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TABLE OF CONTENTS

NOTE FROM THE EDITOR

In this issue, our Canadian colleagues Drs. Paul Wishart and Sherri Melsrose share their thought-provoking qualitative research which utilized a grounded theory approach to understanding the experience of DSPs. Dr. Thomas Scheidemantel reflects upon the ethical challenges inherent in medical decision-making on behalf of adults with intellectual and developmental disabilities. Connie Boyer Frenzel mirrors these concerns about autonomy and duty to care in the Family Corner. She writes about the need for broad social acceptance and adequate programming to safely mainstream individuals with disabilities and behavioral health challenges into the community. Melissa Cheplic shares information about this year's recipient of the NADD Direct Support Professional Award for Excellence who was honored at NADD's 34th annual conference. Congratulations Ryan Trihey!

Consider contributing to this space by sharing your research, practices and policies that advance the lives of individuals with developmental disabilities and co-occurring mental health disorders.

Best wishes to Dr. Rob Fletcher in his retirement. He has made singular contributions to the field via the creation of NADD, mentorship of professionals, and advancement of professional practice. His work has enabled the creation of a community of like-minded professionals and other stakeholders who promote mental health and well-being for individuals with the dual disabilities of developmental and mental health disorders.

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Beyond Physical Inclusion: A Grounded Theory of Belonging

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Abstract

We used *grounded theory* to analyze interviews with support workers evaluating a program for individuals with dual diagnosis. Our *grounded theory* research started with the question, "What is going on in the data?"

From our data analysis, our grounded theory of *belonging* emerged. There are two components to our grounded theory that conceptualize what is going on in the data. The first is the main concern, which is *stopping short*. The second is the core variable, which is *belonging*, and resolves *stopping short*.

Stopping short is the main concern, and is the process that accounts for making resolution difficult. Several underlying concerns reinforce *stopping short*. These are *being left out*, *(limiting) inclusion*, *logical elaboration*, and *turnover*. A lack of awareness of the influence of these concerns can reinforce Stopping short. Awareness of them and their influence is part of the contribution to resolving Stopping short through the core variable of Belonging.

The process of *belonging* is supported by increasing Awareness and an emphasis on *relationship*. *Reciprocity and support(ing) relationships* and *awareness* provide the meaning and relevance of *belonging* for people supporting those living with dually diagnosed. The significance of using *grounded theory* for our analysis and the contribution *belonging* makes for those supporting and working with individuals with dual diagnosis are discussed.

Grounded Theory

Grounded theory is a general research methodology used to generate relevant theory through the analysis of data. Grounded theory can be used on any data (Glaser, 2007). Often grounded theory research starts with the question, "What is going on in the data?" (Glaser, 1998). Instead of traditional approaches, where preconceived theories or patterns drive the analysis, with grounded theory the analysis is guided by the many rigorous steps of grounded theory noted below, woven together by the constant comparison process (Becker, 1993; Glaser, 2002a). Through constantly comparing codes to codes, generating a concept, and compar-

ing codes to concepts to generate categories, the analysis generates similarities, differences, and degrees of meaning which inform the properties and dimensions of the emerging theory (Glaser, 1978b). It is through the constant comparative method and memoing that the grounded theory acquires its grab, fit, and ability to work the data (Glaser, 1978b). Grab, fit, and work imbue the theory with relevance and meaning, so that there is a high probability that it will make a difference within the area from which the data was acquired (Glaser, 1978b).

The Research Approach

In our re-examination of interview data from our primary research project, two aspects of classic grounded theory methodology, the package and the product, were of particular value. The package explains how a grounded theory is generated. The product clarifies how to recognize the core attributes of a grounded theory.

