without competing needs
- Portability

#3 Difficulties
- Physical damage to homes
- Assault issues
- Inconsistency meds/lag time (meds mgmt changing needs – crises need)
- Resource in rural areas
- Fetal alcohol syndrome
- Lack of professional respect

#1 Supports
- Fragmented systems e.g. county, state, brokerages, who has authority

#2 Placement process
- Foster placements – staffing networks via little family industries ~nepotism~

#3 Difficulties
- Wide variety of ages
- Bed model
- Clinical challenges
- Staffer of DD clients and prejudicial (neg) attitude

#4 Staff needs
- Training
- Flexibility in budget
- Supervision
- Money (living/equitable wage to assure consist service

#5 Organization Needs
- Resource usage spanning counties per specific individual's needs
- Provider resources when one provider cannot meet some needs

#6 Partnerships
  - Mental Health
  - PSRB
  - Child welfare system

#4 Staff Needs
  - Need turnover as needs higher
  - Different skills set needed for capacity to include crisis supports

#5 Organization Needs
  - Requiring RFP process to refer for supports/referrals
  - System needs-include state ops should participate in rate restructure

#6 Partnerships
  - Law enforcement

#2 Solutions
  - RFP all state ops to community providers
  - Grant app to get MD's (psychiatrists): OHSU – internships
  - Hook up with large foundation
  - Creation of different system of PSRB that deals with (understands) DD
  - Recognition of different skill set needed to build crisis support capacity

#1 Up front funding for capacity building
  - To serve 20+ people vs. 1 person at a time
  - Stabilize current system
  - Physical housing supports (bricks and mortar)

Appendix D: Family Focus Groups Summary

1.   Summary of focus groups of family members and significant others

Perspectives of Families and Significant Others

Family Supports:
- Families of children who are very challenging get little support from the system in Oregon. Too little. Too late.
- Ignored by both systems (MH /DD).
- No training or assistance in addressing healthy sexuality.
- Education is often a battleground and schools may actually make situations worse.
- Even families who are strong and have resources will burn out.

Process / Context:
- Access to comprehensive system is *crisis*. By definition it is not a planful process. Frightening. Threatening. Shattering.
- Language is dehumanizing. Providers are going to "review the file" "negotiate a rate" and the individual might get a "bed."
- Significant others in the individual's life are often left out.
- The result may be a serious lack of important and accurate information.
- There is often no way to provide input at the point it is needed.

Comprehensive system:
- Isolated communities
- Accountability? Who is really watching?
- Who are they living with?
- Who are the people supporting the individual? Really!?!?

Role of significant relationships in the individual's life:
- Current system is not used to dealing with families.
- Often very judgmental. Too involved. Not involved.
- Redefine family. Most individuals have someone who cares or cared about them and they deserve to have them in their lives.
- Facilitate relationships! (The system needs to make a personal advocate an important part of the Quality Assurance System.)
- Control is often issue. Questions / concerns result in defensive /reactive responses.
- Values – rarely specific discussion. Often the staff imposes their values and they may not reflect similar values of the individual or significant others.
- Information is difficult to access.

Staff / Training:

- Staff without training is simply engaging in "animal husbandry."
- House manager is key. Determines whether the house works or not. Whether staff is trained or not.
- Turnover!!!! Never make progress.
- Communication is often difficult. Managers out of touch with what is really happening. "Misinformation" at many levels.
- Wages are only one part. Professionalism. Respect by managers. Ongoing training and education opportunities. Support.
- Need to engage significant others in training.
- Don't understand self determination. Respect for adults with disabilities. Sometimes don't even understand the basics…not children. VALUES (Credo for Support)

Issues:

- Personal hygiene
- Clothing
- Food
- Sexuality
- "Experts" – take a class and think they know everything.

Appendix E: Training and Technical Assistance Recommendations

1   Summary of training and technical assistance recommendations from interviews, group discussions and Think Tanks

Summary of Training and Technical Assistance Recommendations

Training and Technical Assistance recommendations can be found throughout the themes of Personnel; Placement Process, Crisis Services, Ongoing Services; Specialized Resources and Ancillary Services presented in the main body of the text and in the Summary Table in Appendix F. This appendix compiles the recommendations from individual interviews, group discussions, and Think Tanks across these themes to assist in future planning for training and technical assistance initiatives. Because this is a list of ideas, not all items included in this appendix are listed elsewhere.

It also should be noted, that items listed in the Appendix F Summary Table under categories of Partnerships, Provider Actions, or System Development also may require the support of training and technical assistance. These items are not included here.

