This report is the second in a series on a system change collaborative with state developmental disability agencies in Georgia, North Carolina, Oregon, South Dakota, Tennessee, and Virginia. The National Association of State Directors of Developmental Disabilities Services, Support Development Associates, and Virginia Commonwealth University respectively manage parts of the initiative.

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Introduction

Most state developmental disabilities (DD) systems have supported the development of best practice pilots and have defined the desired best practice outcomes. But the challenge to move typical practice toward best practice to “take best practice to scale” remains. To do this, state leaders need to clarify what “expected practice” is and create positive pressure for change so that there are a set of actions that move typical practice toward best practice. But how and where can we draw a new line and say here is “expected” practice? This paper explores what we understand about best practice, a way to think about expected practice, and the learning that has occurred about the challenge of making change at scale. Crucial to this change is clarity about vision, mission, and values.

Vision, Mission, Values

One of several critical functions of the leader of a state DD system is developing a shared vision of the system’s future. The overall direction, what needs to change and why, needs to be clear and everyone impacted must feel that they had a voice and were listened to. The leader must assure that there are clear expectations about how the system will move toward the vision, including what is “expected” practice on the part of those who provide services.

The efforts begin with developing the vision, mission, and values. While the vision statement describes the broad outcomes, the mission describes the purpose of the system. The original design of many Developmental Disability systems was intended to keep people healthy and safe. Most of the current system structures were designed to meet that purpose. Over the years, the vision has changed. While it began with “people are safe and healthy”, it then changed to “people are healthy, safe and independent”; and now has evolved to “people live a self-directed life in the community with a balance between staying healthy, safe and happy”. While the vision has evolved, some of the structures within the system have not. The mission, or purpose, has become muddled with parts of the system solely focused on health, safety, and functional skills, while other parts are focused on supporting choice and helping

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1 By “best practice” we mean those services or activities which are considered innovative or exemplary approaches to address existing system struggles. These services or approaches result in outcomes which are either articulated by or implied by the vision. By “expected practice” we mean the series of activities, processes, or services which are designed to merely meet standards for outcomes as set by leadership as a near term target; outcomes that, with reasonable effort, all organizations are expected to achieve.
people determine and achieve their own goals. While it is necessary to focus on each of these, the parts of the system responsible for each often do not work together, and in some situations actually operate in conflict with one another.

To have a system where the parts work together and where expected practice is clear, there are several sets of questions for which we need to provide answers. Using the same type of inclusive process that goes into creating a shared vision, the state director needs to lead the development of a set of coherent answers to the following questions.

Given the state’s vision for community services for persons with Intellectual/Developmental Disabilities (I/DD):

- What are the expected outcomes for each part of the system? (e.g., service providers, service coordination, monitoring agencies, licensing agencies, quality or program integrity agencies)
- What does success in meeting these outcomes look like for -
  - People who are supported and their families?
  - Employees?
  - The organizations delivering the services?
  - The full Developmental Disability system?
- How will we know we have made progress towards success?
- How will those who provide service be held responsible for meeting these outcomes?
- How will system managers be held responsible for meeting these outcomes?
- What efforts are needed to achieve each outcome and what support does the system offer?

Then each person with a role in the system needs to be able to answer these questions

- What am I expected to do?
  - What standards do I need to meet?
- How am I doing in relation to meeting the expectations?
  - Where does my performance fall relative to the expectations?
- If my performance falls short of expectations, how do I know what to do to improve?
  - What support is available to me to meet them, or to improve my performance?