1. *The Grounded Theory Package*

Glaser (1998) refers to the essential components of grounded theory as the grounded theory package. Using the package helps researchers develop their theoretical sensitivity and increases the probability of generating a meaningful grounded theory. There are several components we used in generating our theory of *belonging*:

a. *Coding*

Coding is the fracturing of the data into the smallest pieces of meaning, selecting words, phrases, or stories "that contain a single unit of meaning" (Schreiber & Stern, 2001, p. 69). This is the analysis stage where the researcher defines what he or she sees in the data pieces (Charmaz, 2006).

b. *The constant comparative method*

The constant comparative method, or constant comparison, is one of the most important components of GT (Glaser, 1978b; Glaser & Strauss, 1967). Glaser explains the sequence: first the researcher compares indicators (incidents or codes observed in

the data) to other indicators. Once a conceptual code (a repeated idea that becomes apparent) is generated, the indicators are then compared to that emerging concept or idea. Constant comparison forces the analyst "into confronting similarities, differences and degrees of ... meaning between indicators" (Glaser, 1978b, p. 62).

c. *Memoing*
Writing theoretical memos is the core stage in the process of generating theory. "Memos are theoretical notes about the data and the conceptual connections between categories. ... If the analyst skips this stage [of writing theoretical memos] by going directly to sorting or writing up, after coding, he/she is not doing GT" (Glaser, 2004, para. 61).

d. *Theoretical codes*
Theoretical codes are important in generating a grounded theory as they provide the organizational foundation for the emerging theory. "The final theoretical code is the one that emerges, through the coding process, and serves to integrate all of the substantive categories with the core category" (Hernandez, 2009, p. 52).

e. *Sorting and writing up*
This is the final component of GT, which involves sorting theoretical memos into piles and writing them up in a manuscript or book, to disseminate the findings. "Sorting is essential—it puts the fractured data back together" (Glaser, 2004, para. 67).

2. **The Grounded Theory Product**
a. *Relevance and meaning*
Glaser asserts that a grounded theory must be relevant and meaningful, rather than just interesting. And not just to those from whom the data was acquired. Relevance and meaning drive the generalizability or transferability of the grounded theory. A good grounded theory is applicable to a wide, multidisciplinary audience.

b. *Grab, fit, and work*
A relevant grounded theory consists of the following attributes: it must grab, fit, and work the data (Glaser, 1978b, 2001). A grounded theory is also able to be modified (Glaser, 1978; 1998). Note that these crite-

ria are in contrast to an oft mistaken goal of a grounded theory, that it is accurate (Glaser, 2002b, 2007) and a proof (Glaser, 1978b). A grounded theory is not accurate as it does not describe nor is it a proof; it is a theory, a hypothesis.

To clarify, grab (Glaser, 1978b, 2001), the theory has clear and grabbing implications, it makes sense. It grabs the reader's attention. Fit (Glaser, 1978b, 2001) is where there is a close connection of the theory with the incidents the theory is representing, that it connects. Work (Glaser, 1978b, 2001) is where the theory deals with real concerns of participants and captures attention. A grounded theory works when it explains how a meaningful concern for the participants is resolved. Therefore, a grounded theory that has grab, fits, and works the data has a high probability it will be relevant, that it will be applied, and that if necessary it will be modified (Glaser, 1978; 1998).

3. **Data**
In his well-known article "All is Data", Glaser (2007) emphasized how data from a variety of sources can be used to generate a grounded theory. Commonly, interviews, observations and documents are used. In our work, our data consisted of interviews with caregivers who support individuals with dual diagnoses. Throughout our analysis and as new concepts emerged, we reviewed additional literature and discussed our project with experts.

Our Results
The results of our analysis are presented below, in Table 1. There are two components to our grounded theory of *belonging*, the patterns of Basic Social Psychological Processes (BSPP) which explain what is going on in the data. The first component is the main concern, which is *stopping short*. The second component is the core variable of *belonging*. *Belonging* is the core concept which resolves the main concern of *stopping short*. Both *stopping short* and *belonging* emerged from our Grounded Theory analysis of the data. In addition, there are several relevant components of the GT package that were indispensable in generating our grounded theory of *belonging*. These are addressed in the Discussion section in this article (Glaser, 1978a).

Table 1: The relevant concepts of our grounded theory of Belonging

Results of our GT analysis	
Main concern	***Stopping short***
Underlying concerns	• *Being left out* • *(Limiting) inclusion* • *Turnover*
Core variable (resolving the main concern)	***Belonging***
Theoretical codes	• *Relationship* • *Awareness*
Substantive codes	• *Reciprocity* • *Support(ing)*

In the section which follows, we discuss our conceptualization of the relevant concepts from our analysis and how they connect to both the main concern of *stopping short* and the core concept of *belonging*. Together, *stopping short* and *belonging* constitute our grounded theory of *belonging*, a Basic Social Psychological Process.