Vision:
- Oregon's Training and Technical Assistance System is adequately funded, responsive, coordinated, valued, and strategically planned based on the principles of Continuous Quality Improvement.
- The field and all stakeholders (families, individuals with disability, community partners) are internally motivated to seek T & TA rather than it being externally imposed.
- The system is built on collaboration and partnerships and increases the expertise and marketability of all participants.

Long Term Strategies

- Develop a Master Strategic Plan for delivery of Training and TA
- Develop better statewide and local system to disseminate available training information.

Design of Training
- Address regional and geographic issues through the use of technology and developing some type of mobile resources.
- Cultural competencies need to be integral part of T & TA

Partnerships
- Build regional partnerships with providers to encourage sharing T & TA resources including written regional delivery contracts with outcomes.
- Build in local training coordination as job duty: Use County QA coordinators or create separate county or regional position.
- Revive Regional Training Committees.

Resources & Personnel
- Increase the number and capacity of expert trainers at the statewide, regional and local levels.
- Provide mentorship and technical relationships for these expert trainers to continually improve and expand expertise. Example: Expert trainers have ongoing relationship with

knowledgeable psychiatrists, physical therapists, occupational therapists, speech pathologists etc. TA for TA providers.
- Develop a list of current statewide, regional and local experts as well as all existing training and training curriculums.
- Develop cadre of therapeutic paraprofessionals using the OIS model: examples: CBT, recreational art therapy.

Short-Term Actions
- Establish core competencies in training and behavior support methodologies and provide regular and ongoing training.
- Create coalition or consortium for pooled core comp training
- Identify competencies beyond the 90 day mark of Oregon's Core Competencies
- Provide training to help people from different service systems understand each other and work together better
- Establish an in-house OIS training in every agency
- Provide basic training for direct service staff regularly and in different locations around the state
- Form provider support groups
- Improve training, coaching & feedback for agency staff and families.
- Establish systems to further formal education for staff

Training Content Needed:

Community Partners
- Working with courts, probation and parole (e.g., strict rules, alarm systems, consequences, behavior contracts)
- Understanding how other systems work (e.g., courts, parole and probation, mental health)
- Sponsor local/regional forums for people from across disciplines to begin to form relationships, determine common ground, and share solutions and approaches
- Develop a presentation to enhance interests & knowledge of psychiatrists, primary care physicians, other specialists, dentists, etc., to serve the DD population
- Offer technical assistance to community partners
- Provide training to understand how to work with the conflicts between developmental disabilities services and other systems
- Provide support for agencies placing people in the community, to help overcome "not in my backyard" response

Supporting People with Complex Needs
- Information specific to diagnoses (e.g., personality disorder, autism)
- Sexual abuse
- Traumatic brain injury
- Fetal Alcohol Syndrome
- Working with sex offenders
- Psychotropic medications
- Mental health issues

- Models for serving people with dual diagnoses[1]
- Training technology (e.g., Structured Teach Program for people with autism and others as well)
- Developing individualized job environments
- Job assessments (e.g., in 5 or 6 jobs for several days each)
- Writing and following protocols (e.g., for hospitalization, medical issues)
- Rights and restrictions
- Personal and sexual relationships
- Look at people holistically
- Provide training on effective approaches for supporting people with dual diagnosis or other complex support needs
- Provide training to service coordinators and agencies related to how to provide services to individuals within the existing rules for people adjudicated and others
- Provide training to managers and supervisors on skills needed by direct service staff so they can mentor staff in skills needed
- Develop models of services based on individualized planning and create training for those specific support issues building in assurances that they will meet OAR and core competencies. Ex Proctor care and "inclusive day" of paid and natural supports. Not a canned training.

Behavioral Support
- Strong behavioral training, applied behavioral analysis
- Behavior support plans
- Predictability, consistency, structure (even for those w/o autism)
- Positive behavior support
- Supporting people in highly integrated settings doing things they really enjoy
- Visual systems and alternative communication systems
- Pre-crisis plans v. reacting to crisis
- Precursors and patterns of behavior
- Train more behavioral specialists

Treatment Teams
- Organizing a team, roles and responsibilities in interdisciplinary teams
- Group dynamics
- Working with a treatment team
- Provide support to providers to help them to develop these treatment teams or create regional teams.

