

A Person-Centered Approach to Problem Behavior: Using DIR®/Floortime with Adults Who Have Severe Developmental Delays

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Abstract

The developmental disability field, especially adult services, is characterized by contradictory paradigms as the “support” or “disability rights” movement has established powerful consumer and professional credibility in a sector that has been dominated by educational and medical models. The author proposes a practical resolution to this paradigm clash by describing an integration of evidence-based principles with a person-centered approach to problem behavior. It is recommended that applications of essential teachings in the field of infant mental health can forge an alliance between the historically incompatible approaches of the disability rights movement and applied behavior analysis. This resolution is rooted in a model of assessment and treatment known as “Floortime.” “Floortime” is a form of interpersonally contingent developmental interaction, formulated by Stanley Greenspan, M.D., that exemplifies Carl Roger’s “person-centered therapy” but that can be used with people who are nonverbal. Floortime is described as a way of encouraging spontaneous, developmentally appropriate interactions within the context of a clinical model called Developmental-Individual Differences, Relationship (DIR®) as formulated by Dr. Greenspan then later refined in collaboration with Serena Wieder, Ph.D. For the past six to eight years, the author has been adapting Floortime techniques to address problem behavior and developmental issues for adults with severe delays. Two brief case descriptions are provided which demonstrate significant improvement in aggressive “problem behaviors.” All work was done in community settings using staff people who already provide direct support services for the subject individuals.

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A paradigm clash is being played out in services for adults with developmental disabilities. The field, historically, has been rooted in both a medical model and educational models. For de-

cadecades, the medical model dominated services for people with developmental delays. Throughout the nineteenth and much of the twentieth century, developmental disabilities were perceived, essentially, as medical conditions. The disease model implicit in this approach was part of the array of failings cited by those who sought to replace that model during the mid to latter part of the last century. Gradually, the medical approach was supplanted by the “developmental model” - an educational paradigm based on operant principles. For almost forty years, service delivery has been guided by the behavioral orientation that learning occurs most efficiently when observable, measurable behavior is manipulated through analysis of environmental events.

However, in the 1980’s, a different approach to developmental disability services began to emerge. As the disability rights movement gained strength through a network of federally-funded centers to encourage independent living, a holistic approach to adult support began to infuse the developmental disability field. A significant part of the purpose of these independent living centers was “advocacy” – including, especially, “self-advocacy.” As a result of the disability rights personal and systems advocacy process, the philosophical basis of developmental disability services has been slowly changing. A focus on learning and other “needs” and, by implication, individual adaptive deficits is being gradually replaced by concentration on inclusion and self-direction. Founded on the disability-rights model, the philosophy of self-determination has become the most widely endorsed paradigm in the field. Yet, there remains a fundamental tension in addressing challenging behaviors between the operant conditioning paradigm, with its emphasis on external control and determinism, and the values implicit in the concept of “self-determination,” with its core concepts of internal control and spontaneous freedom. The reflective supporter of self-determination must ask – where is the locus of control? If behavior is changed from the outside – even by the “positive” manipulation of environmental variables – who makes the final decisions on which of those variables are changed

and how? How often are approaches to behavior change – even “positive” approaches – truly based on consumer self-direction?

The values of self-determination are often referred to as “person-centered” approaches. This revivifies ideas that were widely supported in humanistic psychology during the mid-twentieth century - such as Carl Rogers’s “person-centered therapy” (Rogers, 1961), Maslow’s theory of “self-actualization” (Maslow, 1968) and other like-minded orientations. There is a well-recognized theoretical discordance between person-centered approaches such as these and the field’s historical reliance on the operant orientation of applied behavior analysis (ABA). My contention is that there is a similar discordance or tension between the self-determination paradigm and our general approach to using behavioral analysis to intervene with challenging behavior. The very notion of “operant” action is the practice of manipulating environmental variables. Traditional behavioral interventions tend to be based on the assumption that settings and responses should be analyzed by an outside agent – “the professional” – who manipulates environmental contingencies based on the subject’s responses and the achievement of “target behaviors” determined as “desirable.” This is an inherently authoritarian model that, through externalization of the locus of control, subtly undermines and calls into question the person’s capacity for choice.

