

# “It’s Not the Asperger’s That Causes the Anxiety, It’s the Communication”

## Person-Centered Outcomes of Hope and Recovery in a Cultural–Clinical Borderland

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This article focuses on a narrative account of a therapeutic journey experienced by 2 of the authors: an individual (P.D.) with a diagnosis in adulthood of autism spectrum disorder (ASD) and a speech–language pathologist/researcher (I.W.). Instead of adopting a traditional expert clinician treating an impaired patient stance in a highly formalized clinical setting, with concomitant role expectations of power and perceived inequality, a cultural–clinical borderland was coconstructed. The figurative notion of *borderland* in this context is used to describe a physical and psychological space characterized by a more flexible, informal, and authentically shared therapeutic relationship, influenced by a merging of cultures. The cultures at play in this context were an ASD and non-ASD culture and the culture and practice of speech–language pathology. Accounts of social communication experiences, challenges, and anxieties focused on personal reflections, when misunderstandings and miscommunications surfaced from perceived cultural differences. Instead of reinforcing experiences of otherness and difference—which may be an inadvertent by-product of impairment-focused therapy—a positive trajectory of hope and recovery emerged from these interactions when they were placed within a person-centered context. **Key words:** *autism spectrum disorder, hope, narrative, outcomes, person-centered, social communication*

**T**HIS ARTICLE is an account of a collaborative therapeutic journey taken by two of the authors, spanning a number of years. The therapeutic collaboration described here is between a person with a diagnosis of Asperger’s syndrome (i.e., P.D.) who was

seeking support for communication and social interaction and a speech–language pathologist/researcher (i.e., I.W.) working in a university clinic setting. These individuals worked together in a nontraditional way, within what can be considered a cultural–clinical borderland, where the roles of therapist and client—often interpreted as expert clinician treating an impaired patient—receded to be replaced by a more equal, shared, and flexible working relationship. *Borderland* is a figurative term used in this article to describe a physical and psychological space where a desirable merging of an autism spectrum disorder (ASD) and non-ASD culture (Bogdashina, 2005) shaped the therapeutic trajectory. Working in a person-centered way was influenced by a number of factors, including particular

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concerns for the participants at the outset of the collaboration. For P.D., the concern centered on her attempts to cope with stressful and anxiety-provoking communication challenges as part of a late diagnosis of ASD in adulthood; P.D. was seeking guidance from a speech-language pathologist being acutely aware of her ability to talk (i.e., “I can speak . . .”) but not, in her opinion, to communicate competently and successfully. I.W.’s concern was a desire to work differently with people with the diagnosis, that is, to work alongside the person in a truly collaborative manner, as opposed to working solely on the presenting features of the impairment or perceived deficits. Hence, a third culture was challenged in this borderland context—that of a more traditional, exclusively impairment-focused, speech-language pathology practice.

Before discussing the nature of how these cultures came together within the context of a cultural-clinical borderland, it is important at the outset to establish the origins of the data analyzed in this article.

In the initial meetings between I.W. and P.D., P.D. explained how she liked to keep diaries. In these diaries, P.D. recorded events and personal reflections. When shared with I.W., it was obvious that many of these reflections were concerned with feelings related to her late diagnosis of ASD in adulthood and her thoughts and ideas on day-to-day experiences of communication interactions. Maintaining a diary was important to P.D. P.D. explained how it helped clarify her thoughts and feelings, particularly in instances where communication was experienced as challenging, frustrating, or difficult. During regular meetings between P.D. and I.W., the contents of the most recent entries were shared and formed the basis of discussions.

Through the discussions between P.D. and I.W. and follow-up consultation meetings with C.J. as part of the therapy process, the decision to write this article was made. C.J.’s consulting role was to support both P.D. and I.W. in achieving their respective goals and was characterized by questioning and

reflecting, both on an individual basis and together, at various stages during the interactions. As these meetings and consultations progressed, P.D. became increasingly motivated to share her ideas, initially with the students on the speech-language pathology program at the university and then to a wider audience (Walsh & Delmar, 2011). In addition, C.J. and I.W. had previously discussed and developed the related concept of hope as a therapeutic dynamic in speech-language pathology practice (Jagoe & Walsh, 2013), informed by their experiences of working with P.D. and others challenged by communication difficulties. The data analyzed for this article were drawn directly from P.D.’s diary entries. A thematic content analysis was conducted, loosely applying the methods as suggested by Attride-Stirling (2001).

Coming together to write this article meant that P.D. participated as an equal member of the writing team. However, given that P.D. began this journey ostensibly in a patient role, the authors recognized that publishers would want reassurances that her participation and naming in the article was voluntary. The research ethics committee of the authors’ host university was consulted and considered precedents in the field of patient and public involvement in research. Looking to practice in the United Kingdom, the National Patient Safety Agency of the National Health Service states that

the active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. (INVOLVE, 2009, p. 1)

The National Patient Safety Agency included reporting and communicating research findings as active involvement not requiring ethical approval. Hence, to follow best research practice in this context, the authors submitted a specific query to the relevant ethics committee for its consideration, the response to which confirmed P.D.’s involvement as a coresearcher and

coauthor in this context and not a study participant.

In this article, the authors seek to show how this context of interaction took place in what came to be recognized as a cultural-clinical borderland, defined and constructed by the interactions and the discourse moments within it, along with cultural influences. This concept of borderland along with concepts of hope and recovery is further defined later, following an overview of the diagnostic category of ASD. In addition, an account of Labov and Waletzky's (1997) narrative framework is given as it is employed to describe the therapeutic journey under discussion. Finally, some principles of Cognitive Behavioral Therapy (Beck, 2011) and a model of Collaborative Deliberation (Elwyn et al., 2014), both approaches that helped guide and inform the interactions discussed, will be outlined before narrating the person-centered therapeutic process as the focus of this article.

