Building on Partnerships

Successful Transitions from RHC to Community Living

Mission

Roads to Community Living *engages and collaborates with individuals, their families, community members, paid providers, and other involved people so that individuals with developmental disabilities can:*

- *Make informed choices about where and how they would like to live*
- *Live, work, play, and contribute in the community of their choice*
- *Lead safe and healthy lives*
- *Strengthen and enrich the communities in which they live**

* For more information on RCL: http://goo.gl/DI9QiB

To celebrate the practices and attitudes that have created successful transitions from RHCs to community living, strengthen networks and identify opportunities to continue to improve transitions, Roads to Community Living convened four workshops (see page 10).* Their conclusions can be summed-up:

> **A good transition is created when honest and open communication builds trusting relationships that actively involve the person with a developmental disability, family members, RHC staff, Regional DDA staff and community services staff in developing supports for community living that meet the person's needs for accommodation and assistance and offer the person meaningful new opportunities in community life. Everyone involved focuses their distinctive contribution on promoting the person's wellbeing during and after their move and each is willing to learn from the others.**

* **John O'Brien and Connie Lyle O'Brien** facilitated the workshops and compiled these notes by reviewing presentations and the posters and reports made by the small groups. They identified and summarized common themes and possibilities for improvement. The word cloud summarizes all the words that small groups recorded.

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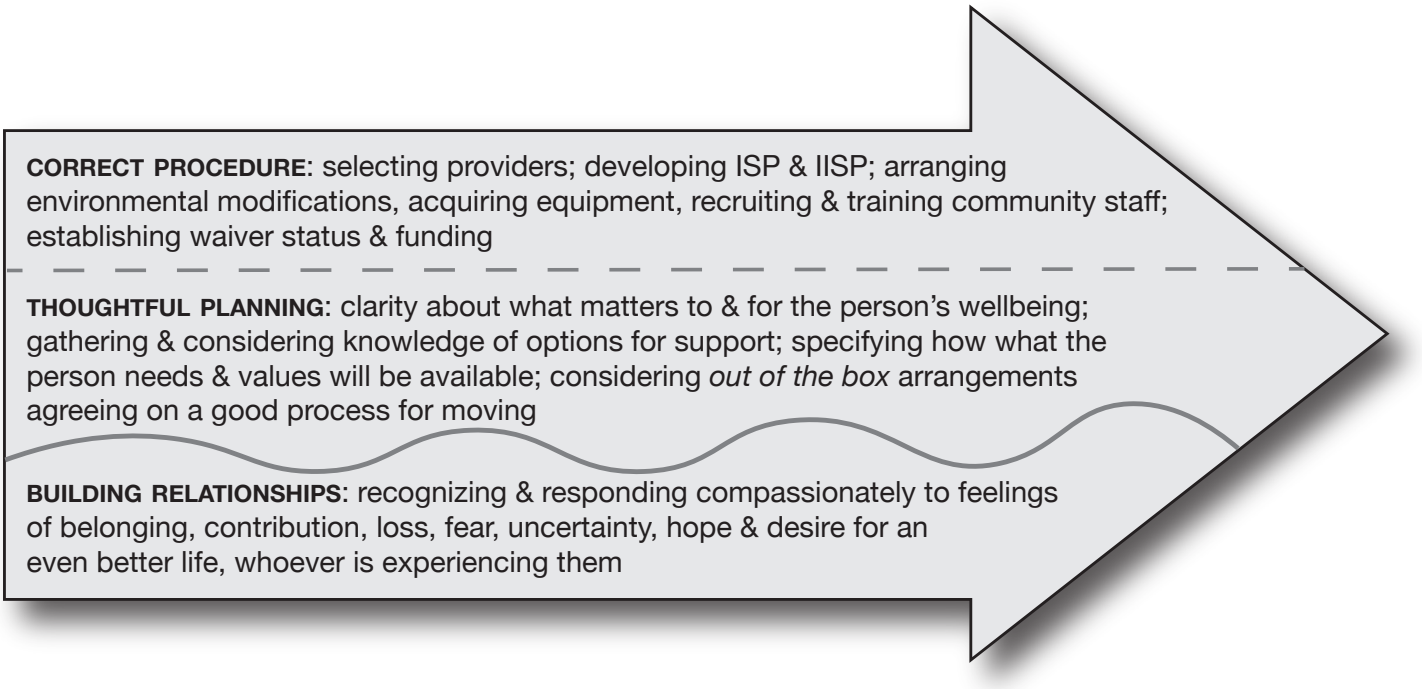
Good relationships lead to good transitions