Creating clarity about expected practice

One way to define expected practice is by using the following diagram. This has worked well in describing what we mean by minimum standards, expected practice, and best practice when talking about people who have developmental disabilities and who receive residential services. Here service life represents typical minimum
Standards; a good paid life represents expected practice and community life represents best practice. In more detail -

**Service Life**

Service life refers to receiving services that focus on health, safety, and functional skills. Those things that are referred to as being important to the person (those things that make the person happy, content, fulfilled, satisfied, or comforted) are not a focus for the organization. In some locations, the pursuit of what is important to is actually viewed with a negative eye — and are typically labeled “attention-seeking” or non-compliant, and result in a behavior plan rather than a change in the circumstances. Someone can meet the criteria of being healthy and safe but can also be very unhappy. Meeting the criteria for service life has been the minimum standard to which organizations were held. But the minimum is moving toward a good paid life in many places by expecting organizations to recognize what is important to people.

**Good, paid life**

When an organization commits to paying attention to the presence of those things that are important to the person and sees their primary purpose as creating a balance between “important to” and “important for” the person moves toward a “good paid life”. This is not a bad place to be as most of the things which result in the person
feeling happy or satisfied are present. But it depends upon people who are paid to be in the person’s life. When we look at who is present in the person’s life they are either family, other people who use services, or are paid. What is missing are reciprocal connections with members of the community who are not paid. If system leaders look at what they can do at scale; what they can expect of all providers given what we know at this moment; then a good, paid life is a reasonable way to describe expected practice.

Community life

As people move toward the far end of the diagram, community life, they begin to make connections. Community life is not defined simply by being in the community but by having relationships. When there is a web of reciprocal relationships, where there are people who care about the person and are not paid and not family and are engaged in their lives, then people are connected to a community life. This does not mean that those people supported no longer have paid people in their lives. It simply means there are more people in your life than only family members or paid supporters. Typically, there are people who are paid who still provide critical services, but there are also people who watch out for you, advocate for you, and who see you as someone who contributes to their lives.

The advantage of the graphic is that it helps us see what we can do at scale while keeping best practice in mind. If a good paid life is the new expected practice, how does that translate for service providers, service coordinators, and system managers? For this to become expected practice and then (over time) the new minimum, how does the system structure need to be re-designed? To reach this, those who manage the system must -

- Remove barriers
- Provide any necessary technical assistance (or access to it)
- Sustain it as the new minimum

Those who coordinate services or supports must, for each person supported:

- Have a good description of the balance between important to and important for
- Assist the person in evaluating current or proposed services and supports against that balance
- Seek ways in which the supports provided enhance inclusion rather than segregation

Those who provide services must:

- Understand what is expected of them
- Engage in ongoing evaluations of existing practices and structures against the new expectations
- Have a coherent strategy that moves people away from service life and toward community life
- Recognize and seek the assistance they need to meet expectations
While we seek to have “a good paid life”, expected practice that becomes the new minimum, we need to also learn how expected practice can move toward community life. Community life remains the destination - the vision we have and what we strive to achieve with everyone. As we look at best practice examples we ask if they can be delivered at scale or if there is learning that will help us move expected practice forward.

Taking Best Practice to Scale - depth and breadth strategies

System leaders need to identify and evaluate current best practice efforts and determine, to the degree possible, how big an impact each potential effort will have. Some of the most powerful best practice models, such as micro-boards, require commitments from those around the person of such intensity that they can only be supported for a small percentage of the people using services. But the learning from micro-boards support changes at scale. System answers to questions about managing individual budgets and families as employers are coming from the learning around micro-boards and other self-determination pilot efforts. At the same time these best practice efforts show us what the vision looks like when it is present in local communities. But by themselves they are not system answers. Given the remarkable outcomes for the individuals who participate, they need to be supported and encouraged but not held up as system answers.

Best practice that we cannot scale up beyond 15% of those who use services cannot become part of expected practice. But some of the approaches they employ and the outcomes that they represent can inform and become part of expected practice. However, looking at the elements must go beyond simply seeing what pieces of a best practice approach can be implemented. Another part of the analysis is to look at how the parts that can be implemented at scale work with other parts of the system. In systems thinking, we learn that the individual parts must work together to meet the desired outcome. (Ackoff) Having individual parts that function independently may actually minimize the effectiveness of the other parts, thus making it impossible to efficiently meet the overall purpose of the system. When adding an approach from best practice reduces the efficiency of the system it may be an indication that what is needed is a re-design of the basic foundation so that the parts work together efficiently to support a variety of options.