## AUTISM SPECTRUM DISORDER

Autism spectrum disorder, as a diagnostic category, has a long history related to its classification since Leo Kanner first described *early infantile autism* in 1943 (Kanner, 1943), and Hans Asperger described *Asperger's syndrome* (or *autistic psychopathy in childhood*) 1 year later (Asperger, 1944). Since then, the question has remained as to whether Kanner and Asperger were in fact outlining the same condition to describe a common syndrome among individuals who presented with social interaction and communication difficulties, with a tendency for stereotypical play, repetitive behaviors, and restricted interests (Achkova & Manolova, 2014; Wing, 1991).

Until recently, Asperger's syndrome was listed as a separate diagnosis within the category of Pervasive Developmental Disorders in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR*; American Psychiatric Association, 2000). However, clinical presentations of Asperger's syndrome

and what was termed *High-Functioning Autism* were often considered similar, leading to attempts to differentiate the two conditions. Some concluded that individuals with Asperger's syndrome manifested milder symptomatology developmentally, with better outcomes, and differences were mainly considered in terms of degree of impairment or severity of symptoms (Ozonoff, South, & Miller, 2000). More recently, Tsai's (2013) extensive review of 128 publications based on more than 90 clinical variables in Asperger's syndrome and Autistic Disorder/High-functioning Autism found that the majority of these studies (i.e., across 94 published articles) concluded that there were statistically or near-statistically significant levels of quantitative and/or qualitative differences between the two conditions. However, the diagnosis of Asperger's syndrome is now subsumed under the more general diagnosis of ASD in the most recent version of *DSM-V* (American Psychiatric Association, 2013). This decision was made despite arguments put forward by some for its retention as a separate diagnosis (Ghaziuddin, 2010) and despite a plausible prediction by others that Asperger's syndrome might return to *DSM* classification in the future (Tsai).

To account for the diversity of clinical presentations across the spectrum, the revised classification of ASD (*DSM-V*, American Psychiatric Association, 2013) takes into account severity levels across the two main parameters of deficits: (i) social communication and interaction and (ii) restricted repetitive patterns of behavior. Three severity levels (Levels 1–3) are defined on the basis of an individual's need for support, with Level 1 described as *requiring support* to Level 3 *requiring very substantial support*. Diagnostic criteria related to age of onset and limitations to, or impairment of, everyday functioning are also included in *DSM-V*. Given these recent changes to classification and the more generic use of a spectrum of disabilities, the term *autism spectrum disorder* is used for the remainder of this article.

## CULTURAL–CLINICAL BORDERLANDS

Mattingly (2010) introduced the concept of *borderland*, drawing on both (i) a literal definition of the term, as, for example, “an indeterminate region” (Collins English Dictionary, 2007, p. 193), and (ii) a figurative comparison to the lobby or waiting area of a health care facility, “with its in-between transient character” (p. 9) where people are in a place that is intended to be temporary (Collins English Dictionary, p. 8) and are waiting to move on. Mattingly’s notion of *clinical borderlands* may also describe spaces that are defined by “practices that bind people together who wouldn’t otherwise belong together” (p. 7). This practice-based focus reflects Rosaldo’s (1989) argument that, in ethnographic research agendas, there is a need to move from centers to borderlands or “zones of difference” (p.28), that is, not just at the boundaries of “officially recognized cultural units, but also at less formal intersections, such as those of gender, age, status, and distinctive life experiences” (p. 29). In this article, the distinctive life experiences discussed are those experiences that seem to emerge from within and outside the culture of ASD (Bogdashina, 2005), considered within the additional context of a culture of speech–language pathology practice. Therefore, a cultural–clinical borderland in the context of this article is characterized by three elements.

First, the borderland incorporates a coming together or meeting of cultures, that is, an ASD and a non-ASD culture. Second, it also represents a psychological and physical space at the edges of the world of formal clinical practice and the world of an individual living with a diagnosis of ASD. The edge of the formal clinical context here refers to the relatively informal context of this university setting, where some clinical consultations may be exploratory or less constrained by the service-driven demands of a busy hospital or community clinic. The edge of the world of somebody with ASD is that of P.D.’s experience of a late diagnosis in adulthood and her quest for support with communication. Third, the bor-

derland space is characterized by the orientations or stances of the participants in these settings, in this case, P.D., who was seeking help in an open-minded way, and I.W., who was exploring a different way of working alongside people with ASD. This borderland then is created at the edges of these worlds and constructed by the people who occupied this space, bringing to it their values and beliefs from their respective cultures, identities, and concerns. Thus, the cultural–clinical borderland takes on the characteristics of a more flexible space, where the boundaries are less rigid and where the shared goal is the “creation of common ground” (Mattingly, 2010, p. 12). The person-centered context is one of mutual respect, where participants are free to set their agendas as they work alongside each other and, in this context, are focused on the business of tackling social communication in all its complexity.

A narrative framework is employed to describe the therapeutic journey under discussion in this article. In relation to narrative, Mattingly (1998) proposed a concept termed *therapeutic emplotment* referring to the work done by therapists and patients in “creating story-like structures through their interaction” (p. 2). Therapeutic emplotment is distinct from just the telling of stories in therapy but instead is a creation, across the therapeutic process, of a story-like construct—the story of the therapy itself. Mattingly (2010) also focused on the practical purposes of narrative in clinical contexts and stated that one purpose of storytelling is that it presents a means to configure the plot and understand the situation by offering a sequence of events, roles, and relationships. A second purpose, Mattingly explained, is that stories are about the unfolding present, they are meaningful in the present, and situated between the past, which they report, and the future, which they influence.