Discussion

Our grounded theory of *belonging* is a conceptualization of what is going on in the data. We will discuss our grounded theory of *belonging* from the perspective of two key aspects of the process: the main concern of *stopping short* and the core variable of *belonging*, which resolves the main concern of *stopping short*. Both concepts emerged from the data and together form our grounded theory of *belonging*.

1. The Main Concern Is Stopping Short

Stopping short is our conceptualization of the process which blocks or prevents people from feeling involved in their environment, that is, from feeling a sense of *belonging*. Several significant concerns emerged from our analysis which support and reinforce *Stopping short*. These are *being left out*, *(limiting) inclusion*, *logical elaboration*, and *turnover*. It is important to see how these concepts relate to *stopping short* of *belonging*. *Stopping short* links them as the main concern. Understanding their influence, one can see how they impact *stopping short*; either reinforcing *stopping short* or resolving *stopping short*, as they influence the core variable of *belonging*.

Stopping short is a conceptual representation of the difficulties in realizing the goals of care and support of individuals who have a dual diagnosis. The conceptualization of this main concern and the underlying concerns that support the process can cumulatively hold back or prevent caregivers from realizing their goals of caring for their clients who have a dual diagnosis. In this context it is the lack of awareness of the process that prevents or obstructs the caregiver from reaching the goal of care and support for their clients. Awareness will be discussed later in the context of theoretical codes as part of the conceptualization of the core variable of belonging.

These concepts underlying *stopping short* will be discussed later as they relate to the main concern of *stopping short*, followed by how *stopping short* relates to *belonging* as a BSPP and the concepts that undergird *belonging* which leads to the resolution of *stopping short*.

a. *Being left out*

Being left out was the first concept that emerged as we began our re-examination of interview data from our primary project. *being left out* is a very strong concern that emerged from the data analysis, one which was shared by support staff, their supervisors, and family members caring for and supporting the individuals with a dual diagnosis who participated in the project. The data yielded many indicators of the profound impact *being left out* had on clients. Two examples, below, illustrate this impact particularly well.

The first indicator is a client carefully dressed in clothes, newly purchased in anticipation of attending a family event. The client stood

waiting, alone, on their apartment doorstep. They were waiting for a previously arranged pickup by a family member, a pickup that never came. This person was *being left out* of their family event.

The second indicator comes from a client living with a supportive roommate. Although the roommate made meals and provided clean living arrangements, the client was not invited to join the roommate to join in shopping trips for food, making meals, or watching TV in the evenings. Consequently, the client withdrew to their designated room, coming out only to eat prepared meals. The client's behavioral regression was noticeable, attributed to the consequences of *being left out*.

These two examples of *being left out* speak to the emotional charge associated with the experience of being and feeling left out, as well as the negative contributions made to health and well-being. *Being left out* is certainly not just a consideration or concern for individuals who have a dual diagnosis.

b. The Basic Social Psychological Process (BSPP) of being left out

In our analysis, we identify *being left out* as a relevant, basic social psychological process not only relevant for support workers and staff supporting individuals who have a dual diagnosis, but also for families and the clients themselves. *Being left out* impacts individual and collective well-being, and lack thereof. Initially, with the prevalence and impact of *being left out*, it appeared to be the main concern emerging from the data.

c. Inclusion resolving being left out

Once we identified the impact of *being left out*, we discovered a complementary process that seemed to fit as though it might be a pattern that resolved *being left out*. This process is *inclusion*. *Inclusion*, or simply including people, seemed to be an excellent process for resolving the disturbing experience of *being left out*.