New standards of expected practice often result from taking depth efforts to breadth.

We want to find ways that 100% of those supported can experience the vision, while recognizing that the approaches might each be 15% solutions. What outcomes can we reasonably expect for everyone? What efforts are both

Some of the “best” of best practice cannot go to scale; it is a superb individual answer but not a system answer.
affordable and will move these outcomes from being best ‘depth’ practice to expected ‘breadth’ practice? (Smale) The key is to design the core elements of the system to allow for (and support) best practice while also creating pressure for expected practice that meets the desired outcomes of all people supported

Deepening and Spreading the Learning

In our efforts to improve typical practice we have encouraged services to develop local ‘depth’ and ‘breadth’ strategies. Initial depth strategies are focused on a small part of the organization where a cycle of positive change and learning can be started. Initial breadth strategies take advantage of efforts that will work across the organization or system to create change that impacts a broad spectrum of people. We then encourage participants to look for the ways in which depth can inform breadth. As the “depth” efforts proceed, organizations are supported with structured time to learn from these efforts and see how they can be more broadly applied. Broad training in person centered thinking tools (see below) is an example of a breadth strategy. Supporting a small group of people in applying person centered thinking skills is the typical initial depth strategy. Implementing structured ways for the organizational leadership to listen to those engaged in applying the skills results in the organization learning how to develop the breadth strategy and thereby change expected practice within the organization. Those who manage the larger system need similarly structured and intentional learning efforts in order to discover what can move from small, local best practice projects to expected practice across the full system (the breadth). To do this also requires planning for the strategies needed to make the transition from best practice to expected practice without losing the quality of the work. For states seeking to have supported employment become expected practice a depth strategy is offering technical assistance to selected traditional day service providers in how to convert to employment. The breadth strategies include employment first policies and rate changes that favor integrated employment over segregated services.

Failure to meet minimum standards requires a plan of correction and substantial failure over time causes an agency to be closed. But minimum standards are just that, minimums.

2 To learn more about person centered thinking tools go to http://www.nasddds.org/Meetings/2009_Annual_Conference/2009_Ac_Presentations/SMULL&BOURNE-TheImportanceOfPersonCenteredThinking.pdf or http://www.learningcommunity.us/documents/PCTCurriculumDescriptionJuly2006.doc.
Minimum standards and expected practice

Minimum standards are just that, minimums. Compliance with them is typically a basic requirement for legally doing business. Failure to meet them requires corrective actions and substantial failure over time results in the termination of an organization’s right to do business. But minimum standards fall short of what can be and is expected. They are the floor, not the ceiling, of expected practice. While minimum standards serve a useful purpose in large systems, without a clear vision and engaged leadership, the minimums often become the goal rather than a basic requirement. Robert K. Merton refers to this as “goal displacement” when compliance to bureaucratic process becomes the objective rather than staying focused on the true purpose. (Reed, p. 10) In a system that values both learning and acting on the learning, minimum standards continuously rise as our practices advance. Yesterday’s expected practice becomes today’s minimum standard. System leaders and agency leaders must find a way to manage this without resulting in chaos. Expected practice is what the disability system expects organizations to be doing or actively working on routinely. They are the things that move the full system toward the clearly conveyed vision.

For example, in a person centered system, expected practice for those who plan with the person supported, and those who implement plans, includes knowing:

- What is “important to” and “important for” each person.
- How a reasonable balance between important to and important for can exist for each person.
- What needs to happen to address issues of health or safety while taking into account those things that are important to the person?

The process for plan development then clearly defines expectations for:

- Participation of people who genuinely and deeply care about the person.
- Steps required to assure the goals/outcomes of the plan create opportunities which directly reflect the presence of what is important to the person.
- Conversations that demonstrate respect for people supported and their family and cultural values.