Mattingly’s process of emplotment is considered crucial to the recovery process. Within this context of therapeutic emplotment and potential healing, Mattingly (2010) points out that hope can emerge and be

viewed as “discursively centered in cultural genres that shape its cultivation and suppression” (p. 53). Hope and the associated concept of recovery are explored further within the context of this article.

## HOPE AND RECOVERY

Hope is identified as a significant element in health care and within the processes of recovery (Wiles, Cott, & Gibson, 2008). It is linked to adjustment and well-being (Snyder, Haridi, Michael, & Cheavens, 2000). Although hope is an elusive concept, with definitions that vary in subtle ways, it is a legitimate concept in the literature. However, it is a concept that is rarely considered overtly in speech-language pathology contexts (Jagoe & Walsh, 2013). An exception is the work by Bright, Kayes, and Mc Cann (2013), who provided one of the few focused explorations of the concept in relation to aphasia. However, in disciplines such as health psychology, nursing, and allied health care, hope may be treated as a measurable quantity (e.g., Herth, 1992; Snyder et al., 2000).

Hope is dynamic, rather than static (Larsen, Edey, & Lemay, 2007). Learned hopefulness is related to a sense of psychological empowerment (Zimmerman, 1990), and hope may play an important role within the context of therapy, as “a malleable strength that can serve as an important therapeutic change agent” (Magyar-Moe, 2014, p. 244). In this context, hope is viewed as something that can be nurtured, shaped, and developed as a positive force in therapeutic interactions to support well-being. Hope also has been viewed as central in the therapeutic use of stories (Coppock, Owen, Zagarskas, & Schmidt, 2010; Dwivedi, 1997), having an impact on functional outcomes in mental health recovery (Schrank, Stanghellini, & Slade, 2008). Solnit (2016) suggested that hope is not a false sense of a future in which everything is right but rather “an account of complexities and uncertainties, with openings” (p. xi).

The notion of *openings* within hope has echoes in definitions of recovery, especially

within the context of mental well-being and health. Recovery too can be defined in a number of ways, but for the purposes of interpretation in this article, recovery shall be defined according to Anthony’s (1993) description, that is, not a cure or return to a premorbid self but instead a process of change to allow for a “satisfying, hopeful and contributing life” within the context of illness (p. 17). Anthony explained that recovery from a mental health disorder is highly complex, involving more than just recovering from the condition. Recovery also involves recovering from any stigma that may be associated with a condition and which may have become core to a person’s self-identity. Anthony’s conceptual framework of recovery has been the subject of a systematic review, leading the authors to conclude that the framework is “a theoretically defensible and robust synthesis of people’s experiences of recovery in mental illness [which] provides an empirical basis for future recovery-oriented research and practice” (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011, p. 445).

Deegan (1996) also discussed recovery as a process of transforming oneself by gradually accepting one’s limits and being open to new opportunities and possibilities, that is, “a slow, deliberate process that occurs by poking through one little grain of sand at a time” (p. 13). Hope is crucial to this sense of recovery: “without hope recovery is not possible. There can be no change without the belief that a better life is both possible and attainable” (Bradstreet, 2004, p. 5).

These definitions of hope and recovery resonate through the account of interactions between I.W. and P.D., which follows. Analysis of the interactions revealed accounts of many uncertainties and complexities in communication and social interaction but opportunities for change and recovery also.

## NARRATIVE FRAMEWORK FOR DESCRIPTION

In the analyses for this article, we adopted Labov and Waletzky’s (1997) narrative

framework as a useful and efficient way to structure and tell the story of this therapeutic journey, according to the following components: *abstract, orientation, complicating action, evaluation, resolution, and coda*.

As Labov and Waletzky (1997) explained “narratives are usually told in answer to some stimulus from outside and to establish some point of personal interest” (p. 29). The point of personal interest in this context was social communication. Furthermore, the lived, or indeed living, experience of having a diagnosis of ASD is core to this story.

## **ORIENTATION**

The orientation of a narrative serves to “orient the listener [or reader] in respect to person, place, time, and behavioral situation” (Labov & Waletzky, 1997, p. 27). In the orientation, the participants, the place(s) of interaction, and the behavioral situation (i.e., the dynamic of the interaction), all require identification and explication.

### **Participants**

P.D. had received a late diagnosis of Asperger’s syndrome/high-functioning autism mild range at the age of 42 years. In earlier adulthood, P.D. had been diagnosed with general anxiety and was prescribed medication. It is not unusual to have an associated diagnosis of anxiety with ASD. For example, Bridge (2016) referred to the debilitating nature of her own anxiety as associated with her ASD diagnosis. Recent debate has raised questions whether anxiety is comorbid or part of the ASD presentation (Davis III, 2012; Kerns & Kendall, 2012; Scahill, 2012). Regardless of this question, anxiety was a significant part of P.D.’s presentation, with anxious behavior associated particularly with social communication interactions, against a backdrop of competent language skills. P.D.’s mental health issues led to retirement from office work and resulted in her nonreturn to full-time employment, despite having the motivation to do so. However, subsequently, P.D. successfully completed two courses in a com-

munity college in training for a veterinary assistant. Although P.D. was not engaged with speech-language pathology services at the time of first meeting, she was involved with some other support services in the community (e.g., occupational therapy).

Also relevant to the identification of the participants is the fact that at the outset of this therapeutic journey, both participants were middle aged and at same age and life stage during this collaboration. This fact proved relevant and important, as shared experiences of communication dilemmas relative to daily life were shared and mutually understood.