The point of transition is not simply to change a person's living arrangement. A good transition offers people new life opportunities in the community they choose. Participants in the workshops who have played a part in good transitions say that the experience is satisfying because they feel like they belong to a team that focuses on putting in place what a person needs to be successful in community life. An effective team will include the person, family members, RHC staff (including people who offer day-to-day support), case management and other necessary staff from the DDA Region, and community providers (including direct support workers when they are matched with the person). As honest communication builds trust and openness to new ideas, the person will benefit from the variety of experience and knowledge and different perspectives represented on the team.

Good transitions happen at three levels

As those who have experienced good transitions talk about them, there is more to successful transition than following correct procedures to move a person who chooses community living. The process can be visualized as having three related levels, each of which can strengthen or weaken the other two.

Moves are complicated and the detail coordination that **correct procedure** provides is essential. People whose complex needs require specialized equipment, environmental modifications, adapted access to local health or mental health services and staff with particular competencies rely on correct procedure to assure that they have what they need to make the best of the opportunities community living offers.



Good transitions demand **thoughtful planning**. This supplements required formal plans and assessments with creative consideration and synthesis of personal knowledge and trying new things on a small scale (for example, giving people supported opportunities to test some potential community experiences while they are in the RHC). Person-centered planning can be helpful in guiding this level of thinking. For example, identifying what is **important for** the person is necessary to assure that needs are well met. Identifying what is **important to** the person matters both to assure that people can continue doing what is already meaningful to them and trying the new experiences community living can offer.* Especially when people have experienced trauma in situations before they entered the RHC, reaching past usual practices to gather and employ knowledge of what can be in the way of assistance can often prevent the costs, personal and financial, of the failure of supports.

A thoughtful plan answers the question, "What does a meaningful day look like for this person?" There is far more to community living than avoiding incidents, receiving specified assistance and attaining habilitation goals. A thoughtful team will provide the resources to discover what meaningful activity will fill a person's day both before and especially after the move. Given DDA's priority on employment and paths to employment, a thoughtful plan will include skilled and creative provision for access to work.

No matter how good a plan is, it is almost certain to need revision once the person moves. A thoughtful plan will build-in flexibility so adjustments are easy to make. Some of these adjustment will be necessary because the person finds good opportunities that could not be foreseen from the RHC. Other revisions will respond to the challenges of adjustment to new settings and expectations.

Breakdowns that cannot be repaired in community settings and require re-admission to an RHC have substantial, multiple costs. Not least of these costs is damage to the person's confidence and reputation among service providers. Planners should consider the resources that will increase resilience to breakdowns. They think safety nets that can catch a person who tries and falls, not straight jackets that deal with potential problems by restricting people's capacity to try. Good plans and placements are tested with frank team discussion of these questions, "How could this fail?" and "What could go wrong?" Honest answers to these questions can identify where more work is needed. Thoughtful plans will attend to lessons from the breakdown of previous community living arrangements. For example, experience shows the importance of a crisis back-up plan that doesn't create surprises for local first responders or rely on police or hospital Emergency Departments to manage difficulties.

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* For more on this important step in thoughtful planning, see http://goo.gl/TPYPxS Several storytellers in the workshops have found Essential Lifestyle Planning (ELP) useful; the exercise on this site is one of the Person Centered Thinking Tools that makes up ELP.

Building relationships matters. Good transitions happen in a web of personal and professional connections and sometimes strong emotions come up. Even good new experiences involve loss and stress. Giving up familiar arrangements can cause fear or re-open painful questions for people and their families. Ignoring fear, feelings of loss or worries about what is uncertain by treating transition as though it were just a matter of impersonally following correct procedure can lead to delays, confusion and less than adequate plans and living arrangements.