With the advent of “positive behavior support” (PBS), many behavioral practitioners have tried to reconcile this contradiction by relying solely on positive reinforcement technology to address problem behavior. This movement has suggested that the “function” or the purposeful meaning of problem behaviors must be considered, so that practitioners can understand the communicative intent of a client’s behavior. However, for many people with disabilities, who have little functional input into the planning process, positive behavior support is still overly reliant on professionals and support personnel to interpret behavior and direct the learning process. This approach begs the question: how much of the time do professionals guide the individual toward choices that are perceived as desirable by support personnel but not, necessarily, by the individual? Often, the subject’s expression of desirability may be difficult to discern, but it is nonetheless critically important in any self-determination-based model. Positive behavior support offers another way of describing the process of using reinforcement technology as a mechanism for managing socially difficult behavior.

A person-centered approach, using Rogerian philosophical principles, would be far more consonant with the disability rights model of support. However, a major reason that Rogers’ person-centered therapy and other humanistic approaches have not, historically, been used with people with developmental disabilities is because of the perceived reliance within these therapeutic models on “insight” – based on the subject’s ability to use symbols and abstract concepts. Because challenges with abstract concepts and logical thinking have always been a definitive characteristic of the developmental disability rubric, the “insight” approach has been considered inappropriate for this group of people.

Another problem has been that these therapeutic models have not, traditionally, provided a strong evidentiary basis. The premium on evaluating behavior change interventions in a systematic – observable and measurable – fashion is the greatest contribution that behaviorism has provided the developmental disability field. Operational accountability has been an incontrovertible boon for the quality of services provided to people with severe developmental differences. Yet, data-based program design need not, necessarily, be inconsistent with self-determination and person-centered approaches. The critical tenet of positive behavior support – that problem behaviors should be replaced with behavior that is more adaptive, functional, and individually meaningful – must remain paramount. Therefore, to reconcile the differences between the authoritarian aspect of behavioral approaches and more person-centered ways of supporting positive behavior, we need a theoretical model that includes that core demonstrated strength of applied behavior analysis – an operational foundation for service design, evaluation, and modification – but that is guided by the choices and personal interests of the individual. A new model of addressing problem behavior should provide an observable, measurable basis for intervention while finding a way to rely on the individual as the locus of control insofar as concerns the direction and nature of the learning process. Ideally, that model would harness the power of emotionally-invested – or self-determined – learning in assisting individuals with severe delays to overcome the barriers presented by “problem behavior.” Reinforcing events, the timing and nature of which are controlled by professionals, are, currently, the central tool used to establish motivation for positive behavior with adults with severe developmental differences. Primary reliance on artificial rein-

forcement, however, leaves the manipulation of environmental variables to the professionals and support personnel. This inherently takes control away from the individual. An approach is needed that allows the individual to lead throughout the intervention process in order to not only maximize self-direction but also to build increased relatedness, self-direction, and competence in daily decision-making.

The Developmental, Individual-Differences, Relationship-Based (DIR®) model, developed by Greenspan and Wieder, may provide such an approach. Through their work with children affected by all kinds of regulatory, developmental, and learning differences, including autistic-spectrum disabilities, Greenspan and Wieder have offered a “road map” for development which helps us use “*Floortime*,” and other relevant therapies, in a way that encourages individual self-direction and relational autonomy. Grounded in the study of infant mental health, Greenspan and Wieder describe a functional-emotional developmental progression that tracks the child’s healthy emotional development from the initial capacity for self-regulation into the love relationship between the baby and her caregivers and on through the growth of emotional reciprocity, empathy, symbol formation, and the ability to use ideas and the full range of human emotion, freely and flexibly. This is the developmental contribution of the model – or the “D” in “DIR”. This developmental trajectory, described through the emergence of six core “functional/emotional” levels, is consistent with the most current neurobiological knowledge of child development. The *Greenspan Social Emotional Growth Chart*, based on these functional emotional levels, has been tested with over a thousand infants and children and found to be a highly reliable screening tools for developmental problems in young children.

The developmental trajectory described by DIR is only a part of the model’s potential applicability. As part of the DIR assessment and intervention process, specific strengths of each individual are identified through the development of an *individualized processing profile* that addresses sensory processing (including auditory and visual-spatial processing, tactile reactivity, proprioceptive and kinesthetic functioning) as well as motor planning. This “profile,” a description of an individual’s dynamic and ever-changing biological, personal, and developmental characteristics, can profoundly contribute to an evolving understanding of the person’s development within each of the core

functional capacities that are the basis for establishing meaningful relationships and self-determined forms of environmental control. This individual processing profile also provides critical clues as to how to best work with the person – using emotionally satisfying play to bring out an individual’s best capacities. Intensive work – both with *Floortime* and with related therapies such as speech, occupational, and physical therapy – is necessary for each child – or seriously challenged adult – to reach her optimum level of personal development.