Personnel Recruitment, Selection and Management
- Preventing staff burnout
- Staff retention strategies (e.g., opportunities to further formal education, recognition)
- Establishing clear expectations for staff
- Debriefing incidents with the treatment team or trainer
- Problem-solving skills
- Provide training for relief staff

- Provide training for families and managers on recruitment and selection strategies to get the _right_ staff
- Use quarterly forums to share best practices in recruitment, selection of staff, e.g., OIS, ORA, Case mgt forums
- Provide training from OIS.08 manual module on how to support staff during and after crises
- Provide training on mentoring and coaching, and other methods for retaining staff

Core Competencies
- Develop core competencies that go beyond initial training (agencies & foster)
- Identify Core Competencies for service coordinators
- Provide competency-based training for service coordinators, including rights v liability, maximizing independence, developmental disabilities issues
- Define core competencies for all existing traditional services

Training Methods
- Improve training strategies and materials; evaluate effectiveness
- Provide training regionally, increase use of technology— videos, telecasts to minimize impact on staff scheduling

Other
- Cognitive behavioral therapy (E.g., personal choice care/tree)
- Emerging needs of the system
- Working with the community to gain their support/responding to issues
- Training for proctor families
- Working with families, family dynamics
- Provide training on basic computer skills
- Provide training on effective quality systems, including long term vision
- Proactively invite families to participate in any appropriate training

Appendix F: Summary of Barriers, Strategies and Actions

1   Summary of Barriers/Issues, Long-Term Strategies and Short-Term Actions derived from individual provider interviews, group discussions, and the Think Tanks

Summary of Barriers/Issues, Long-Term Strategies and Short-Term Actions

Note: This is the most comprehensive list of the issues, long-term strategies and short-term actions recommended during interviews, group discussions and the Think Tanks. It therefore includes more ideas than the lists included in the body of the paper.

Theme: **Personnel**
Vision: We envision a system that supports:
- Professionally diverse, specialized and stable workforce in desirable, well-defined, manageable positions.
- Livable wages that are commensurate with demonstrated competencies.
- Compassionate and passionate leadership
- Information systems to support quality (including use for quality planning, quality assurance and quality improvement)

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
There is a huge gap between what is needed in staff skills and the applicants we attract • Hard to attract good staff with the poor wages we offer • Risk factors of challenges presented by individuals make hiring even more selective • Poor pool of applicants (education, criminal history, drug use, poor math and literacy skills, lack of ambition, not physically able to do the work, mentally unstable) • Staff don't have the skills to deal with complex mental health issues, or implement behavior plans	Create a new tier of direct service staff that is better paid, better trained. Increase professionalism. • Increase level of qualifications required for direct support workers, increasing their status/pay to attract better qualified applicants with higher skills, greater cognitive capacity, higher educational level (e.g., BA required) • Create structured opportunities for growth and development in the field (career ladder). • Consider direct service certification through community college/workforce development programs • Invest long-term in staff development	Training and Technical Assistance: • Provide training for families and managers on recruitment and selection strategies to get the <u>right</u> staff • Develop core competencies that go beyond initial training (agencies & foster) • Use quarterly forums to share best practices in recruitment, selection of staff, e.g., OIS, ORA, Case mgt forums • Provide training regionally, increase use of technology— videos, telecasts to minimize impact on staff scheduling • Provide training on basic computer skills • Improve training strategies and materials; evaluate effectiveness • Proactively invite families to participate in any appropriate training

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	Develop future funding models to include staff training Develop strategies to better support families to be successful in supporting their children/adult children at home Build on what has worked in the past Research how to better use technology	Provider Actions • Seek ways to pool aspects of recruitment efforts or share applicants; develop marketing plan • Create tiers of direct care staff, with different titles, with more advanced staff acting as mentors and providing support during crises • Use flexible staffing models to make best use of resources; creative scheduling • Use a person-centered plan to develop a vision for person's preferred living situation so they do not stagnate in a program
Providers don't have enough staff to do the work • Not enough staff • Hard to find live-in staff • High turnover (and need for constant training) • Managers are covering more shifts, burning out and leaving	Establish partnerships and shared resources • Establish partnerships for jointly recruiting and training • Establish organizational marketing programs for recruitment and selection of staff • Explore ethnic/cultural groups that can help us improve our cultural sensitivity and other "naturals" for partnership, e.g., faith-based organizations Develop future funding models to include staff back-up	Training and Technical Assistance • Provide training from OIS.08 manual module on how to support staff during and after crises Partnerships • Develop partnerships with community colleges to explore strategies for recruitment and certification programs for direct service personnel • Investigate ways to work with other providers to ensure that all staff are adequately supported during and after dealing with crises