### **Places of interaction**

The setting for the series of meetings that took place between the participants (i.e., I.W. and P.D.) was usually in a room in the university as opposed to a more formal clinic room in a medical facility. On occasion, the participants opted to meet in even more informal spaces such a café, a library, or an art gallery. *Space* is a borderland theme, as discussed by Kovarsky (2018). For these participants, space outside of the traditional trappings of a clinic room proved important in setting the dynamic of the working relationship, that is away from “architectural layout, furnishings and modes of dress [which] dictate an obvious authority hierarchy” (Simmons-Mackie & Damico, 1999, p. 313).

### **Dynamic of the interaction**

The dynamic of the interactions taking place between I.W. and P.D. was shaped by the culture of ASD in relation to the culture of people without ASD (Bogdashina, 2005) and another culture, that of the culture of speech-language pathology practice. With regard to culture, Cameron (2001) suggests that it is necessary to “try to understand that [a] community’s culture—its ways of acting in the world and making sense of the world in the way community members understand it themselves” (p. 47).

The concept of an ASD culture is not new, as it helps explain, accept, and respect the differences in ways of behaving and

communicating as a member of that culture (Bogdashina, 2005). P.D. admitted being preoccupied by her ASD diagnosis and associated features that she and other people attributed to her autism. In this sense then, ASD could also be viewed as a membership category (Jensen, 2013; Sacks, 1992). This membership category could be said to be that identity which P.D. assigned to herself (i.e., to make sense of her way of being in the world) and that which was assigned to her by other people (e.g., other health care professionals she had come into contact with). Although P.D. initially appeared as a shy and anxious person, once a trusting relationship was established, she exhibited qualities of a bright, articulate, often witty, and insightful individual, perhaps illustrating the effects of positive relationship and rapport building in therapeutic encounters (Walsh & Duchan, 2011; Walsh & Kovarsky, 2011).

In considering the influence of the culture of the speech-language pathology practice on the dynamic of the interaction, it is necessary to identify the nature and processes of the community of practice in the professional world (i.e., the habits, routines, expectations, behaviors, values, and discourse of the speech-language pathology clinic). In addition, it is important to consider the traditional mapping of impairment, assessment, evaluation, and interventions by an expert (e.g., Kovarsky & Duchan, 1997; Panagos, 1996; Simmons-Mackie & Damico, 1999; Walsh, 2013).

At the time of meeting with P.D., I.W. had begun to question her philosophy of intervention and had a desire to challenge the traditional therapist-as-expert and client-as-error-maker roles (Kovarsky & Maxwell, 1992), along with the inherent paradox of therapy, as described by Simmons-Mackie and Damico (1999), which asserts that “the goal of therapy is to build communicative competence, yet the assumptions required for treatment demand that the client be incompetent” (p. 313). This questioning stance, along with P.D.’s evident insightfulness around her diagnosis and social communication difficul-

ties, influenced the dynamic of the interaction from the outset, as in discussion both I.W. and P.D. recognized that a different approach to working together was needed.

P.D.’s insights and acute awareness of the complexity of communication, especially the challenges in real-time, moment-by-moment conversation, indicated that didactic teaching of communication and conversational skills, either as part of, or separate to an individual or group-based social skills training program, was counterintuitive. However, Hotton and Coles (2016) review of the efficacy of social skills groups for adolescents and adults with ASD showed that social skills training can be an effective intervention for this clinical population. This review was limited to group interventions only and did not include studies where one-to-one social skills training was included.

It was decided that an alternative, more experiential-discursive approach could be adopted. This decision was also influenced by I.W.’s own uncertainty of the effectiveness of working didactically on conversational skills training with adults (e.g., Walsh, 2002/2003; Walsh-Brennan, 2001).

Hence, both P.D. and I.W. were ready for a different way of working, and joint goals were based on revealing strengths and abilities toward P.D. becoming “an enabled rather than a disabled conversationalist” (Walsh, 2002/2003, p. 119). In other words, the goal was for P.D. to become a “competent consumer” as opposed to an “incompetent patient” (Simmons-Mackie & Damico, 1999, p. 314). The subsequent meetings, over a number of years, took the form of discussions of entries from P.D.’s reflective logs and diaries that she maintained throughout the process and which were reviewed together at each meeting. These entries often concerned scenarios where social communication apparently failed or was unsuccessful, leading to frustration and at times, distress. In particular, with such reported communication challenges and failures, issues pertaining to P.D.’s sense of self, belonging, and emotional health were discussed. A mutual sharing

of each other's concept of what communication means, including communication within the context of social relationships, marked this work as person-centered. These discussions were characterized by seeking alternative explanations to negative constructions of events, expressing preferences for different courses of actions, and most significantly, validating these experiences as real and common to many. These discussions were structured by incorporating the principles and elements of a Cognitive Behavioral Therapy approach (e.g., Beck, 2011; Gkika, 2010) and a model of patient care called Collaborative Deliberation (Elwyn et al., 2014). As these approaches guided and help shape the dynamic of interaction between the participants, they are outlined as relevant to the *orientation* component of the narrative framework.

### **Cognitive Behavioral Therapy**

Cognitive Behavioral Therapy is based on the premise that thoughts and behaviors underlie the emotions experienced by individuals and that through exploring and challenging beliefs, new more flexible beliefs can be nurtured (Gkika, 2010).

