To: RCL Team

From: John O'Brien and Connie Lyle O'Brien

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Our Reflections on Transition for People Who Are Likely to Have Experienced Trauma

Two RCL team members invited us to reflect on a discussion of a transition that did not work for a person. We have had a number of opportunities to support person-centered work with people whose behavior challenges services and assist in planning, evaluating and documenting both crisis and long term supports to people with complex and challenging behavior, both in North America and in the UK. None of this experience qualifies us to comment on the specifics of this person's situation. What we can do is note what came up for us as from what we heard and read about the situation. In making these comments we do not assume that those involved with this transition have failed to think about or act on these possibilities, only that they did not come up in the discussion or the written briefing paper.

In his trainings on supporting people with extreme behavior problems, Professor Rob Horner emphasizes two fundamental qualities essential to those who offer good positive behavior support: curiosity and humility. We identify the questions that came up for us as we listened to the discussion. We offer our curiosity in a spirit of inquiry.

We wonder if transitions make full use of Positive Behavior Support

Our understanding of PBS is well expressed in a paper that summarizes the work of the consortium of Research and Training Centers that developed Positive Behavior Support as an applied science that has evolved from Applied Behavior Analysis and incorporates person-centered approaches and a focus on community inclusion and contribution.[1] We think that this understanding of PBS is entirely consistent with DDA's purpose statement and RCL's goals. Nearly 25 years of research and application provide rich resources for RCL to draw from. From this perspective, when difficult and dangerous behavior is a possibility, transition will include at least these features.

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[1] Carr, E. et al. (2002). Positive behavior support: Evolution of an applied science. *Journal of Positive Behavior Interventions. 4*, 1: 4-16, 20. For a copy, www.beachcenter.org/Research/FullArticles/PDF/PBS16_PBS%20Evolution.pdf The Association for Positive Behavior Support endorses and distributes this paper as a foundation document for PBS. We have highlighted some key characteristics of PBS from the paper and drawn implications for the transition process based on our own experience. For those who favor the language of applied behavior analysis, see the work of Gary Lavigna and his colleagues for parallel approaches to good support (http://www.iaba.com/iabaresc.htm)

- The primary focus is on applying educational methods and making environmental and systems changes to expand the person's repertoire positive behavior: all those skills that increase the likelihood of success and personal satisfaction in community settings. Efforts to prevent problem behavior through such measures as improving communicative competence and developing self management skills are critical. The work of minimizing problem behavior happens in the context of a lifestyle that increases the person's opportunities to display positive behavior. Success means increasing behavior that is functional and meaningful in community contexts that are or can become important to the person, not bringing problem behaviors to zero in a controlled environment. Indeed, when they have good support, many people live good lives in community settings and continue to experience problem behaviors. A successful transition will result in active support for participation in typical household routines, employment or participation in a pathway to employment, and participation in leisure and civic activity. The assessments and interventions that matter will take place in the community environments that people move into. This means that most of the work of PBS needs to be done after the person has moved and resources, including PBS expertise, must be deployed accordingly.
- Individualization and active engagement with the person are essential. The more difficult the person's behavior the more individually tailored must support be. Person-centered planning is integral to PBS and affirmative support for active participation of the person in planning is a necessary condition of PBS, even when the person's participation remains difficult to enlist. This is both a sign of and a means to encourage the collaboration and self-determination that is essential to the success of transition. Making a sustained and creative effort to learn the person's interests and preferences, what works and what doesn't work for them, what is important to them, and how they understand breakdowns and difficulties is not just a simple matter of respect for the person's dignity. It is critical to good transition planning. In the RHC, Person-Centered Thinking Tools have proven effective in gathering and organizing knowledge in ways that give the person, their family and those who know the person voice and choice in the transition.[2] After a person has settled in, the Discovery Process provides one good way for

[2] Smull, M. & Sanderson, H. (2005), *Essential lifestyle planning for everyone.* Stockport, UK: HSA Press. The tools are well described in *The person centered thinking Mini-book* http://www.hsapress.co.uk/media/9852/hsaminibookusa.pdf. See http://www.learningcommunity.us.

community staff to get to know a person through an active process of discovering capacities and interests that also sets the person on a pathway to employment.[3]