Good transitions engage diverse perspectives & capacities

The person who is stepping into community living is the reason for the process. A good team holds the person at the center of their concern. They will make opportunities for those who are coming into the person's life to spend time getting to know the person outside formal meetings and assessments. As an integral part of thoughtful planning the team will learn as much as possible about the conditions that allow the person to make their voice heard and their thoughts and feelings known. As much as possible, people will be an active part of problem solving and decision making. In involving people who may have cognitive or communication impairments it is particularly important to presume competence and search widely for ways to support the person's voice. For some people this means adapting the way meetings are organized and conducted.

Family members are a key resource to people in transition. If they serve as a person's guardian they hold responsibility in the choice to engage with RCL. When they are fully engaged they bring knowledge of the person and desire for the person's wellbeing that no one else can. They can act freely to advocate for what the person needs and for what is meaningful in the move to community living and when the person is established in a community living arrangement. They can offer a critical measure of continuity as and after people move. Heeding and addressing their concerns for the person's wellbeing provides an important safeguard.

When they are able to actively engage, parents and family members deserve recognition and respect as the real and natural advocates for their family member. When they are not available it is critical to assure that a person has a designated advocate, with the freedom, direct and involved knowledge and support to speak up with or for the person when their wellbeing is threatened.

Some family members in the workshops spoke of the importance of support and encouragement from other family members who have experienced transition. They stressed that keeping a mind open to learning is as important for families as it is for staff involved in transition. Approaches to community support are developing rapidly, and there is a good chance that anyone involved in the process, parent or professional, will discover things that they didn't know they didn't know if they are willing to search outside the box of past practice.

Because family members are sometimes at a distance and often unfamiliar with the way correct procedure unfolds its important to offer them a specific con-

tract person who is available to them to explain the process, answer questions and keep them updated. Some families may not want this accommodation, but families should have the opportunity to say no to a specific offer of a well informed liaison.

Anyone who holds legal guardianship is obliged to understand the decisions they are authorized to make and the importance of taking due regard for understanding the person's own point of view and preferences. Having a guardian is a safeguard that strengthens a person's voice and judgment, it does not extinguish their voice or take away their right to express their preferences and have their desires and concerns taken seriously.

RHC Staff make an important difference throughout the transition. Storytellers* expressed appreciation for what the RHC offered. In deciding to move, they thought carefully about what they risked losing by leaving the RHC. Their reason for choosing the road to community living was not to escape something bad but to take a next step in hope of new opportunities.

Choosing the road to community living means moving into uncertainty. Some people have experienced the breakdown of community living supports before moving to the RHC, some of them even more than once. Some people and families are not sure exactly what they are moving towards. In these uncertain situations, RHC staff can play a decisive role. Several storytellers identified RHC staff belief that a person will be well in community living as a critical influence on their decision to move and their success after the move. The power of RHC staff to encourage a move forward does not seem to depend on position or formal authority. It is not the result of professional assessment, though that certainly figures in thoughtful planning. It is a matter of personal knowledge that comes from experience with a person and the trust the person invests in them, especially when a person experiences hard times or develops new skills. In an important sense, it is an expression of confidence in the effectiveness of the support they have provided. At the level of relationships, trusted direct support staff members' belief in a person is just as much a resource as the judgment of professional staff.

Thoughtful planning will be most effective when it involves RHC staff who know the person by sharing their day-to-day life as well as those in other professional roles. RHC direct support staff deserve a voice throughout the process. Often they want to check out for themselves the places people will live and the people who will offer community support.

Under the best circumstances, transition takes time. Once a person has chosen RCL, RHC staff can ask themselves, "What can we do now to improve the chances of people's success in community living?" People can practice self-regulation in community settings and activities. Depending on how easy

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* **"Storytellers"** are the people who shared their experience of transition in the workshops. They included people with disabilities, parents and family members, involved RHC staff, community support staff and managers, case mangers and sometimes family advocates.

it is to visit the place they are moving to, they can become familiar with their new neighborhood and what it has to offer. They can meet community members they can connect with after the move. They can learn public transportation routes. They can try out new possibilities or exercise skills. This can require adjustments to RHC routines and staff assignments.

RHC staff don't stop being a resource when the person moves. A number of them expressed an interest in continuing their relationships. In one inspiring instance, RHC staff members transfered to SOLA out of commitment to a person they have successfully assisted through very challenging times.