In traditional DIR® therapy, an individually attuned picture of the child helps to truly individualize the nature and direction of a child’s interactive learning. This constitutes the DIR recognition of “Individual-Differences” (“I”) in sensory reactivity, sensory processing, and motor planning. This evolving picture of each child’s “sensory profile” helps guide teaching and therapy. My own clinical experience suggests a comprehensive understanding of individual differences is just as critically important in working with and addressing problem behaviors for adults and adolescents with severe delays.

The DIR model rests on the recognition that all critical early learning occurs through, and is mediated by, the nature of primary relationships. Emotional interplay drives the dynamic process of active, engaging relationship that teaches us to hone our interpersonal sophistication, our sensitivity to others, and to learn more flexible usage of ideas and symbols. “Relationship” is the “R” in “DIR.” Critical learning is best embedded through the medium of modulated, but invested, interpersonal emotional experiences. That kind of emotion is elicited and regulated through supportive relationships. These supportive relationships begin with an attitude on the part of the teacher, or caregiver, which effectively parallels what Carl Rogers described as the fundamental therapeutic orientation toward the client: “unconditional positive regard.” Affirming the individual, without conditions, is the basis for *Floortime* interactions. It establishes the conditions for the mutual engagement that is the doorway to developmental growth.

The usage of “*Floortime*” or “developmentally appropriate spontaneous interaction” is the practice of following the child’s lead and interests and letting the child become “the director” of the interactive “play” while the support therapist is the “assistant director.” As a result, the process becomes person-centered because the interaction is directed and controlled by the subject. Similarly, the DIR method and *Floortime* allow us to follow

the interests and directions of adults with severe delays. Some recent research (Surfas, 2004), suggests that this interactive process can support adults and adolescents in developing additional communicative skills. My own clinical experience strongly suggests that this process, and the communicative behavior that it engenders, very often seems to *replace* problem behaviors with more functional affective communication. Because *Floortime* was developed for children who can often be limited in their ability to use language and abstract concepts, it can also be used with adults who face limitations with symbols and language. The “insight” and reflective capacities that have seemed to be unreachable for many people with severe cognitive challenges can be replaced by using preverbal interaction, or “affective signaling,” as a basis for what Siegal calls “shared subjectivity” (Siegel, 2001).

The six core functional-emotional capacities can, in my experience, be used to guide developmentally-appropriate spontaneous interaction with people of all ages and degrees of disabling conditions. These interactions, on an intense and regular basis, appear able to engender new ways of replacing problem behavior. Self-regulation, engagement, the need for two-way communication, and long flowing chains of problem-solving interactions are part the preverbal communication that are tracked by Greenspan and Wieder’s developmental “road map” to the first four of their identified six core functional emotional capacities. They are critical to understanding some of the issues in communicative development that give rise to what are called “problem behaviors.”

One example has to do with the capacity for two-way communication – the third level in the DIR developmental progression of functional emotional development. Greenspan posits that this capacity comes in as the developing infant begins to recognize that she can influence the behavior of others with her behavior. As a result, the child continues to use affect-signaling behaviors as a way of getting significant others in her life to respond. Over time, for the typically-developing child, these behaviors grow more sophisticated and specific to particular needs, wants, situations, and people. The child continues to use and develop these affect-signaling behaviors because of their effectiveness. However, adults with severe delays can often show disruptive, rigid responses that, typically, serve as blunt mechanisms for environmental change and rough two-way communication. For adults who have a drastically limited behavioral repertoire,

the reinforcing power –negative or positive – of affecting the environment – and, especially, influencing the behavior of others – cannot be underestimated. As a result, it may be posited that many forms of problem behavior are simply the effect of being stuck with limited ability to continue to develop further sophistication and specificity in two-way communication. My experience is that adults who gradually move away from problem behavior are those who have also developed more finely attuned and functional ways of affect-signaling interaction. In other words, these adults develop more specific and precise ways of expressing their needs, wants, desires, and emotions rather than being “trapped” with a more diffuse and global increase in excitation and activation that can neither be adequately expressed nor discharged.