*“Important to” refers to those things that make a person happy, fulfilled, and comforted. “Important for” refers to issues of health and safety and to those things that contribute to a person being seen as a valued member of their community. For more information go to [http://www.learningcommunity.us](http://www.learningcommunity.us).
The approach required to assure information will be collected that reveals what the team knows about addressing what is important to each person within the context of health, safety and valued social roles (important for). But expected practice goes beyond what people know, it includes what people do. In the information age, professionals have many opportunities to know what is possible. Expected practice for those monitoring for quality and outcomes includes looking at people’s lives for clear evidence that what is known is also used to guide actions. They look to see if the outcomes that are written for the person reflect both what is important to and important for and the balance between them. Quality monitors do not look for only the issues that are important for the person (health, safety and valued social roles). They also look for issues that are important to the person. And they look to see that those outcomes are producing actions.

Finally, all of this needs to occur in a way that makes the most effective use of available public dollars. The approaches used to meet expected practice will always be looked at through the lens of efficiency as well as the lens of effectiveness. But these are two very distinct topics. The classic definition of efficiency is maximizing the output with a fixed level of inputs (resources such as money time). Because we are talking about people, we need to refer to outcomes rather than outputs. We often talk about “cost effectiveness” when we refer to efficiency. But, if we haven’t spent time defining the outcome then we fall back on the old outcomes that linger in the culture. The implicit outcome may be “keeping the largest number of people safe and occupied for the least cost”. By using a narrow definition of efficiency, sheltered workshops (where 1 staff member can support 6, 8, or even 15 people) can appear more efficient than employment (where the costs often begin with one job coach supporting 1, 2, or 3 people). Effectiveness, on the other hand, is defined by the “customer”. (Ackoff, 1999) The changes in the vision have changed who the customer is and changed the desired outcomes. Effectiveness refers to what the person and/or their family finds valuable, or put another way, how well a service meets their expectations. Research has demonstrated that in employment services, looking at efficiency and effectiveness is a win-win-win. As Rob Cimera notes, “Numerous authors have found that employment is cost-efficient and cost-effective compared to sheltered workshops” (Cimera, 2002). When we add the person and their family as “customer,” effectiveness is again present. However, effectiveness and efficiency do not automatically co-exist; to define expected practice and move toward best practice both are needed. As with developing the vision and mission, they each require discussions and decision making, which require time for conversations with all partners involved.
Best practice becoming expected practice - scalability

Where ever possible, best practice should become expected practice. But this needs to be done in a way that assures that the desired outcomes are present. For example: Everyone should have the opportunity to control their own resources. This is a core element of a person centered system. But it will not have the desired outcome without other things being in place. First, there has to be an equitable way to determine what is funded and the amount of funding for each person. Then each person must receive the support they need to determine how they want to live and the role that the funding plays in living that life. Finally, they must have access to buy the services and supports they need in order to achieve the desired life.

A core element of a person-centered system is the expectation and opportunity for employment for every working age adult. “Employment is the natural state for adults in Western society.” (Walker & Rogan, 2007). Supports and public resources offered to enable a person to engage in employment will vary, but expected practice includes opportunities for employment for everyone. Research demonstrates that employment makes sense for those who use disability services, employers and taxpayers, and therefore ought to be expected practice in all disability systems. We are in difficult economic times with high unemployment rates. But an unemployment rate of 76% for people with intellectual or developmental disabilities clearly says that employment is not expected practice. There appears to be no positive pressure to create employment opportunities as a measure of expected practice.