- Careful analysis of the purposes of problem behavior that informs systematic education in alternative strategies that will allow the person to satisfy their purposes without resort to problem behavior. Given the unpredictable impact of transition and the new opportunities, demands and challenges of community settings, functional analysis needs to be pursued and updated by skilled people on site if problem behavior threatens success after the person moves.
- PBS recognizes that significant change takes time and depends on the quality and responsiveness of the community environment. This makes it highly desirable to have the back-up capacity to hold a person through crisis rather than returning them to an RHC. Experience in other places suggests that this involves developing local or regional crisis capacity, including very short term crisis housing (which has been successfully implemented in well supported shared family settings as well as in more typical crisis homes or emergency hospital admissions -sometimes for as little as 12 hours), additional staff and easily available expertise.
- PBS depends on direct support staff. Staff can't respond competently to difficult situations based on directions from distant teams or even in-person support from an expert while a person is settling in. Those who are with the person the most need to be active collaborators in the development and revision of routines and plans. Person-centered planning provides a good context for this collaboration. The information captured by Person-Centered Thinking Tools is an effective way to transfer knowledge about the person from RCH to community services and Person-Centered active support has demonstrated an effective and resilient way to organize routines, especially when people with substantial intellectual disabilities are involved.[4]
- PBS focuses on environmental and system change to create a context for successful application of educational methods to improve meaningful skills and reduce problem behavior.

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[3] Callahan, M., Shumpert, N. & Condon, E. (2009). *Discovery: Charting the course to employment*. Gautier, MS: Marc Gold & Associates. http://www.marcgold.com/Dis-Pro%20Order%20form%20for%20both%20books%206-24-2013.pdf.

[4] See, for example, Beadle-Brown, J., Hutchinson, A. and Whelton, B. (2012). Person-centred active support: Increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 25*, 4: 291–307.

Breakdowns and failures offer valuable and costly feedback on necessary system changes. The transition process needs to include a way to convert unfortunate experiences into real change.

We wonder if it would make sense to invite some people with expertise in PBS to review the transition process and identify ways to strengthen the contribution that PBS could make, especially in situations where supports have failed people and led to return to an RHC.

We wonder if people in transition benefit from as wide a range of ways to understand and support them as is possible

Behavior that challenges services has multiple, interacting causes. PBS interventions are frequently complemented with medications thoughtfully prescribed and regularly monitored to treat diagnosed anxiety, depression or psychosis. In addition to understanding derived from Positive Behavior Support, communication therapies, psychiatry, neurology and medicine, good understanding will also include careful consideration of relationship and psychological factors. The large scale move to serving people in community has been supported by guidelines for integrating these approaches with other perspectives and practices which are necessary for a good understanding of situations in which people are at risk of exclusion or restrictive measures.[5]

Availability of research and demonstration funds and rising demand for professional services in community services for people with developmental disabilities have engaged a wider spectrum of psychologists and other professionals with people with intellectual disabilities. This has resulted in the adaptation of a growing variety of perspectives and interventions to the community experiences of people with intellectual and developmental disabilities. While capable clinicians remain in short supply in many places, this reversal of the long standing pattern of professional avoidance of people with intellectual disabilities holds promise for people in transition.

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[5] For example, Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007). *Challenging behavior: A unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. College Report CR144. London: The Royal College of Psychiatrists. Note that “learning disability” is the British term for what we in the US now call “intellectual disabilities”. www.rcpsych.ac.uk/files/pdfversion/cr144.pdf unified approach

Trauma Informed Support is a key strategic initiative for SAMHSA (the US Substance Abuse and Mental Health Services Administration).[6] While the lasting effects of physically or emotionally harmful circumstances depend on the way individuals experience them, there is reason to consider trauma a helpful perspective on the design and delivery of community supports when there is a history of adverse events: family or caregiver dysfunction resulting in harm or threat of harm, exposure to violence either as victim or observer, withholding of material or emotional resources necessary to healthy development, significant losses in childhood or adolescence, or multiple out of home placements in childhood. In those who are vulnerable, difficult events are exacerbated by a dysregulated nervous system in a social environment that cannot contain this dysregulation. Effects of trauma for a person can include disengagement and inability to trust and benefit from relationships; significant difficulty in managing emotions, memory, attention, thinking and behavior; and inability to cope with everyday stress. Moreover, trauma can effect groups and organizations: a staff team can experience trauma and declining effectiveness as a result of adverse experiences such as feeling powerless to find ways to deal with escalating threatening problem behavior.

Trauma Informed Support offers two contributions to good transitions. First, it identifies a set of principles that organizations offering trauma informed support strive to implement in order to realize the values of safety, trustworthiness, choice, collaboration and empowerment (clearly consistent with DDA's mission and purposes). This provides a framework for assessing and developing the culture of the community settings a person moves into.[7] For example, safety, the first principle, commits an organization to decreasing the chances that people will be re-traumatized. Given some people's histories, implementing this principle may be less straightforward than it initially seems. It's necessary to consider safety not just from a third person perspective but through the eyes of the person. Some people with developmental disabilities experience restraint as trauma. Others have come to associate safety with very low demand situations or even with restraints –weighted blankets, splints, physical holding. They may feel unsafe when they are asked to deal with a stressful situation when familiar restraints are withheld in the name of respecting a person's rights. What safety means for each person

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[6] See http://www.samhsa.gov/traumajustice/traumadefinition/index.aspx and following pages and Elliott, D. et al. (2005).Trauma-informed or trauma denied: Principles and implementation of trauma informed services. *Journal of Community Psychology, 33*, 4: 461-477.