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	Improve personnel management practices • Provide strong supervision and support at all levels of the organization • Develop leadership skills at mid-mgt level to build knowledge and skills as senior managers are retiring • Develop/ identify staff management models that provide high levels of support.	Training and Technical Assistance • Provide training on mentoring and coaching, and other methods for retaining staff • Provide training to managers and supervisors on skills needed by direct service staff so they can mentor staff in skills needed • Provide training on effective quality systems, including long term visions Provider and County Actions • Create clear job descriptions for manageable work loads (# on caseload; # of hours) for direct service staff, managers and case managers
Some service coordinators are poorly informed or poorly trained.	Improve how service coordinators work with people and programs in crisis • Develop service coordinators who understand what agencies do, have realistic expectations, are part of the team, and provide good back up to providers (kids case managers is a good model) • Inform county management structure about developmental disabilities issues	Training and Technical Assistance • Identify Core Competencies for service coordinators • Provide competency-based training for service coordinators, including rights v liability, maximizing independence, developmental disabilities issues

Theme: **Placement Process, Crisis Services, Ongoing Services**

Vision: We envision a system that uses:

- An interdisciplinary, standardized, person-centered, and holistic approach to services—including helping people stay or become connected with family members—where money from different funding streams is blended, and follows and is directed by the person
- A proactive timely response to emerging consumer needs to stabilize placements before going into crisis
- Partnerships that are cooperative, contractual, inclusive of and equally value the expertise of all key stakeholders, based on shared values, emerging/shared technology, and creativity—not bound by tradition—and result in win-wins

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
The placement process is crisis driven with little planning and no training for provider staff. As a result, placements are driven by vacancies and are not person-centered. - Some providers aren't given the opportunity to apply to provide services. - Poor placement process: e.g., too fast, too long, often disregards established relationships - Not understanding what's going on with individuals and why	Decouple the delivery of crisis services from "crisis-diversion" funding Establish a new design for the systems for dealing with crisis and emerging problems, and for delivering long term intensive services, based on: - Identifying individuals with a high probability of requiring short-term crisis services and long term intensive services - Careful matching for the individual's (initial) placement - Designing environments to support success - Delivering enhanced technical assistance and training to support maximum opportunity for success in their (initial) current environments - Providing a team of expert support to provide quick response, relief and planning during a period of crisis (both	System Development - Clearly define what we mean when we say "crisis" - Develop a standardized global, comprehensive assessment process for people with complex support needs and their environments to anticipate issues, to assist in creating proactive supports and to analyze crises. The process should include the Supports Intensity Scale, Functional Assessment of Behavior, and medical and medication reviews, as appropriate. - Complete a critical analysis of what is happening now and why, number & types of crises, number/percent who move, etc. - Establish a work group to begin defining a new design for a crisis system, for emerging problems, and for long-term intensive services - Ensure that each region has the ability to provide services to people with high needs

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	internal team and external county/regional team) • Establishing regional acute crisis programs for short term stays Developing strategies for supporting individuals who have infrequent high-level support needs. Pilot the system in selected counties or regions. Improve contracting for crisis services • Develop contracts to include 30-60 days start up time and 6 month reviews • Issue RFQs and get contracts in place before they are needed • RFP for services for several people, to give providers sufficient resource to develop capacity	• Use creativity and person-centered approaches • Address the needs of families as well as providers, and engaging families as a resource for support • Establish a pre-need Request for Qualifications (or similar) system and contracts that include startup time, sufficient funding, and periodic reviews, allowing proactive capacity-building; improving flow of information for planning purposes, and review of viability of contract • At the start of each biennium, earmark part of the budget for start-up funds (Counties or Regions) • Review how we are managing vacancies, how they are used for crises • Support developing overall county vision and planning for serving people with complex needs
Having to group people who present difficult challenges • Five-person homes may not work, they teach others bad habits • Group work settings	Develop individual environments • Develop affordable housing projects in various regions around the state (smaller units, duplexes) for providing supported living or very small living situations (alone or with one other person) • Develop individual work environments that match needs of person with support needs • Consider different housing models,	Partnerships • Develop a relationship with a county housing authority to learn when low-income housing projects are available and to establish a pilot project • Ensure that everyone has supports that make sense for the person