Case Managers and DDA Regional Staff hold primary responsibility for assuring that community services meet the person's needs and support them in making the most of the opportunities in community living. Case Mangers run interference and encourage systems to stretch to meet individual circumstances. Along with Resource Managers they steer the process in such a way that correct procedure coordinates the flow of necessary resources on schedule. They make sure that the person gets the greatest possible benefit from the extra resources available through RCL. Their responsibility to represent the person as they develop and coordinate services, their experience of multiple situations, their knowledge of available and potential services and their responsibility for effective ISPs, IISPs and, when necessary, Behavior Support Plans makes them essential participants in thoughtful planning.

People in transition count on Case Mangers and Resource Managers as a safeguard so that plans accurately reflect with is important to and important for the person and services are customized to fit the plan. Sometimes this means customizing available services to suit a person's individual needs. Sometimes it means developing new supports around a person.

Community service providers offer the person a secure home and the skilled, sustained, and competent assistance they need to maintain wellbeing and participate meaningfully in community life. They come later to the team, entrusted with the person's future after careful consideration and through correct procedure. Even later come the direct support workers and support staff identified to match the person's needs and future intentions. They usually have to invest in getting to know the person and those who currently know the person and care about them. They are not only taking their seats in planning meetings, they are establishing their place in the web of relationships that holds the person's community future.

Storytellers speak with appreciation of community providers spending time getting to know people before the move. They visit the person at the RHC, share activities both on and off the RHC grounds, host the person's visits to the community the person will move to, and find ways to involve the person in preparing their new home and establishing access to their chosen community.

Community providers join the rest of the team to figure out best to use the extra resources available through RCL in the year following discharge. They look for investments that will build capacity to support the person. They assist

in designing and making environmental modifications and acquire adaptive equipment. They think carefully about how to match support staff to the whole person. They consider the training and continuing consultation that staff will need to understand and respond effectively to the person. They consult the person and those who know the person best to identify where provision needs to be make for back-up to avoid breakdowns of support. They recognize that some staff turn-over is inevitable and budget for recruiting, orienting and training replacement staff. They line up necessary community resource people –physicians, mental health providers, dentists, OT, PT, etc– and provide for orientation or extended introductions if that is necessary. They prepare to update thoughtful planning when the person gets established and there is new learning to account for.

Good communication leads to good relationships

All those involved in good transitions work at collaboration in an intentional and sustained way. There are real obstacles to successful and satisfying teamwork.

- Most team members have very full schedules and long to-do lists, so time is in short supply and multiple demands can make time feel even more pressed than it is.
- Following correct procedure demands documented, on schedule attention to clearly defined steps in the process. This can compete with the more open space that allows exploration of options and thoughtful planning.
- Sometimes its hard to find providers who are good matches for people. Developing new capacities to meet individual needs, especially when situations are challenging, makes demands on resources that are already stretched thin and can accumulate delays that decrease a team's momentum.
- Trust takes time to grow. Especially when direct support staff are involved people may be meeting each other for the first time. Community providers and RHC staff often lack direct experiences of each other's work and so have to overcome stereotypes by updating their experience with the exchange of visits. Community staff members ideas about what life is like in RHCs often need updating. RHC staff may judge all community supports on the basis of their direct experience of some people who return to RHCs because they have been failed by community supports. Though DDA assigns RHCs a clear and important present and future role, there are conflicting and unsettled political and legal positions at both state and federal levels that can leave RHC staff feeling undervalued and uncertain about their future. When short-term RHC placements have been necessary because capable community supports have been unavailable, people and their families need definite reasons to believe that the next effort will be better.

Good communication gives all those involved in the process the information they need to make their own contribution to a person's success in community life. This includes a clear map of the whole transition process, including the

development of community supports, and regular updates on progress through the steps and stages of transition. One of the first steps in thoughtful planning will be figuring out how best to make the process clear to the person and family and how to keep the person and family up to date on the steps that happen behind the scenes. An early step in team building is creating a clear chart of roles and responsibilities and a visible way that the whole team can see what each member has agreed to do and track the fulfillment of agreements. Some workshop participants thought that graphic templates would be a good resource and others added that RCL should test ways to create individual web pages that would keep track of steps, roles, responsibilities, agreements and progress (one group suggested testing an application called BaseCamp).