A Cognitive Behavioral Therapy approach takes the stance that people are active agents in our world, and their interactions are guided by how we interpret or evaluate that world. Moreover, the fact that such interpretations are cognitive in nature (e.g., in the form of thoughts or images), they are therefore accessible to consciousness and can be changed (Beck, 2011). Change is seen as within a person's control in a Cognitive Behavioral Therapy approach, through a process of *cognitive restructuring*, defined as "a strategy to recognize negative, inaccurate thoughts and replace them with alternative ones that are more realistic and helpful" (Traeger, 2013, p. 452). Associated with cognitive restructuring are the processes of normalizing and validating behavior. Normalizing is essentially the process whereby the person is guided to view the distress from experiences as understandable and normal (Dudley & Turkington, 2011) and involves, at times, some personal disclo-

sure from the therapist of similar experiences (e.g., a phobia or fear) that may be compared and discussed. In so doing, a person's (perhaps intrusive) thoughts or perceptions are considered against others and realized as similar in nature, or more usual, than one realizes. Normalizing is part of the process from the start in Cognitive Behavioral Therapy, where the therapist is encouraged to "establish rapport and trust with patients, normalize their difficulties, and instill hope" (Beck, 2011, p. 60). Validating is giving validity or respecting the truth value of such thoughts for the person (e.g., that the fear or anxiety is real for the person). These were important and pivotal processes in the discussions between P.D. and I.W. and enabled P.D.'s true voice concerning her communication anxieties to be heard and respected.

Cognitive Behavioral Therapy has an extensive evidence base for the treatment of a wide variety of psychiatric, medical, and psychological problems, including anxiety (Butler, Chapman, Forman, & Beck, 2006; Chambless & Ollendick, 2001). Sze and Wood (2007) describe a case study in which Cognitive Behavioral Therapy was used as a successful treatment for an 11-year-old with high-functioning autism and comorbid anxiety to improve adaptive and social functioning. Sze and Wood support the notion that it may be a viable approach for use with this client group, particularly when enhanced by other interventions. The application of Cognitive Behavioral Therapy approaches within the profession of speech-language pathology may allow for specific communication concerns to be addressed, within the context of the psychological issues that may surface within the therapeutic process (Brophy, forthcoming). It is also accepted that clinicians can use the techniques of cognitive therapy, without conducting a full structured Cognitive Behavioral Therapy session (Beck, 2011).

### **Collaborative deliberation**

The principles of a complementary model for patient care known as *Collaborative Deliberation* (Elwyn et al., 2014) were also



useful in this context to describe how interpersonal aspects can “affect how decisions are made and intentions are formed in health-care interactions” (p. 158). The model by Elwyn et al. (2014) helps theorize a description of collaborative working that helps clinicians and patients address the processes of decision making, consideration of alternatives, and behavior change. Put simply, applying these principles gives rise to the following processes (Elwyn et al.; paraphrased here as simple questions as applied to this context of interaction): (i) *recognizing alternatives* (what can we do differently?), (ii) *comparative learning* (do we do take one course of action or another?), (iii) *preference construction* (what do we prefer to do?), and (iv) *preference integration* (let us do it). These processes can be operationalized within a context of the emotional states of the participants and activated when health care interactions are characterized by curiosity, respect, and empathy. This model was loosely applied to the contexts of interactions described here and more specifically to the processes of problem solving about communication dilemmas and differences. The model proved to be an easy framework to apply, while at the same time honoring the ethical principle of autonomy and maintaining an empathic approach to engagement (Elwyn et al., 2014).

### COMPLICATING ACTION

The complicating action of a narrative is described in Labov and Waletzky's (1997) framework as “a series of events” that “may actually consist of several cycles of simple narrative with many complication sections” (p. 27). P.D.'s accounts of frustration and distress within social communication situations comprised complicating actions within the narrative of this therapeutic journey.

At initial meetings, P.D. reported feelings of hopelessness, rejection, and difference, as she explained from a reflection in her diary:

The story starts. I was happy as a child. Then the disease. A discomfort. Why? Other people because of possibly, probably. Then, was it me? I learnt I had

to fix me. Still, the discomfort. A steady recognition of oneself. An observer of self. How can i fit in? and be in the world? [sic]

P.D.'s reflection suggests what Bhabha (1994) described as a sense of *otherness* (p. 12; see also Kovarsky, 2018 and Smith, 2018). This otherness was characterized by P.D.'s repeated experiences of communication breakdown and miscommunication on a daily, even moment-by-moment basis. The issues around communication and anxiety that emerged for discussion between I.W. and P.D., at different points over the timeline of the interactions, are grouped under the following themes: Daily communication dilemmas; Difference, Identity, and Otherness; and Diagnosis. The communication challenges referred to are characterized by anxiety, misunderstanding, and frustration, often leading to a negative impact on self-worth and self-esteem. In addition, along with P.D.'s comments (which were selected by all three authors for illustrative purposes here), references to other first-person accounts of communication challenges in autism from the literature will be used to supplement and reinforce the concepts expressed by P.D.

### Daily communication dilemmas

What came to be termed by P.D. and I.W. as *Daily communication dilemmas*, were discussed in detail, similar to what Leahy and Walsh (2010) define as dilemmas or problems that arise from speech, language, and communication impairments. Table 1 provides excerpts from P.D.'s diary of reflections that were collected over time. Those comments illustrated in Table 1 were recorded early on in the working relationship and schedule of meetings (as reported previously by Walsh & Delmar [2011]).

The comments in Table 1 point to the confusion (“Why wouldn't I be confused with language, people have their own meanings; People don't say what they mean and often they don't want to say what they mean”), distress (“I'm afraid of myself not understanding people- people can use words to trip me

**Table 1.** Daily communication dilemmas<sup>a</sup>

P.D.'s reflections taken from diary entries:

"IT'S NOT THE ASPERGER'S THAT CAUSES ANXIETY, IT'S THE COMMUNICATION (LEAVE IT IN CAPS!)"

"I'm afraid of myself not understanding people—people can use words to trip me up."