“Lying” and “stealing” are two other examples of “problem behavior.” Wieder and Greenspan teach us that, during the early development of proficiency in “representational capacity and elaboration,” the child can often misinterpret cause and effect in the world of abstract thought. During the development of this capacity, children may think that taking something makes it belong to them or that saying something is true makes it become true. How many adults with severe challenges, whose behavior is called “stealing” or “lying,” are really in a state of having a very primitive capacity for representational elaboration? How many are simply at the early level of elaboration in their thinking and believe that wishful changes can be made real simply by saying or acting as if they are?

These are just a few examples of how an understanding of the development of functional-emotional capacities can enhance our ability to interpret and understand challenging behavior. Functional behavioral assessment is a process through which professionals try to determine whether a given behavior is maintained through either a positive reinforcement paradigm (getting a particular kind of event) or a negative reinforcement paradigm (escaping a particular kind of event). Also, functional assessment can sometimes identify the key environmental barriers that may predict the function of a behavior in various different settings. From these elements, the clinical practitioner must generate predictions about when the targeted behavior is most likely to occur and when it is least likely to occur. These hypotheses guide the initial development of a plan for supporting positive behavior. In typical practice, the foundation for both hypotheses about a behavior’s function(s) and predictions for

its occurrence are founded on a data-base consisting of “Antecedent-Behavior-Consequence” (A-B-C) recording and informational interviews with those who know the person best as well as “observation” time spent with the person. However, financial constraints, systemic rigidity and the subjectivity of recorders are examples of common elements that can markedly decrease the reliability and limit the functionality of these kinds of data. Hypotheses and predictions about targeted behaviors must often be inferred from less than optimal data.

The DIR model of assessment and intervention can provide a means of increasing our ability to understand the limited data that is immediately available. These data are provided through interaction – and the observation of interaction – with the person who displays the problem behavior. The practitioner who is skilled in identifying individual differences as well as a person’s functional-emotional developmental progress can often develop very workable hypotheses as the result of engaging in and observing direct interaction with the person. Although interviews with staff and others who know that person best, as well as recorded “A-B-C” data, must still buttress or refine these assessment observations, the DIR data-base provided by direct interaction and the observation of interaction, can add a critically important information source. Taken together, all of these data sources can provide the skilled practitioner with the relevant information needed to formulate sophisticated hypotheses about the function of problem behaviors as embedded in an experiential and communicative context. The Greenspan-Wieder progression of functional, emotional, developmental capacities can often assist with interpreting and understanding the communicative behavior of adults with severe delays. Operational indices of the six core functional emotional levels have been outlined by Greenspan, Wieder and others (Greenspan & Wieder, 1998; Greenspan, DeGangi, & Wieder, 2000). Using these indices, DIR® can allow us to maintain the evidence-based approach that is behaviorism’s core strength.

Understanding these functional emotional capacities can guide the community clinician in identifying the circumstances under which the person will use problem behavior to escape or secure certain outcomes. An understanding of these capacities can also often lead to accurate predictions about *when* and *why* problem behaviors will be used to achieve either negative or

positive reinforcement outcomes.

The hypothesis of this paper is that a clinical understanding of a person’s functioning in the context of these functional emotional capacities can provide sophisticated guidance for the functional assessment process for adults. A core assumption in this formulation is the inference that adults with severe communicative challenges will follow a progression similar to that of the developing child in developing increased communicative competence. Similarly, an understanding of specific individual differences in sensory integration and auditory and visual-spatial processing can also inform and direct the functional assessment process in order to lead to more sophisticated and accurate predictions of behavior. As part of the DIR assessment and intervention process, specific strengths of each individual are identified through the development of a sensory processing profile that addresses sensory reactivity, processing strengths and weaknesses, and motor planning. What is inferred about a person’s auditory and visual-spatial processing is also informative. By formulating this “processing profile” for each individual, we begin to develop the basis of an evolving understanding of the individual’s development and, most critically, the processing barriers to that development. Understanding a person’s unique processing profile also provides critical clues as to how to best interact with the individual in a way that will be emotionally satisfying for both the person and the therapist. That interaction is then elicited through the process of “following the person’s lead” while introducing small problems as a way of maintaining interest and of gradually increasing a person’s repertoire of response. For children, the process of engaged, spontaneous, developmentally appropriate interaction is called “*Floortime*.” For adults, a similar approach can be called “*Intentional Interaction*” or “*Coregulation*.” For both children and adults, the important role of affect must be emphasized in the progression up the developmental ladder. Affect, when experienced within the context of regulated, emotionally-attuned relationships with other persons, forms the basis for helping children and adults with developmental and processing problems to experience “coregulation” – the process of learning to manage internal states through shared subjectivity and the contingent responses of the caring other. This *coregulation* forms the basis for therapeutic effectiveness in the DIR model and in “*Floortime*” interventions.