Good communication builds trust and creative relationships. The reason for transition is new life opportunities, not a change of placement. This has the best chance of happening when people belong to a team where trust in one another grows because team members discover more about who a person is and figure out practical ways to deliver supports that will bring a person good new opportunities. Teams practice a person first attitude, not only in language but also in the way they think about and act toward the person and one another. Team members' relationships with the person anchor and connect the team. For members who don't have regular contact with the person, this means making some time to be with the person outside formal meetings. E-mail and other electronic media are effective for transmitting some kinds of information, but they can't substitute for face-to-face contact when teamwork matters.

Trust and effectiveness at identifying and solving problems grow when team members speak honestly and listen with openness to different points of view and new ideas. In some ways, listening is an even more important contribution to building good relationships than speaking. This means acting on two beliefs: no one has all the right answers, and differences among team members can be a resource for more thoughtful planning. When there are differences, especially about managing risks or providing effective support, teams explore the assumptions in each position and consider what each position could contribute to a person's wellbeing. When differences call for choosing one way rather than another, the team will build in ways to check on the results and update their decision with experience.

Teams benefit from some up front time to connect to one another, the person and their shred goals. Some participants in each workshop suggested that RCL invest in resources for team building. Ideas included training interested people for a designated team facilitator role; providing a neutral facilitator, either for a team building process as a team forms, in an ongoing role or as a consultant when teams get stuck; or having team building workshops for multiple teams.

Stories play an important role in sharing learning and building understanding of what transition might offer other people. Workshop participants appreciated storyteller's openness in acknowledging the positive contributions that RHC staff made to their lives, speaking openly about some of the difficulties, dis-

appointments and uncertainties of community living, highlighting the many different people who contribute to the person's new opportunities and their recognition that the move from the RHC is only the beginning. Some RHC staff said that people, family members and staff from RHCs would benefit from hearing these stories, especially through in-person exchange. Reactions to RCL's video stories varied. Some found them informative and inspiring. Some experienced them as propaganda: offering too neat and polished a view of community living. Several participants thought that stories of good transitions should feature in RHC newsletters.

Opportunities for improvement

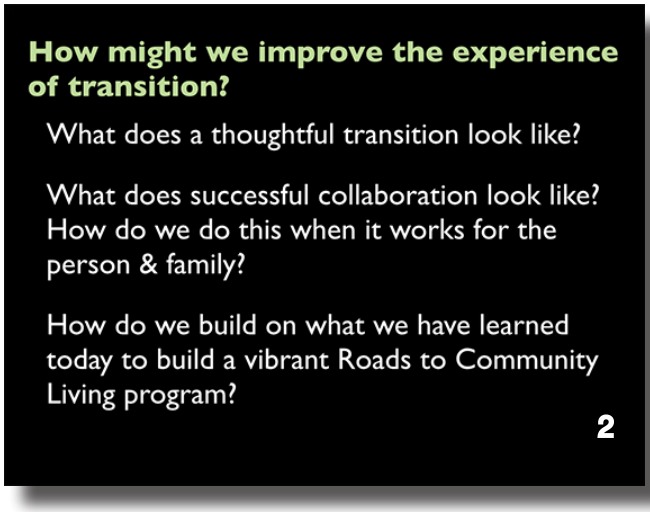
- How might we make the process more transparent and roles, responsibilities and agreements more visible and easier for team members to track? Graphic templates and individual web sites are possibilities to explore.
- How might we increase the repertoire of supports to people's voices throughout the transition process? This might involve technical support to communication or devoting a trusted person's time to assisting the person to understand and prepare for meetings, or assuring that the person has a support person to facilitate their participation in any transition related discussion.
- How might we increase the options for supporting team building?
- How might we offer more opportunities for RCL staff, community service staff, Regional and County staff to "rub elbows" and find ways to see and appreciate one another's contributions to the big picture of a system of long term support?
- How might we engage RHC direct support staff more effectively throughout the process?
- How might we offer RHC staff who have a relationship with a person better opportunities to see how the person is doing in community life and share what they see?
- How might we engage the direct support person who will work with a person even earlier in the process?
- How might we further streamline the process and reduce delays created by waiting for necessary resources?
- Sometimes people have good reasons for wanting to live where no suitable provider yet exists. How might we develop new capacity in a timely way when and where it makes sense for a person?
- How might we learn from breakdowns in support for community living and improve provider capacity?
- How might we assure that people with corporate guardians have good opportunities to engage with RCL?
- How might we increase the number of family members, especially family guardians of long term RHC residents, who connect with the Family Mentor?
- The stories that people are living together are powerful. How might we tell them even more widely and even more effectively?