"Why wouldn't I be confused with language, people have their own meanings; People don't say what they mean and often they don't want to say what they mean."

"My (conversational) 'to and fro' doesn't swing like a pendulum."

"Conversations fade and don't get resolved—people need to give me time [and they don't]."

"Milk, bread, fear, dread" [shopping list].

"Why do people laugh at me?"

<sup>a</sup>Adapted from *It's Like Learning to Swim Without Being in a Pool: Two People in Conversation About Asperger's Syndrome*, by I. P. Walsh and P. Delmar, 2011, November, Dublin, Ireland: Poster session presented at Irish Association of Speech & Language Therapists Biennial Conference. Adapted with permission.

up"), and frustration ("My [conversational] to and fro doesn't swing like a pendulum") that P.D. talked about and encountered during conversational interactions. Two comments listed in Table 1 warrant further explanation. In the comment "IT'S NOT THE ASPERGER'S THAT CAUSES ANXIETY, IT'S THE COMMUNICATION (Leave It in Caps!)," P.D. requested that the highlighting in capitals (i.e., "IN CAPS") remain for emphasis and explained that the single biggest stressor for her was the communication challenges she was experiencing, not the other features that may be associated with the Asperger's diagnosis (e.g., an inflexible adherence to particular rituals or routines that are non-functional (*DSM-IV-TR*; American Psychological Association, 2000). These particular sentiments are not uncommon among people on the autism spectrum. For example, Higashida (2017), who is nonverbal and also has ASD, echoed those thoughts, as he described struggling with what others expect of him in what they perceive as easy and effortless communication interactions. Likewise, Bridge (2016) described her confusion of how much information to give her interlocutor with the apparently benign but routine conversation opener "How are you?"

The second example of note from Table 1 is a shopping list of "milk, bread, fear, dread." Here, P.D. explained how going shopping—a simple and routine event for many people—

was a task that instilled apprehension and fear at the thought of the anticipated communication challenges and adverse reactions to her attempts at normal interactions ("Why do people laugh at me?"). P.D. shared a more recent reflection from her diary of such communication dilemmas, prompted by looking back over the years on discussions and formulations in the writing of this article. A hint of acceptance around communication struggles seems evident here, even if the experience remains painful and difficult:

It is an ongoing challenge with communication. There is always a new time when an instance of communication gets upsetting. When it happens it's always like it's a first time, yet like, Ground Hog Day—it always happens. It's always a surprise, always disappointing. I am never ready or newly able to communicate. It's always there this Groundhog Day condition.

### **Difference, identity, and otherness**

The examples of reflections in Table 2 are also taken directly from P.D.'s diary entries recorded throughout the interactions and point to her struggle with difference, identity, and otherness.

The first comment in Table 2 explains how receiving a diagnosis in midadulthood prompted P.D. to reflect on her childhood, explaining that she knew that she was not "just shy" but aware that she was "alright."

**Table 2.** Difference, identity, and otherness

P.D.'s reflections taken from diary entries:  
 "I knew I wasn't just shy but thought I was alright as a child."  
 "I blamed myself most of the time, I was an anxious person and I couldn't mix. However, it wasn't made easy for me."  
 "I was into the world of mental health or mental illness, a world of definitions like, OCD [obsessive compulsive disorder], and other terms I hadn't learnt in school. This wasn't good for how I thought of myself. Was I any of these terms?"  
 "I'm an Aspie, you are neurotypical."  
 "My life was a journey: from not knowing yourself to getting to know yourself; am I this? Am I that?"

As she grew into adulthood and was in employment, P.D. reflected on how she "blamed herself most of the time [being] an anxious person and I couldn't mix." Her follow up-comment, "However, it wasn't made easy for me" suggests that others, perhaps fellow employees, helped perpetuate the anxiety and sense of otherness, something that perhaps was socially constructed.

Other comments in Table 2 show that in searching for help and support, P.D. engaged with professionals in the field of psychiatry and "was into the world of mental health or mental illness, a world of definitions." She explains how this was not helpful for how she thought of herself because she felt reduced to a set of definitions ("was I any of these terms?"). P.D. knew of the slang term *Aspie*—a term first coined by a person with Asperger's syndrome in the 1990s (Holliday Willey, 2015) and used by some people with the diagnosis to describe in-group membership, and the term *neurotypical* to describe people without the diagnosis. P.D. described these two worlds as separate, not being quite sure where she fits. This statement is resonant of others caught in a similar identity dilemma, for example, with reference to the Deaf community, those who consider themselves deaf and people who use (or do not use) sign language (Maxwell, Poep-

plemeyer, & Polich, 1999). Similarly, Kaye (2011), a mother of a teenage girl with Asperger's syndrome, explained how her daughter does not fit into the world of the disabled because her needs are too mild, nor does she fit into the world of the "fully-functioning" (p. 7). Kaye compared this with her daughter standing on a bridge between two worlds but not fitting in to either. Such sentiments are further echoed in P.D.'s comment "Am I this? Am I that?" when she raised concerns about other possible diagnoses. A more recent reflection from P.D. further underlines this concern with difference, yet now considered "part of [her] my strengths":

It [autism] does not however define my personality, who I am. I am a person who has autism. Yet I do not feel it is separate from me. It is part of me. Part of my weaknesses and part of my strengths. We are human beings programmed from birth for interaction. I was not programmed or else my programming was faulty or different.

### Diagnosis

Table 3 lists some of P.D.'s reflections on her diagnosis and how receiving a diagnosis was a "relief." Such comments were recorded at different times throughout the interactions, when issues of diagnosis were discussed and reflected upon.