The core technique for DIR intervention –

Floortime – rests on the recognition that all critical functional emotional communicative learning occurs through the medium of primary relationships. The use of relationship-based approaches with adults and adolescents recognizes the continuing power of primary relationships across the life span to affect and influence individual growth. The position described in this paper asserts that DIR provides a mechanism through which we can not only positively affect what have been called “problem behaviors,” but that DIR also effectively embodies the principles of person-centered approaches in the positive behavior support process. “Unconditional positive regard” and other affectively supportive responses are expressed through facial expression, body language and voice tones as well as the process of following the person’s lead and “tuning in” to that individual’s pace and emotional set. This reciprocal and mutually influenced interpersonal exchange is, fundamentally, a *coregulatory* process. *Coregulation* implies that the communicative partner assumes responsibility for the nature of the helping interaction but also plays the supportive role of following the subject individual’s lead in interaction. It implies a nurturant commingling of shared regulation through sharing attention with the individual. The reliance on spontaneous, developmentally appropriate interaction embodies the belief that human beings, even those who have been highly stigmatized and devalued, have the propensity to continue their communicative development in positive, healthy ways if there is adequate relationship-based support.

Greenspan’s notion of “playful obstruction” can be taught in a way that is intended to reduce dysregulation and frustration. Staff training for DIR intervention with adults is geared to providing staff with a “conversational” understanding of the individual in the following areas:

1. The person’s sensory processing profile: the subjective experience of having sensory integration, auditory and visual spatial processing, and motor planning challenges; and
2. The person’s current capacities in each of the six core functional emotional capacities through teaching examples of the person’s behavior in specific situations.

Adapted *Floortime*, relabeled as “*Coregulation*” or “*Intentional Interaction*” for adults, is taught using the following general approach:

Directions for “*Coregulation*”

1. Experiment with interaction with the

person. Focus on securing as many pleasurable circles of communication (back and forth exchanges) as possible. Try to find out how to approach the person and what kinds of interaction the person likes.

2. Spend 5-20 minutes with the person. Focus on doing what they do. Take an interest in their interest. Try to get the “dialogue” going back and forth. This can be through asking questions or slapping hands. It can be through mirroring what the person does. It can be through making vocalizations that the person makes. The goal is to actively go into the person’s world and enjoy their experience while getting the person to share, even a little, with you. Try to embrace what is in the person’s mind.
3. Try to get a back and forth exchange going. You open a circle of communication by putting yourself into what the person is doing. They close that circle *and open a new circle* by any action that responds to your action. *Your responsibility* is to insert yourself into back and forth interaction by always finding a way of closing the person’s circle of communication and opening yet another circle.
4. Enjoy the process. Take pleasure in your interaction with the other person and try to convey that sense of pleasure. Be funny. Laugh. Experiment with being dramatic and overblown in your responses or being quiet, slow and warm. Encourage a response. Keep it all in the spirit of genuinely liking each other and your time together.
5. Try to keep the rhythm going. Wait for the person’s response. Always respond, yourself, even if it’s a silly response. Keep the flow going.
6. Work in challenges to make the interaction longer and more complicated – but keep up the connection and keep it enjoyable for you both.
7. Do this five or more times during the time while you’re with the person – when you feel the person might like playful interaction. Try to get the time longer during each interaction session. Your goal is to have sessions that go continuously for 15-30 minutes.
8. Do as many sessions as possible for as long as possible. Look for natural oppor-

tunities to harness a person's interests and wants in order to extend circles of communication.

During their sessions with individuals, staff persons are encouraged to focus on flowing interaction and shared enjoyment of the experiences. They are also encouraged to continue interaction as long as possible *while the person appears to be enjoying the interaction*. They are told to quit interacting if the person appears to be becoming dysregulated or signals, in any way, an overall dislike of the experience. Role-playing is often a critical part of the process of teaching these interaction techniques to staff.