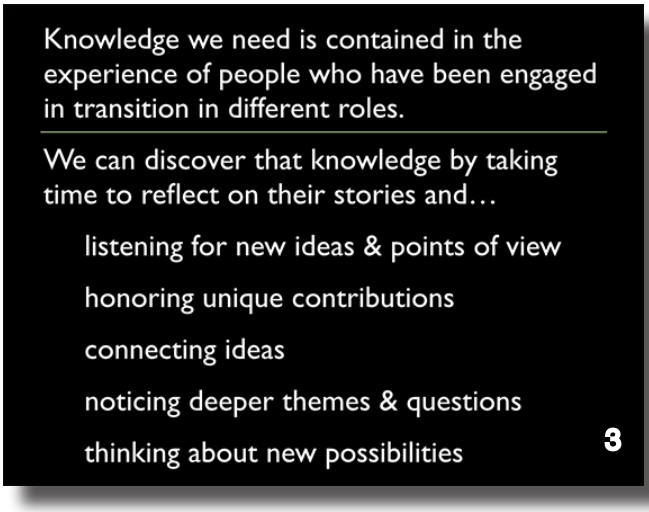
How we worked together

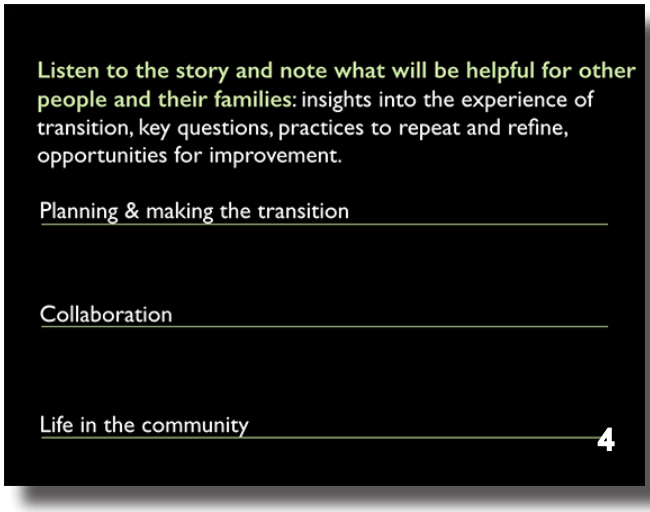
Each workshop brought together people with developmental disabilities, family members, RHC staff, community service providers, and Regional staff involved with transitions from one RHC: Fircrest School, Rainier School, Yakima Valley School and Lakeland Village. Each workshop was organized and hosted by a group that included RHC and DDA Regional staff and RCL team members .

The day long workshops followed a common pattern.

- DD Deputy Assistant Secretary Don Clintsman set the process of transition from RHCs to community living in the broader context of system development.
- The group heard and reflected on three stories of transition told by people who have made a transition, their family and members of the team involved.
- The RCL team described their role and the resources they can offer.
- Participants worked in small groups to name practices and attitudes that make for a good transition and what to do more of in order to create and sustain good collaboration. The slides outline the introduction to the day's process (1-4) and the small group work (5-9).







What do we want to remember from what we heard this morning?

5

Slow down

Focus on what matters

Keep going when you think you are finished

Listen to understand

Speak from your mind **and** heart

Move past what you knew before today

Encourage each other to contribute

Capture the connections by linking & building

Top 3

What practices make for a good transition & how might we get even better at performing them (be as specific as you can)?

7

Top 3

How can we do that?

How can we do that?

What do we need to do more of to create & sustain good collaboration

8

What might I do, personally, to contribute to better collaboration & better transitions?

9