[7] See for example, Fallot, R. & Harris, M. (2009). *Creating cultures of trauma-informed care: A self-assessment and planning protocol.* Washington, DC: Community Connections. http://www.healthcare.uiowa.edu/icmh/documents/CCTICSelf-AssessmentandPlanningProtocol0709.pdf

with problem behavior is a significant question for the person-centered planning process to answer. For some people real freedom from restraint will be the achievement of an intentional process of developing trusting relationships and alternative safety strategies which create a social environment that can support the person to control dysregulation.

The second potential contribution of Trauma Informed Support is to expand the repertoire of pathways to recovery from Trauma Related conditions such as Post Traumatic Stress Disorder. These pathways increase the person's capacity to maintain engagement, prevent dissociated states and build cognitive structures that allow a wider range of choices.[8] Because trauma related difficulties are often persistent and can recur if a person is re-traumatized it is most important to purposefully develop links to these positive practices in the communities people will live in rather than to expect that interventions implemented in the RHC will generalize to community settings.

Approaches to psychological and relationship intervention that are compatible with Trauma Informed Support and support DDA's mission and purpose. Given the current state of the art, no one way of understanding people with developmental disabilities is sufficient and no single approach to support benefits everyone. Any effective approach is founded on respect for each individual's dignity, expressed in persistent and creative efforts to collaborate with the person to discover and support the person's capacities to develop and contribute. We have seen individual people with complex and very challenging behaviors benefit from access to competent and respectful practitioners who are willing to accommodate a person's cognitive and communicative differences as they apply their skills. These interventions are most effective when direct support workers and managers add what these perspectives say about the person to the story they hold about the person's challenges and possibilities and find ways to incorporate practices from the approach in the daily routine. Some staff report adopting practices they have learned with the person in their own lives.

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[8] See Sims, B. (2012) *What is trauma and why must we address it?*. Washington, DC: National Center for Trauma Informed Care http://www.aca.org/conferences/winter2012/WorkshopPresentations/A-1B%20Increasing%20Safety%20and%20Success%20Implementing%20Trauma%20Informed%20Principles.pdf and Pitonyak, D. (2011). *Supporting a person who is experiencing post-traumatic stress disorder (PTSD*). www.dimagine.com/PTSD.pdf

Skilled counsellors and therapists use a wide variety of approaches to good effect. We have seen good therapists adapt Dialectical Behavior Therapy (DBT);[9] and Acceptance and Commitment Therapy (ACT);[10] to the needs of people with cognitive impairments and make an important difference in situations where people struggle with dysregulation that results in injury to self or others, threats of suicide, running away into dangerous situations, multiple emergency admissions and high rates of staff turnover, in part due to trauma because the person makes staff feel helpless and victimized. Both of these approaches encourage mindfulness practices. In addition to good effects from both of these therapies, the literature is beginning to reflect benefits of incorporating mindfulness practices into daily routine.[11]

Our point is not to endorse these particular methods, though we know people with intellectual and developmental disabilities and staff teams who have benefited from each of them. Our point is this. Staff hold an important part of a person's story. Their sense of who a person is, what the person values and how the struggle with problem behavior effects their relationship strongly influences the way they think about and offer support. When a person is especially challenging to assist and the challenges persist over time, both the person and the staff involved with them will benefit from a rich variety of narrative resources and specific practices that support coping with problem behavior and increasing self-direction and active pursuit of socially valid, personally meaningful goals. A competent functional analysis will provide a person specific formulation of what a person is trying to achieve through problem behavior and lead to educational interventions that increase positive alternatives to problem behavior. A good person-centered planning process that begins in the RHC and continues through the person establishing him or her self in community services will provide a strong sense of what is important to and important for the person and knowledge of the person's goals and capacities that leads to action that offers new opportunities for contribution and development. Trauma awareness frames the creation and organizational culture that is better and better able to deliver

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[9] http://www.behavioraltech.org/ see also Linehan, M., et al. (2006). Two-Year Randomized Controlled Trial and Follow-up of Dialectical Behavior Therapy vs Therapy by Experts for Suicidal Behaviors and Borderline Personality Disorder, *Archives of General Psychiatry 63*(7):757-766

[10] Hayes, S., et al. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy 44*: 1-25.