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	including apartment complex with 24 hr support staff for transition age young adults	
When an individual is moved to a new provider: • Information packets are incomplete, old, and often misleading; diagnoses, medical and mental health assessments out of date • Arrivals are not well-planned and coordinated, including arriving during med holidays or with no meds • The new home may be unaware of special situations (such as suicidal tendencies)	Improve information and coordination • Develop an expectation of complete and accurate information about the individual and their challenges, history, what has worked and not worked. • Provide accurate and complete information for all placements	Systems Development • Implement guidelines for information packets consistently across regions • Develop guidelines/ checklists for moving Training and Technical Assistance • Provide training on contents of information packet and on coordinating moves and improve consistency across counties and regions
Service providers are not funded for the level of support that is needed • Difficult to negotiate rates • No funds for start-up costs • Poor/non-existent back-up • Rates don't cover individual's needs • Rates are cut if the service providers don't use the hours • Rates don't support having the most skilled and highest paid staff who are the ones needed for	Improve funding for people with complex needs • Build capacity for providers to serve several people, in individualized settings, rather than addressing the issue one person at a time • Develop rates that support people • Reassess present model of crisis budgeting • Make resources more flexible: Facilitate use counties and providers based on specific individual's needs	Partnerships • Develop partnerships with schools, mental health, criminal justice… System Development • Develop strategies for supporting individuals with infrequent high-level support needs • Counties earmark funds for start up at beginning of biennium

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
providing crisis services • Providers who serve people with complex needs often lose money • Can't add counseling in budget • Staff travel time and transportation aren't included in the budgets		
Service providers are not skilled in providing services to people with developmental disabilities who are sex offenders, drug users, or have a dual diagnosis of mental health issues.	Implement proven models • Support implementation of proven models for serving people with DD who are sex offenders, drug users, or have dual diagnoses • Inform provider organizations of future service needs, so that they can incorporate that into planning Revise OARs, Contracts, Waivers • Review, revise or develop OARs, statutes, contracts, waivers needed to support the vision; look for opportunities to mesh OARs, definitions, eligibility standards, etc.	Systems Development • Conduct research to identify effective models for serving this population • Explore establishing rules specific to services to sex offenders, kids v. adults • Meet with providers to discuss future development needs Training and Technical Assistance • Provide training on effective approaches • Provide training to understand how to work with the conflicts between developmental disabilities services and other systems • Help providers to understand how to provide services to this population within the OARs • Provide support for agencies placing people in the community, to help overcome "not in my backyard" response • Provide training to service coordinators and agencies related to how to provide services to individuals within the existing rules for people adjudicated and others

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
		Partnerships • Work in partnership with other organizations to ensure individuals get the support they need • Develop local and regional partnerships with criminal justice, schools, mental health

Theme: **Specialized Resources and Ancillary Services**
Vision: We envision a system that has:
- Developed specialized resources/ancillary services that are individualized, portable, flexible, and outcome-based all across Oregon.
- Professionals in other disciplines who are well-trained to work with people with developmental disabilities in a holistic manner that supports self-determination.

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
Systems don't work together - PSRB system does not understand DD - Hard to find quality health care providers who agree with the philosophy of the agency - For sex offenders, the juvenile department and probation offers want consequences, and don't buy into agency philosophy - Poor school supports - MH and DD argue over diagnosis (Funding conflicts) --"This one is yours." - VR is not eager to serve these folks - The system is fragmented, who has authority? County, state, brokerages, MH, DD, Judicial…. - The DD system is committed to permanency v. the fact that kids needs change and get better and need changing supports	Develop partnerships - Establish partnerships across disciplines at the state and local levels, e.g., mental health practitioners, probation/parole officers, crisis units, police, school, hospital staff, hospice, psychiatric medication management, VR, transportation, dentists, physicians (neurologists, PCPs), dietitians, regional crisis units, Child Welfare, Oregon Youth Authority, domestic violence groups, residential and voc providers, shelters, recreation programs - Identify or develop new models that promote different services, respond to different needs, and expand partnerships - Create incentives for specialists to partner Maintain "knowledge learned" and best practices - Provide incentives for achieving outcomes - Move beyond "Care Model," so all settings are viewed as teaching/learning settings - Explore risk in light of serving people with complex needs	Training and Technical Assistance - Sponsor local/regional forums for people from across disciplines to begin to form relationships, determine common ground, and share solutions and approaches Partnerships - Explore models such as "Community Works"—a Medford group including domestic violence and people with DD to develop curriculum to help people prevent sexual abuse - Develop partner agency collaboration at the Executive/ Admin. level to address gaps - Develop formal partnership agreements as appropriate - Support on-going systems change efforts (ReBAR, Mental Health, Children's Programs) - Develop a work group to establish clear guidelines related