What follows are two brief case descriptions of individuals with severe developmental delays. Again, there have been numerous occasions in which I have seen this adapted *Floortime* or "co-regulation" have a dramatic effect on extreme behavior. Although these two examples involve addressing physical aggression toward other people, I have seen similar efficacy in working with a broad range of "problem behaviors" including self-abusive behavior, food-stealing, and inappropriate clothing removal. Both of the interventions described below were implemented by staff who worked with the person in community residential settings. Data were taken from the behavioral recording systems used by the person's supporting agency.

Case I: Henry

Henry had a history of aggressive and destructive behavior that had resulted in the dissolution of several living situations since he was first placed out-of-home at about age eighteen. He had a history of attacking other people – caregivers as well as companions – and breaking items such as furniture and windows. Prior to intervention, agency data showed an average of 9 episodes per month that tended to last between 20 minutes and an hour and included both attacks on other people and significant property damage.

Intervention Process

During an eight-week period prior to adapted *Floortime* intervention, Henry's core team met with me once each week for a two-hour period. During this time, I also observed and interacted with Henry in his home setting. A DIR assessment – seeking to identify Henry's strengths and weaknesses in terms of his individual differences as well as each of the core functional emotional capacities – was developed as part of group training and discussion during the first four meet-

ings. During this period it was hypothesized that Henry was *hyperreactive* to many auditory tones, especially in the higher frequencies, as well as visually *hyperreactive*, especially to movement. He also seemed very tactically defensive. Also, Henry appeared *hyporeactive* in proprioception and balance. In terms of his functional-emotional capacities, Henry had distinct challenges in self-regulation but a relative strength in his capacity for engagement. Henry had developed some two-way communication and he, reportedly, had a history of using some 20 signs as well as an unspecified number of picture cards to identify his wants to others. Yet, his capacity for a sustained, continuous flow of interaction through shared preverbal, problem-solving was quite constricted. Henry's ability to connect ideas also seemed quite under-developed.

During the second four week period, staff were taught – through informal lecture and discussion – the principles of *Floortime* including following the person's lead, tuning in to the person's pace and emotional set, ensuring reciprocity in interaction, extending circles of communication and "playful obstruction." A major teaching tool in each of these sessions was the use of role-playing. One staff person would role-play Henry or a housemate while the other staff tried to build on the person's typical behavior to create sustained, flowing interaction. Other staff would observe, comment, and make suggestions. After the completion of the second set of sessions, staff were encouraged to begin adapted *Floortime* with Henry as much of the time as possible.

Outcomes

During the month prior to intervention there were 13 episodes of aggression coupled with property destruction. However, during the month immediately after intervention, there were only three episodes of aggressive or destructive behavior. An increase to 8 incidents occurred during the second month after intervention, then the frequency of these episodes dropped steadily to zero per month over the next consecutive three-month period. The frequency of aggressive behavior remained below two per month for the last nine months of the data period. Overall, the monthly frequency of incidents dropped from an average of 9 per month to an average of 2.2 incidents per month after the intervention across the 14 months that Henry was followed. (See figure 1.) The following graph illustrates this timeline.