[11] Hwang, Y.-S., & Kearney, P. (2013). A systematic review of mindfulness intervention for individuals with developmental disabilities: long-term practice and long lasting effects. *Research in Developmental Disabilities, 34*, 314–326 and Chapman, M., et al. (2013). The use of mindfulness with people with intellectual disabilities: a systematic review and narrative analysis. *Mindfulness. 4*:108-118.

the values of safe, trustworthy, collaborative, strength enhancing relationships. Third generation behavioral and cognitive therapies like DBT and ACT can offer ways that people and their staff can come to a more hopeful and compassionate understanding of the place of problem behavior in their lives and teach practices that give them practical ways to create better days together. None of this will cure most people, but it will make people and staff stronger and sustain them in the continuing struggle to balance control of dangerous and problematic behavior with the pursuit of a good life as an employed, contributing citizen.

The difficulties of this struggle open the door to the enemies of good community support. Cynicism about a person's capacity for development undermines the development of good support by encouraging blaming and aggressive helplessness in the face of difficulties. Smugness that pretends to have **the** answer blunts curiosity and discourages efforts to enlist the person as a co-experimenter in achieving positive change. Dullness makes people satisfied with low expectations and closes the way to new learning.

We wonder about the vision and strategy for resource development

Capacity to learn and adapt is the hallmark of a competent service system. We see the people whose supports are strained to the breaking point by the difficulties they encounter in establishing themselves in the community as an invaluable source of knowledge that will improve the transition process. This learning can be blocked in at least two ways. First, instead of looking at breakdowns as the creation of the system, those who might learn and change blame the person or the community provider as not ready or not motivated. Second, instead of looking rigorously for areas of improvement in the process, those who might learn and change accept the person's return to the RHC as a regrettable but acceptable occurrence. When these two blocks act together, people could conclude that it's the RHC's responsibility to either get the person ready to return to community services or to offer the person a safe place to be for an indefinite time.

We have noticed five things in places that have systematically continued to reduce the use of psychiatric facilities and jails as well as ICF/ID or nursing homes.

- There is at least one community service provider with a deep commitment to learning how to offer capable assistance to people who have a history of being difficult and dangerous to serve.
- Direct support workers have easy access to crisis support. This includes experienced people who will work alongside them for a time when they are exhausted; onsite help by people who

will collaborate in revising plans and practices when necessary; easy access to a prescriber who knows the person and can adjust medications as necessary; and access to a safe house that can be used for short term stabilization but requires continuing involvement of direct support staff. This capacity can be an organization contracted by local service system managers, such as a UCEDD,[12] or it can be a capacity developed within a community service organization.[13]

- Organizations committed to people with substantial problem behavior assertively and systematically build a network of relationships with mental health service providers, first response agencies, housing agencies, transportation providers and other human service agencies. Typically these networks grow stronger through the organizations persistent advocacy for individuals they assist.
- System managers (similar to DDA Regional Management) value organizations with this commitment and invest regularly and substantially in improving their competency.
- System managers review breakdowns, especial when they result in psychiatric admission, ICF/ID admission, or time in jail or prison. Based on this review, they collaborate with committed and capable providers to strengthen available supports. This can result in the implementation of new types of service or the development of new, specialized provider organizations.[14]

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[12] For example, Community TIES in Dane County, Wisconsin http://cow.waisman.wisc.edu/crisisresponse.html. See Junker, A., Garvey, B., & Rossiter, D. Crisis, What crisis? Supporting person's with challenging behavior in the community. *TASH 2000: Our Turn Now.* Washington, DC: TASH. Pp. 120-125 http://cow.waisman.wisc.edu/documents/Crisis_What_Crisis.pdf

[13] O'Brien, J., et al. (2007). *Never give up. Assets Inc's commitment to community life for people seen as "difficult to serve."* Syracuse, NY.: Center on Human Policy, Law and Disability Studies. http://thechp.syr.edu/wp-content/uploads/2013/02/Never_give_up.pdf

[14] In England, The Department of Health has responded to a pattern of deficiencies in local supports that led to a significant number of people being served in large group settings away from their local area, and to public scandal created by mistreatment in some of those facilities, by developing expert guidance for service system managers prepared by researchers and practitioners who specialize in community supports to people with challenging behavior. A translation note: the UK equivalent of service development and contracting is "commissioning" and "learning disability" refers to what we in the US label "intellectual disability". See, Mansell, J. (2007) *Services for people with learning disability and challenging behavior or mental health needs.* London: Department of Health. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129 and McGill,P., Cooper, V., & Honeyman, G. (2010) Developing better commissioning for individuals with behavior that challenges services. Canterbury: Tizard Centre. www.challengingbehaviour.org.uk/learning-disability-files/Better-Commissioning-full-report.pdf

Holding a high standard is fundamental to improving any process. The standard for every transition is a full and successful life as a contributing citizen. When a person lives with impairments or a history that results in challenging behavior the standard safe and competent support that allows the person to prevent or deal with problem behavior without the loss of a person's place and valued roles in the community. Some people's situations are complex and we will fall short of these standards. Learning from these shortfalls and developing better responses at the individual and system levels is the key to continual improvement in the transition process.