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	• Clarify risk and liability issues and strategies for reducing liability/risk	to liability, rights, risks, protection, county/state/provider liability
Lack of mental health services and other specialists • Lack of mental health providers, especially outside of main metro areas; lack of treatment for sex offenders and people with dual diagnoses • Some families also have psychiatric problems • Access to psychiatrists is slow (sometimes months) with screening through mental health therapists and referrals to doctor • Insufficient access to good psychiatric care and med management • Difficult to get individuals from rural areas to specialists in the city; Poor or no public transportation • Lack of nursing staff; need capacity/flexibility in nursing staff	Improve strategies related to mental health services • Develop staff psychiatrists to support better medication management. and better medical care by others • Hire in-house mental health counselors • Develop fee for service agreements for counselors with mental health funders so that they are paid by the hour, rather than a case rate. (People with DD often require more time and therapists can't afford to see many of them) Develop/enhance resource guides, websites, e.g., Disability Compass	Partnerships • Establish local, county, or regional contracts with psychiatrists and mental health counselors so they may become familiarized with individuals, agency and staff (e.g., "time shares") • Work with local behavioral health organizations to include more therapists who will work with people with developmental disabilities
Specialists from different disciplines do not work together well • Poor communication with service provider • Little communication with others on team	Improve teamwork • Establish a treatment team model that includes direct service professionals, counselor, psychiatrist, staff, family, service coordinator, all working together with frequent contact (e.g., monthly staffing); include administrator who can change	Training and Technical Assistance • Provide support to providers to help them to develop these treatment teams or create regional teams.

Current Barriers/Issues	Long-Term Strategies	Short-Term Actions
	assignments and budgets. • Develop cooperative training agreements for pre-service and in-service training across disciplines	
Professionals in other fields do not understand working with people with developmental disabilities • Mental health therapists do not know how to work with people with DD • OHSU—physicians and psychiatrists • Criminal system • Poor level of medical services • Poor level of care from physicians • Poor quality med reviews • Med management is guessing	Improve pre-service and in-service training for professionals in other related fields • Work with university training programs for professionals from other fields to build information about people with developmental disabilities into their pre-service and in-service training curricula.	Training and Technical Assistance • Develop a presentation to enhance interests & knowledge of psychiatrists, primary care physicians, other specialists, dentists, etc., to serve the DD population Partnerships • Offer technical assistance to community partners
Limited access to qualified behavior specialists • Need capacity and flexibility • No funding for ongoing behavior consultant once things are going well	Improve funding for and use of behavior consultants • Provide funding for behavior consultant to attend staff meetings (4-6 hours/month) to assess effectiveness of BSP, update BSP and protocols, provide ongoing training and feedback, and offer positive support to staff. • Increase the number of qualified behavior specialists available • Increase understanding by the individual planning team of what is in the budget	Provider Actions • Include direct service staff in regular data review/monitoring of plan implementation Training and Technical Assistance • Train more behavioral specialists

Appendix G: Review of Nationally Recognized Models

1.   Review of nationally recognized models of effective partnership and workforce development

Nationally Recognized Models of
Effective Partnership and Workforce Development

An important part of the Capacity-Building project has been research to identify national best and emerging practices. Early in the research, it was discovered that there are few exemplary programs, resources and staff skills are generally poor, and there are pockets of capacity rather than generalized across a state. After reviewing nearly 800 programs, research identified a few that served a region or statewide, and focused on serving individuals with complex support needs similar to those we are supporting in Oregon. Overall, the people that these programs supported who were "a challenge to support" were individuals with dual diagnosis, individuals with severe behavioral challenges, or individuals on the Autism spectrum.

Assessments

The research literature indicates that as many as one-third of all individuals with an intellectual disability have a mental health or behavior problem requiring specialized support services. It also states that people with intellectual disabilities experience the full range of mental health problems, including anxiety disorders, mood disorders, schizophrenia, personality disorders, substance-related disorders, and sexual disorders. However, traditional mental health services available in the community have long been shown to be too fragmented, inaccessible, and ineffective as a treatment option for individuals with intellectual disability. The causal factors of complex problem behaviors might relate to biology, physical environment, social environment, life experiences, psychological well-being, or any combination thereof. Because of this, the recommended best practice is to use an interdisciplinary or multi-method assessment approach to effectively assess/diagnose or rule-out health and mental health problems in individuals with intellectual disabilities. Best practice evaluations therefore incorporate a personal/social history (e.g., recording of recent stressors), physical examination and medical history, evaluation of current medication and possible side effects or interaction effects, psychiatric evaluation, and a functional behavior analysis.