Interestingly, *inclusion*, or creating opportunities for clients to participate in community activities, is well represented in the data. There are numerous illustrations in the interviews of how paid support staff, and family members too, collaborated in ways to include clients enrolling them in programs such as swimming, exercise, scrapbooking, and others. However, further conceptualization of *inclusion* ultimately led us to conclude that the main concern was in fact, *stopping short*. Next, we elaborate on the limiting aspects of simply viewing inclusion as a process of creating opportunities for clients to attend activities.

d. (Limiting) inclusion

The complementary nature of *being left out* and *Inclusion* could be viewed as representing a grounded theory. A significant concern emerged from the data, *being left out* and *inclusion* could be the core variable that resolves *being left out*. In other words, creating opportunities for clients to participate in community activities and programs would seem to resolve the concerns and difficulties they experienced when they felt as though they were being left out.

However, as we continued our analysis, we explored the various dimensions *inclusion* might have. It turned out that one of these dimensions, the physical one, was much more prevalent than any other dimensions *Inclusion* might encompass, to the exclusion of any other (at least within our data). It was at this point that the emphasis in our analysis shifted from dimensions of *inclusion* to discovering what was *being left out*. This shift led to the discovery of a key property of *inclusion*, its limitations, which we conceptualized as *(limiting) inclusion*.

(Limiting) inclusion is a concept that connects. Too often, we know, have heard, or perhaps have even experienced this personally situations where we have been physically included but have felt something missing, tangibly or intangibly (maybe even that we may feel we don't "belong"?). Although *physical inclusion,* or physically attending an activity is extremely important, *physical inclusion* is often actually "*stopping short*" of meaningful support as a relevant contributor to well-being. The resources and network may be there, but people may not feel they

are involved or genuinely part of the environment they are in.

This *(limiting) inclusion* contributes to our grounded theory of *Belonging* by pointing us to the concept of *"stopping short."* And *stopping short* explains (conceptualizes) what is going on in the data thus far, by connecting the underlying concerns of *being left out* and *(limiting) inclusion*. As we illustrate, this concept also connects to the concept of *turnover*.

e. Turnover – a multidimensional concept

Turnover emerged as a significant concern in the primary project (Melrose et al., 2013). An increase in anxiety in clients who have a dual diagnosis was attributed to the constant turnover of support workers. Increased anxiety correlated with escalating symptoms of mental illness (Melrose et al., 2013). Increased anxiety was caused by both the lack of continuity and a lack of consistency in client care (Melrose et al., 2013).

Turnover remained relevant in our retrospective Grounded Theory analysis. Studies over the past several decades indicate that *Turnover* affects many areas of support staff well-being. In addition to changing jobs frequently (Casey, 2011; Hendren, 2011; Hensel, Lunsky, & Dewa, 2011; Melrose et al., 2013), staff who work with individuals who have a dual diagnosis feel burned out (Devereux, Hastings, & Noone, 2009; Jahoda & Wanless, 2005; Jenkins, Rose, & Lovell, 1997; Thomas & Rose, 2010) and emotionally drained (Mascha, 2007; Reinders, 2010; Schuengel, Kef, Damen, & Worm, 2010).

In addition, other areas of staff support are affected by *turnover*. *Turnover* occurs with clinicians who work with the clients and their families. A scarcity of resources exists, in part due to funding cuts, and this contributes to *turnover*. Further, clinical and supervisory personnel who provide support and educational opportunities to the front line support workers are impacted by a lack of resources, leading to a loss of support for clinical practice and continuing education for support workers.

Lastly, an interesting dimension of *turnover* emerged during our analysis, a paradigmatic one. This is in connection with the paradigm shift away from caring for people in institutions and towards providing support services in their communities (Lunsky et al., 2013). This paradigmatic dimension of *turnover* has implications for programming and support. As one interviewee astutely noted, the paradigm of care may be changing, but an institutional model of governance may still be directing services provided.

f. Stopping short – summary

In summary, the main concern (or what people find most difficult in a situation) in our grounded theory analysis is that current approaches geared to including people stop short of resolving this concern. Thus, the main concern is *stopping short*. *Stopping short* was the pattern that connected several underlying concerns in the data: *being left out*, *(limiting) inclusion*, and *turnover*. Below, we discuss the core variable, and grounded theory, of *belonging*.

2. The Core Variable Is Belonging

Belonging is the core variable, the Basic Social Psychological Process that emerged from our grounded theory analysis. *Belonging* is the process resolving the main concern of *stopping short*. Both concepts, *belonging* and *stopping short* were derived from the data.