The feeling of relief is not uncommon in adults who receive a late diagnosis of ASD, as explained by Wylie (2014), who was

**Table 3.** Diagnosis

P.D.'s reflections taken from diary entries:  
 "It was a relief to me. I felt vindicated. I wasn't mad."  
 "Do I no longer have 'Asperger's'? I'm cured! Whose decision was that?" [to remove AS from *DSM-V*]  
 "I often think now how an earlier diagnosis of Autism Spectrum Diagnosis, would this have made my life any easier? I don't know and will never know. My life was as it was and can't be changed now."  
 "Usually when you have a diagnosis people don't tell you the things you can do well."

formally diagnosed with autism in his early 50s. Wylie explained how having a diagnosis that explains a history of relationship problems could come as a relief after a person with autism has received a series of misdiagnoses and inappropriate treatments in his or her former life. However, with revisions to *DSM-V* (American Psychiatric Association, 2013), Asperger's syndrome no longer has its own separate entry in the classification system. P.D. reported how this change initially confused her. She experienced the revision as a challenge to her identity (quipping, "I'm cured"). P.D.'s view was that her voice and the voice of all other individuals with a similar diagnosis had not been considered or listened to (i.e., "Whose decision was that?"). Reflecting on past times, P.D. considered whether an earlier diagnosis would have changed things for her "I often think now how an earlier diagnosis of Autism Spectrum Diagnosis, would this have made my life any easier?" She acknowledged, "I don't know and will never know. My life was as it was and can't be changed now." This latter reflection lends an uncertainty to how P.D. feels about herself, part of being on the edges of cultures, almost in limbo.

The final comment listed in Table 3 relates to P.D.'s observation that once a person has a diagnosis "people don't tell you the things you can do well." This comment is consistent with the notion of an *error maker expectancy* (Kovarsky, Kimbarow, & Kastner, 1999) that can refer to circumstances in which disability, not ability, is brought to the forefront in the traditional impairment-focused cultures of speech-language pathology practice, a stance that is particularly prevalent in clinical pragmatics (Cummings, 2009; Jagoe, 2017). The tendency of clinicians to bypass strengths, or at least not take them fully into account, was particularly troubling for P.D., as she struggled with her self-esteem and with how people viewed her. This issue, in particular, was the impetus for working together in a person-centered, more egalitarian manner, while acknowledging the daily demands that P.D. experienced when communicating.

## EVALUATION

Evaluation is the next component of Labov and Waletzky's (1997) framework to be addressed in this narration of the therapy journey. The evaluation is defined as "that part of the narrative that reveals the attitude of the narrator towards the narrative by emphasizing the relative importance of some narrative units as compared to others" (Labov & Waletzky, 1997, p. 32).

P.D.'s evaluation on this way of working—or this event as a therapeutic journey—can be best summarized in her own words. The comments in Table 4 are taken from much later reflections in P.D.'s diaries as she looked back on the interactions and discussions that had taken place over the years. Realizing that there could be "a different way of communicating" was reassuring for P.D. on a personal level. Communication was no longer what she called the "elephant in the room" to be avoided. This led her to experience some hope about her disclosure of difficulties and how such disclosures could help her in some way to "live a good meaningful life." It seems, therefore, that a recovery of

**Table 4.** Patricia's reflections as *Evaluation*

P.D.'s reflections taken from diary entries:  
 "[working in this way] allowed me to understand that there can be a different way of communicating—like I am right-handed and you are left handed—need for that to be known."  
 "This is the time I can introduce the elephant into the room and get on it's back."  
 "I began to feel better about my communication difficulties and became hopeful that I could live a good meaningful life."  
 "I want this [autism] gone yet this is impossible . . . my feelings subside. I become positive again, from glimmers of hope. Hope from a more positive thought or from a happier feeling, or from positive interaction with a thoughtful communicator."

sorts was taking place. Hopefulness was an important by-product of this way of working for P.D., who wrote about “glimmers of hope.” Zimmerman’s term *learned hopefulness* (Zimmerman, 1990) is relevant here, the characteristics of which can include “increased psychological empowerment, proactive behavior, and reduced alienation” (p. 74). Similarly, Higashida (2017) echoed such reflections of hope linked to proactive behavior in his own personal account of living with the diagnosis, especially in his chapter, titled “Advice to My Younger Self.”

It seems too that for P.D., the informal context was key to hopefulness emerging as it was “connected to community life and . . . not deficit-oriented or dependent on professional expertise” (Zimmerman, 1990, p. 74). Hopefulness seemed to urge P.D. on to new openings, which included, for example, working with speech-language pathology students and staff on educational activities (e.g., cofacilitating student workshops, consulting with staff, and copresenting at conferences and academic meetings).

Working together in this alternative, more open and equal way proved rewarding and valid for I.W. also. Although at times it was a struggle to avoid the compulsion to overtly and explicitly fix communication situations and perceived errors (thereby imposing a corrective stance), a process of critically discussing, acknowledging, and authentically respecting differences in communication facilitated I.W. to support positive outcomes. These outcomes were not solely focused on altered behaviors but altered understanding and appreciation of difference over disorder. This change to practice was in contrast to some other more traditional health care interactions that can become overly dominated by impairment-focused or disorder-specific interactions, despite a willingness to engage in alternative and more person-centered, social models of intervention. Lessons and insights from this way of working have since influenced I.W.’s work with other individuals who report experiencing significant anxiety-provoking challenges with social communi-

cation (e.g., adults with attention deficit disorder hyperactivity disorder). The psychological and physical space of the coconstructed and shared clinical-cultural borderland facilitated this more person-centered way of working to emerge, with positive outcomes.