Model programs

Research revealed several model programs with relevance to current issues in Oregon. Six of these are described here:
- START (Systematic, Therapeutic, Assessment, Respite, and Treatment) Model—Boston, Massachusetts
- Crisis Assistance Program—Indiana
- Crisis Intervention Program—Rochester, New York
- Interface—Ohio
- Positive Behavior Supports—South Carolina
- Active Community Treatment Teams (multiple locations)

Additional programs which merit further review, but are not described here, include RISE, Utah; Seattle Mental Health, Washington; Mobile Crisis Intervention Services, California; and Emergency Housing Options, California.

START (Systematic, Therapeutic, Assessment, Respite, and Treatment) Model—Boston, MA

The START Program is a community-based service that offers interdisciplinary clinical services, emergency services, and respite care for individuals with intellectual disabilities and experiencing mental health or complex behavior problems. It is funded by the Massachusetts Department of Mental Retardation. The philosophical underpinnings of the START program is largely person-focused and believes that services/supports will be most effective when everyone involved in the care/treatment is allowed to actively participate in the decision process of planning supports and services.

The START model includes:
- 1 clinical supervisor
- 1 part-time psychiatrist
- 3 full-time senior behavior consultants (with certification)
- 6 full-time behavior specialists (no certification)
- 1 social worker consultant

There are four primary components to the START Model:
- Collaborative Linkages for coordinating the individual's annual crisis and support planning meetings, consultation visits, and follow-up meetings leading to training and technical assistance..
- Emergency Coordination in which the clinician serves as a conduit between the in-patient care providers and the individual's out-patient healthcare and mental healthcare providers, and also ensures that a transition plan is established and implemented.
- After-hours Contact. The START model provides 7-days/24-hours mobile emergency consultation in times of crisis.
- Respite Service provides a 4 bed residential unit that can accommodate a short-term stay in case of crisis or planned respite; an emergency respite is no longer than 30 days.

Crisis Assistance System—Indiana

The goal of Indiana's Crisis Assistance Program is to establish and implement a multi-tiered system that is proactive in preventing crisis situations and provides response supports and services in a least restrictive manner, enabling individuals with challenging behavior to remain in the community in a more efficient and cost-effective way.

The organizational model is implemented by state-contracted vendors in each geographical region of the state. Vendors are chosen by RFP process and are required to meet core service elements. Vendors are responsible to employ or subcontract all personnel; coordinate with other

state/county agencies; serve all persons in the region requiring crisis services, including prevention; and coordinate with the ISP team

Services include:
- 24 hour telephone support
- In-home technical assistance
- Out of home placement
- Follow along services

Crisis Intervention Program—Rochester, New York

The Rochester Crisis Intervention Program (CIP) has been in existence since 1987 and serves all individuals identified as having a developmental disability and residing in Monroe County, New York. The Rochester CIP program is operated out of the New York state's University Center for Excellence in Developmental Disabilities at the University of Rochester and receives its funding directly from the New York Office of Mental Retardation and Developmental Disabilities The philosophy of this community-based crisis intervention program is a strong person/family-focused approach with a commitment to comprehensive bio-psycho-social functional behavioral assessments.

The 24-hours/7-days-a-week services offered through the Rochester CIP include:
- Interdisciplinary crisis team (psychiatrist, behavior analysts, crisis staff)
- **A**cute in-patient psychiatric services
- Specialized "dual diagnosis" out-patient clinic
- Residential services
- Respite services
- Education/training and technical assistance, and
- Person-centered case management.

Interface Program—Ohio

The name of the Interface Program draws from the goal to close an identified system gap and provide an interface between mental health and intellectual disabilities service systems. The Interface Program was developed in 1979 in response to the closing of the developmental centers in the Cincinnati area and in an effort to provide specialized supports and services to address the mental health and behavioral needs of these individuals. The Interface Program service philosophy is that when appropriate types and amounts of supports and treatments are provided in a coordinated, collaborative, and planned approach, individuals with intellectual disabilities and complex behavioral needs can live successfully and productively in their community. The stated goals of the Interface Program are to maximize productivity, quality of life, and community inclusion of individuals with developmental disabilities and co-occurring mental illness.

The Interface Program is a joint venture between the local (Hamilton County) mental health program and the University Center for Excellence in Developmental Disabilities at the University of Cincinnati. Funding from the local county mental health board supports three full-

time professionals and fee-for-service (billing Ohio Medicaid waiver program) funds a fourth full-time position. Almost all services are provided directly in the community although some assessment services are provided in the University clinics.

Interface includes:
- 1 full-time program coordinator (social worker)
- 3 full-time clinicians cross-trained in intellectual disability and mental illness, and
- 1 part-time psychiatrist.