So how does *belonging* resolve *stopping short*? The previous section provides the conceptual basis for *stopping short*, the main concern. This section on *belonging* builds upon the foundation laid by the main concern. *Stopping short* informs the core variable of *belonging* and the underlying concepts that support *belonging*.

Belonging owes its relevance and meaning to one of the key components of grounded theory -- theoretical codes. *Belonging* relies on two theoretical codes which support resolving the main concern of *stopping short* and provide the grab, fit, and work of the grounded theory for people living with a dual diagnosis as well as for those who support them. Two substantive codes also contribute to the area of dual diagnosis.

a. Support(ing) and reciprocity

Support(ing) is one of two substantive codes generated from our analysis. With the emergence of *belonging* as a core concept, we conducted a literature search on the subject. One of the discoveries we made was the work of Peter Block (2009). Block's work provided us with the relevant distinction between *supporting* and helping. From Block's work, care can be viewed conceptually as helping or supporting. In our conceptualization of *belonging*, *supporting* is distinct from helping. *Supporting* conveys more of a dialogical nature to *relationship* and identity. Whether a client or a support worker, Helping is most often directed in unilateral direction; the health care professional or support worker helps the client or patient; the client or patient receives the proffered help. There is little opportunity to consider another dimension or reciprocal direction to the *relationship*. With support, other dimensions and directions of *Relationship* are opened up. Becoming aware of other directions or dimensions of *relationship* facilitates our movement beyond *Stopping short* to *belonging*. Perhaps Supporting is the means to greater resilience and sustainability than helping?

Reciprocity is the second of two substantive codes generated. As we see it, *reciprocity* involves the possibility of mutual exchange. *Reciprocity* provides a relevant distinction between Supporting and Helping. How often might we focus on helping as a default over supporting? How often might we lose *reciprocity* in our *relationship*s through our default to helping? How often in our insistence on helping might we lose the opportunity of being supported? How often might we be *stopping short* in this matter of helping and miss the opportunity to move beyond helping to supporting, to *belonging*?

An indicator of *reciprocity* is recounted in an interview with a client's support worker. Her client was a young woman who experienced heightened anxiety around knives, who, despite this fear prepared a dish containing chopped vegetables for her neighbor who was ill. This unexpected *reciprocity* speaks to the essence of *belonging*, of the client not only receiving, but

in giving as well. *Reciprocity* here spe to opening up unexpected dimensions *relationship* for meaning and purpose emerge and for them to be cultivated supported through *belonging*. *Reciproc* speaks to the essence of *belonging*; of client unexpectedly providing support others as well as receiving it from the support worker.

b. Relationship and awareness

Relationship and *awareness* are two th retical codes that emerged near the end the analysis, during the memo sorting an writing up phase.

Relationship as a process involves co nections and connecting. *Relationship* something we cultivate (Simmons, 1993 The concept of *relationship* also serves as reminder during our analysis; our foci conceptualization and process, connectio and connecting. This is in contrast to whe the emphasis might be on description an describing a phenomenon within the data.

Awareness, the concept, emerged durin the write up of our sorted memos. ser and Strauss discovered the concept o *Awareness* in their original study on dyin the study that led to their seminal publica tion of *The Discovery of Grounded Theo* (Glaser & Strauss, 1967).

Awareness is not a static description bu a process that contributes to increasin *Awareness*. In the naming of *stopping short* there is an opportunity for our *awarenes* to shift from where we are *stopping sho* as a pattern or interaction to *belonging*.

Awareness and *relationship* tie the proce of *belonging* together as an integrated conceptualization. *Awareness* and *relationship* contribute to our "seeing" where *being left out*, *(limiting) inclusion*, *logical elaboration*, and *turnover* are *stopping short* of *belonging*. Without *awareness*, the probability of meaningful movement beyond *stopping short* and *(limiting) inclusion* is diminished.

Conclusion

This conceptualization of *belonging* and the main concern of *stopping short* provides us a

finger pointing, not an accusatory one, but a finger pointing in the direction of resolution, of *belonging*, which is the process through which *stopping short* is resolved and greater well-being is achieved for those involved supporting, living and working with individuals with a dual diagnosis.

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