The question is: which best practice approaches are big enough (as a percent of those served) and effective enough to be supported with the limited public dollars available? Efforts that have great outcomes but only fit for a very small percentage of those served should be:

- Recognized
- Encouraged
- Available and accessible
but otherwise consume few system resources

Whenever we see or hear about best practice we need to learn if it is “scalable” and what we can learn from it that can be broadly applied. We must routinely ask:

- What helped to achieve this success?
- What was the context? What did people do? What did people learn?
- How does this contribute to our desired outcomes? How has it had a positive impact on the people who use services, their families, employees, provider organizations, or the system?
- What are the requirements for success in implementation?
- Given those requirements how "big" an answer is it? For what percent of those who use services do we think this would work?

3 By scalable we mean that it can move from being available for a few people to being done for 15% or more within the resources available.
If it will only work for small numbers, then what can we learn from it that can be applied to larger numbers? Are parts of it “scalable”?

At what percent do we achieve “scale”? What, beyond the ease of doing something with large numbers, works as criteria for investing public resources? What is the minimum percent that should be considered? This is a number open to debate and study but a reasonable rule of thumb would be 15%.

**Looking at the “return on investment”**

Part of creating expected practice is looking at how effective and efficient each approach is. We need to know what works, how well it works, for how many people will it work and at what cost in public dollars.

For each approach ask:
- How does it contribute to our desired outcomes
- What skills, actions, activities and/or structures are required for success?
- What training and technical assistance is necessary?
- Are there changes in system structures or practices needed?
- How big an answer do we think this is - what percentage?
- Is on-going support needed for those who are implementing?
- What is the cost of using the approach at scale?

In answering these questions we are asking, in part, if the effort is “worth it”. What is the cost/benefit?” If we think about it in terms of return on investment and that we have limited funds to invest then we are looking at it in context. Part of that context is looking at the cost of design and development as well as the cost of deployment. Development costs are typically higher than the cost for spreading the effort. They may include funding a pilot and designing training. But development funding is wasted if insufficient effort is put into creating a strategy that will result in the approach being used as designed and then carrying it out with quality checks built in. The best justification for spending significant resources on a few people is that the learning will be used to improve the quality of life for many.

System managers need to view deployment strategies and their associated costs as a core responsibility. They often include more than the cost of communicating the approval of a new service, they include the development of policy, training, materials, and associated support required for success. The strategy for deployment includes both the identification of obstacles to the strategy and identification of what is required to
overcome them. Deployment without considering what it will take to remove the barriers is often deployment that does not result in achieving the desired outcomes.

After the costs are estimated then the benefits need to be considered. Is there an increase in efficiency? Is there an increase in effectiveness, in quality of life? Are the increases in efficiency and effectiveness worth the investment? More importantly, are efficiency and effectiveness adequately defined, and in balance with each other? One example of an effort to answer these questions is the research done in the UK on the impact of person centered planning, where it was found that outcomes in efficiency and effectiveness were worth the investment. But this is also an example of the ease of misinterpretation as many jurisdictions then required person centered planning but overlooked the need for investment in training and support. (Robertson, et al.)

Efforts in employment also reflect the need for a comprehensive, integrated, and sustained effort. The absence of this kind of effort in most states has resulted in the national average amount of employment support to drop from 30% in 1999 to 24% in 2008. By way of contrast Washington State and Oklahoma have engaged in broad and comprehensive efforts. These sustained and comprehensive efforts have resulted in Washington state going from 58% in 1999 (the initial number reflects earlier work) to 87% in integrated employment in 2008. Oklahoma’s rate has gone from 37% in 1999 to 55% in 2008 (Institute for Community Inclusion). In both states employment is expected practice for adults of working age.

Conclusion

Even in difficult times, we need to continuously look for opportunities for positive change. In tough times in industry they not only look for cost savings (cuts) but for the investments that not only help them survive the downturn but position themselves for the upturn. During these times industry leaders ask: where are the opportunities to improve the full system? We must do the same. What opportunities exist to change typical practice? Where will investments and change efforts payoff in efficiency and effectiveness? This is the work that the authors are engaged in through partnerships with system managers. But this effort needs to be taken to scale as well; it needs to be a focus of all system managers. We must expect no less from each other.
References and Further Reading