Services offered include:
- Comprehensive interdisciplinary assessments;
- Functional behavioral assessments;
- Psychotherapy;
- Consultation and technical assistance;
- Continuing education/training; and
- Service system advocacy

Positive Behavioral Supports—South Carolina

Initiated in the mid-1990s the state of South Carolina mandated a group to examine the need for system change in order to better support individuals with complex support needs. A series of focus groups and needs assessments were carried out to identify the training needs to build community capacity to provide adequate treatment to individuals with developmental disabilities and complex behavioral needs. Following this consultation process, a task force compiled the following recommendations to be implemented statewide:
- Develop a training curriculum and train direct support staff and their supervisors in the philosophy and skills required to implement a positive behavior supports (PBS) paradigm in their community-based services;
- Build community capacity to assess and manage complex behavior support needs.

Following this consultation process, a task force compiled the following recommendations to be implemented statewide:
- Provide technical assistance and training;
- Develop a process to assess quality of behavioral supports; and
- Monitor and share information with state personnel.

The PBS training curriculum that was developed consists of 26 modules that are given over four days of training and one day of supervised practice which helps determine proficiency. Once training is completed, the trainee's learning is assessed and certification granted upon a satisfactory performance. Three intensive courses were developed to train direct care staff, supervisors and behavior plan writers that deal with understanding the function of problem behavior, measuring behavior, and how to write an individualized behavior support plan.

A Medicaid reimbursable service was added to the South Carolina HCBS waiver that permits these credentialed behavior specialists to bill for functional behavioral assessment, behavioral

observations, interviews, writing of individualized support plan (ISP), training to the ISP, and monitoring of ISP. There is no annual cap on this service.

Assertive Community Treatment Teams

"Assertive Community Treatment" (ACT) teams are typically defined as interdisciplinary mental health professionals organized in a mobile mental health team that provides treatment, habilitation, and support services that persons with severe mental illnesses need to live successfully in the community. The ACT team model was developed in the 1970s as a community-based alternative to psychiatric hospitalization of individuals with severe mental illnesses and in response to limited community capacity for these individuals.

An mental retardation/mental illness ACT Team in the province of Ontario was described by Gerber & Millar (2002). Their ACT Team consisted of:
- 1 full-time coordinator
- 1 part-time physician
- 1 part-time psychiatrist, and
- 5 full-time specialists (including nurses, social workers, behavior specialists, and occupational therapists).

Gerber and Millar described their ACT team as providing the following array of services:
- 24-hour/day, 7-days/week on-call service;
- Crisis responses and on-site intervention;
- Medication management;
- Comprehensive assessment, management, and treatment of psychiatric and medical disorders;
- Skills training classes;
- Counseling;
- Placement and support regarding residential and vocational placement; and
- Technical assistance and education of community partners and service providers.

Overall Recommendations based on Best Practice Research

The following common program elements were identified from the research:
- Staff competency in person-centered and positive behavioral support values
- Expert inter-disciplinary team of professionals with 24/7 availability
- Acute in-patient psychiatric services
- Systems coordination to facilitate transition to community
- Specialized mental retardation and mental illness out-patient clinic
- Residential and respite (emergency and planned) services
- Person-centered case management
- Education/training and technical assistance
- Medication management
- Stabilization
- Diagnostic work-up

Based on best practice research, it is recommended that Oregon:

1. Establish an "ACT Team"-like model of regional expertise in mental retardation and mental illness. This team should consist of:
   - Coordinator
   - Physician/healthcare professional (medical aspects)
   - Psychiatrist (psychiatric service/prescriptions)
   - Therapist (psychotherapy)
   - Behavior specialist/PBS professional (behavior support)—also to provide training and technical assistance.

2. Establish statewide training and technical assistance for direct support staff and case managers in Positive Behavioral Support and Functional Behavioral Assessment, including:
   - PBS Training complement
   - Person-centered planning
   - Conducting a functional behavioral assessment
   - Developing function-based individualized behavior support plans
   - Implementing interventions
   - Collecting data and evaluating outcomes
   - Developing and maintaining a therapeutic environment

3. Establish statewide training for certification of professionals in:
   - Person-centered planning
   - Positive behavioral supports
   - Conducting a functional behavioral assessment
   - Designing and monitoring individualized behavior support plans

4. Organize Specialized Consultative Services to provide expertise, training, and technical assistance in a specialty area (psychology, behavioral analysis, therapeutic recreation, speech therapy, occupational therapy, physical therapy, or nutrition) to assist family members, caregivers, and other direct service employees in supporting individuals with developmental disabilities who have long term habilitative treatment needs.