## RESOLUTION

The resolution of a narrative poses the question “What finally happened?” For P.D., the interactions enabled her to reconceptualize the anxiety she felt when communicating in social settings. Although still presenting challenges to her, P.D. faces communication with increased confidence, given her greater understanding of her own communication style, her own needs, and the needs of her communication partners in social interactions. For I.W., a different approach to working alongside such adults toward their goals meant leaving the safe space as an expert to enter a borderland of shared responsibility for all stages of the process, from goal setting to evaluation of progress in meeting these goals.

As part of the journey, P.D. and I.W. developed a working relationship that has culminated in the cowriting of manuscripts for publication, copresenting at academic conferences, and coteaching at the university level. This more egalitarian working relationship has allowed the cultures of ASD and non-ASD to come together, within what was an adapted culture of speech-language pathology practice. These cultures came together in a positive and productive way, bridging perceived gaps through establishing connections and shared understandings of communication and its challenges.

## CODA

In narrative analysis, the coda brings the telling of the event back to the now to explain what the event means for the present moment (Labov & Waletzky, 1997). The coda can be considered to be the meaning of the telling of the event, that is, the experiences of this therapeutic journey (Table 5). In a traditional

**Table 5.** Summary of narrative of therapeutic journey according to Labov and Waletzky's (1997) narrative framework

Narrative Component	Narrative Question	Detail of the Event(s)
Abstract	What is this story about?	Story of hope and recovery in a cultural-clinical borderland; SLP working differently alongside a woman with ASD and associated anxiety linked to social communication.
Orientation	Who is involved in the story; where did it take place and when?	Two people (P.D. and I.W.): one with ASD and one without the diagnosis, who is an SLP/researcher; interactions taking place in a university clinic context; over approximately 5 years.
Complication action(s)	Then what happened?	Working in a nontraditional way over time with accounts of communication dilemmas; issues related to a late diagnosis of ASD; and identity, all reflected upon, discussed, and acknowledged.
Evaluation	How did participants feel about what had happened?	More accepting and realistic sense of self and identity for P.D., with a decrease in communication anxiety and an increase in hope. For I.W., a more rewarding, authentic way of working alongside people with ASD.
Resolution	What was the outcome?	A positive trajectory of hope and recovery emerged within the flexible space of a cultural-clinical borderland, characterized by a relationship of equality and mutual respect.
Coda	What does it mean for now?	Finding ways to create conversational spaces in speech-language pathology interactions, where hope and recovery as outcomes can be facilitated to emerge and be maintained.

*Note.* ASD = autism spectrum disorder; SLP = speech-language pathologist.

research article format, the coda can be the discussion or the conclusion of the arguments presented in the article.

The notion of a cultural-clinical borderland proved useful in the context of the interactions and developments described in this article. The borderland was a space where it became possible to “bring communication between two different cultures into harmony” (Bogdashina, 2005, p. 260). Furthermore, the third culture—that of the more traditional or impairment-focused practice of speech and language pathology—was challenged and adapted as an activity in this borderland paving the way for a different way of working.

Constructive engagement and true collaborative working in sharing and reconstructing of communication experiences characterized this therapeutic journey as person-centered. The participants experienced a different type of therapeutic relationship in this context of interaction. Core to the hearing and telling of experiences in a safe and respectful space are considerations of rapport and the relationship. Walsh and Duchan (2011) defined rapport as a cocreated and dynamic process that can render a more egalitarian tone to the therapeutic interaction. The uniqueness of the patient-clinician relationship is what paves the way for progress to be made but where the clinician remains “a symbol of hope” in

a patient's search for progress and healing (Shannon, 2011, p. e114). It seems, then, that speech-language pathologists should adopt what Glover (2005) termed an *intent of hope*. However, it is also apparent that such hopeful relationships do not happen until the power inequality is at least reduced and relationships are marked by a more considered mutuality (Deegan, 1996). Indeed, the fundamental relationship appears central to the hopefulness in this therapeutic employment, in which empowering experiences provided opportunities for learning and for gaining control over the difficult challenges of daily living (Zimmerman, 1990), of which communication is such an integral part.

P.D.'s sharing of her communication experiences and ultimate hopeful aspirations, though certainly unique and personal to her, resonate with others' accounts of communication challenges associated with ASD (i.e., Bridge, 2016; Higashida 2014, 2017; Nazeer, 2006; Wylie, 2014). Hope too emerges in Higashida's (2017) reflection that "if we know there is even a single person who understands what it is like for us, that's solace enough to give us hope" (p. 89). It seems crucial, therefore, to position hope as a valid focus in speech-language pathology contexts in working alongside people with ASD and, similarly, with others who may experience significant communication challenges. Moreover, clinicians need to "create the conversational spaces where reasonable hope rather

than hopelessness is more likely to arise" (Weingarten, 2010, p. 11). This work can be jointly undertaken at the meeting of cultures such as those described in this article, where hope is not only an incidental by-product of interaction but emerges as a more realizable and attainable construct.

## SUMMARY

This article narrated a therapeutic journey of hope and recovery through the sharing of accounts of communication challenges in a person-focused environment of openness and equality. Communication challenges, as described, were characterized by anxiety, fear, misunderstanding, and frustration, often having a negative impact on self-worth and identity, leading to a sense of otherness. The meeting of cultures of ASD/non-ASD experiences, and speech-language pathology practice, acted as the catalyst to authentically discuss social communication in all its complexity. A sense of hope and recovery infiltrated the discussions as they progressed, as difference—as opposed to disorder—was acknowledged and respected. It can be concluded that a positive trajectory of hopefulness and recovery emerged as outcomes from these interactions, facilitated by the cocreation of a congenial therapeutic space, and where Mattingly's (2010) concept of clinical borderland included a salient respect for cultural differences.

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