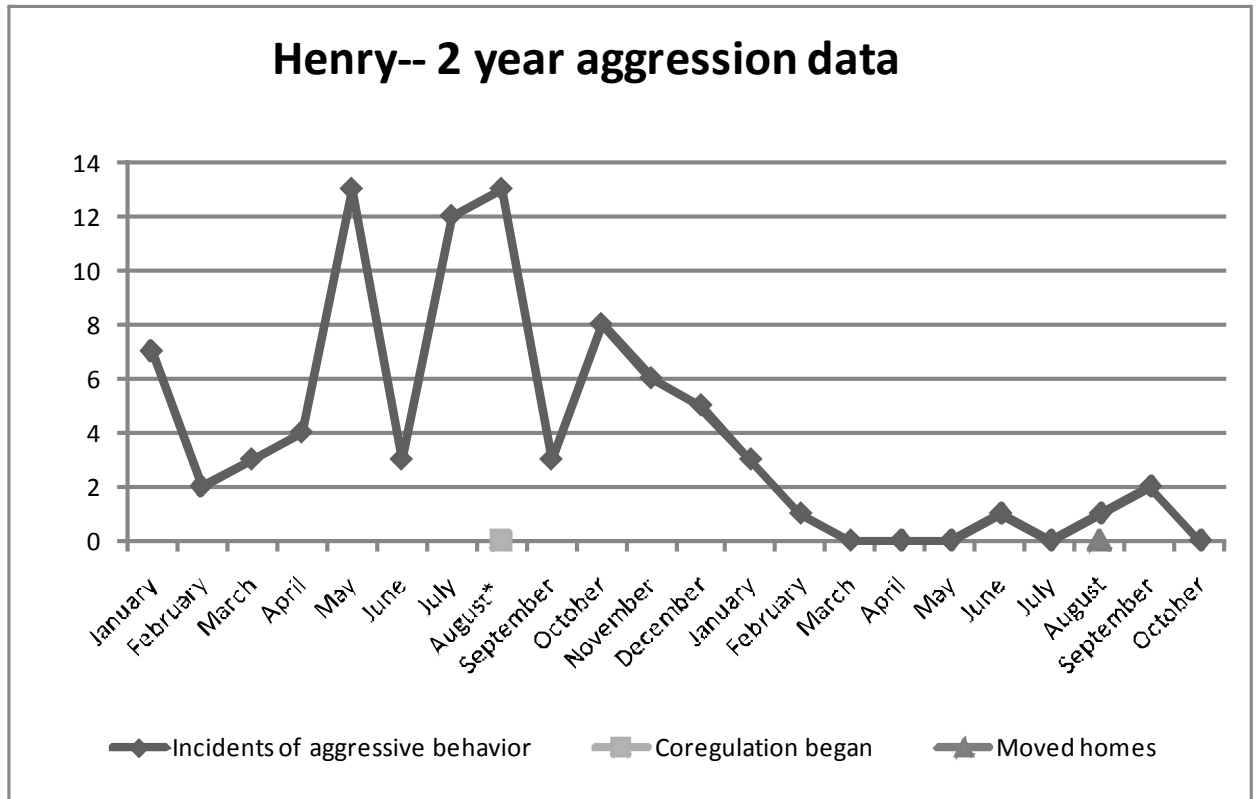


Figure 1. Henry – 22 Month Aggression Data

Mirroring Henry’s behavior in a jocular, friendly way was one of the first ways the involved staff found to create interaction. Henry began to experiment with various forms of nonverbal communication in order to watch staff mirror him. Then he began, intermittently, to mirror staff behavior in the same playful way. Also, Henry loved to eat and had no weight problem. While sharing preparation for a range of foods, staff would consistently try to give Henry the lead in the process by pretending not to remember steps in preparation or needed items. (This is an example of *playful obstruction* – a core principle of *Floortime*.) Within months Henry began to consistently answer simple questions using gestures, sign, and/or monosyllabic speech.

It should be noted that a critical element in Henry’s long-term success may have been staff consistency and ongoing staff training as new people were employed to work with him. Throughout the fourteen-month period, staff trainings were held at least one time per month – more commonly, two to three times per month. These meetings focused on using adapted *Floortime* with Henry as well as his housemates. Discussion, role-play, group feedback, and time with Henry and his housemates were all part of these trainings.

Case II: Minerva

Minerva was 22 years old when the assessment process began. She had lived with her natural family until the age of 12 when her frequent running away behavior, as well as other destructive actions, caused her to be placed with a foster family. She did not show any significant history of aggression as a child. The foster setting proved to be successful for Minerva, and she lived there until she was 18. At that time she had to move out of the child-licensed foster home. What followed was a succession of “placements.” The residential agency where she lived in September, 2002, when the assessment period began, was her fourth such placement. The functional assessment process was focused on Minerva’s aggression toward other people that was, by this time, a critical problem. Just as a written behavioral assessment was completed, Minerva’s aggression became so pronounced that she was placed in respite at the state institution (beginning 9/11/02) for a period of up to 30 days. Police intervention was required to transport her. Minerva returned home on October 10, 2002.

Intervention Process

Minerva’s functional assessment was completed on 9/4/02 and submitted to the program

administrators. However, training on the conclusions and hypotheses of the functional assessment, as well as recommended *coregulatory* interaction with Minerva, did not begin until the first week of October – just prior to her return from the respite situation. At that time, a two-hour training was provided for each of the staff who worked regularly with Minerva. This training addressed her individual differences in sensory and auditory processing. The potential of using individual differences as a critical part of the functional assessment process is illustrated in the following excerpts from Minerva’s DIR-based functional behavioral evaluation:

It appears that Minerva is extremely hypersensitive through sight. Her mom reports that she was always very sensitive to bright light and movement, however, she has always been attracted to bright lights in controlled scenarios such as Christmas decorations and toys with lights on them. This apparent contradiction also illustrates a typical pattern for sensory hypersensitivities – stimulation which can be very aversive when imposed from outside can also be quite reinforcing when people are able to control the dose and duration of that stimulation...Staff report that Minerva has some sound sensitivities such as to the ring of the doorbell at her home. However, it appears that tactile hypersensitivity is also a critical area for Minerva...This picture of extreme sensitivity to light, movement, sound, action, and touch is compounded by the likelihood that Minerva is extremely under-reactive in two near senses – proprioception and balance. Proprioception is that part of our nervous system which helps us to know where our bodies are in space and to perceive pressure and weight. Balance, of course, is the ability to know where we are at all times in relation to gravity...Minerva’s behavior as a child was like children who are seeking constant stimulation through movement in order to stimulate the proprioceptive and vestibular channels...it is difficult to gauge her auditory and visual processing capabilities. It should be noted, however, that when catching a pillow thrown over her head, Minerva is not able to exercise eye convergence to be able to track the pillow through space past a certain point. This strongly suggests serious challenges

in terms of visual/spatial processing... Conversely, staff and her mother reported that they believe that Minerva understands most of what is said to her. This probably suggests a relative strength in the area of auditory processing...Minerva’s motor planning is an unknown at this point. Continued intervention and evaluation should shed light on this very critical component of Minerva’s sensory profile.

In addition, her strengths and constrictions in each of the six core functional-emotional capacities were addressed in that report and briefly covered in the two-hour staff training session. Excerpts from that functional assessment report are provided below:

Calm and Interest in the World – This capacity is the one in which Minerva appears to have the most innate challenges. Her visual and tactile (hyper)sensitivities may well conflict with her under-sensitivities in balance and body awareness causing remarkable difficulty in allowing Minerva to attain *homeostasis* (a combination of both calm and external focus/interest)...

Intimacy or Engagement – Minerva has a history of some strong and, apparently, successful emotional bonds...

Two-Way Communication – This is the developmental stage at which a person learns that they can affect the behavior of others through their behaviors. Minerva seems to have some strengths in this area. Guiding or pushing people out of her apartment, requesting food by leading staff to the refrigerator, and opening rounds of “pillow toss” are all examples of two-way communication. However, Minerva has an obviously limited repertoire in this area.

Complex Communication – ... This capacity is characterized by the ability to sustain long, rapid and complex back and forth communication. When the capacity first comes in for infants it is characterized by preverbal reciprocal, rhythmic exchanges between the infant and caregiver. These usually consist of vocalizations, warm voice intonations, multiple subtle reciprocal facial expressions, gestures and action behavior. In typical development, this capacity flows out of the combination of the three prior capacities.

If an infant can focus on the caregiver, a two-way infatuation or love experience usually automatically develops. Out of that experience grows the desire for the presence of the other and the learning that we can affect the behavior of the other person. This naturally grows into that complex, rich inventory of back and forth dialogue experiences that we characterize as “relationship”.

My hypothesis is that Minerva is so challenged by her sensory and processing system that she was never able to fully negotiate the first capacity for extended periods of time – being calm while sustaining engagement with the world. As a result, even though she bonded as well as she could with caregivers, she was never able to sustain the focus and engagement to overcome severe restrictions in the following capacities (that build upon self-regulation) – engagement, two-way communication and complex communication.

Minerva demonstrates only very slight capabilities in the fifth and sixth functional capacities, *using symbols* and *building bridges between ideas*. A more complete evaluation of her current capacity and potential in these areas will require more extended interaction and observation.

Finally, as part of the two-hour initial training, staff did some role-playing on ways of extending and building more complex interaction with Minerva.

Prior to Minerva’s return home, an “interaction kit” was created that included edible lotions, various kinds of tactile balls for playing catch, and several different kinds of sewing material, reflecting a broad range of different kinds of touch sensation. Staff used this kit as a basis for attempting to create interaction with Minerva as often as their duties would allow. For the next five months, her three core staff – two of whom spent 40 hours a week with Minerva – received consultation and coaching on interactive techniques at least monthly. During this time frame, one staff person estimated that his intentional interaction with Minerva occurred at least 6 times per day for periods ranging between 10 and 30 minutes.

Outcomes

During the month of August, 2002, Minerva attacked other people on 9 out of 31 days in the month or for approximately 29% of the days in

that month. During the first 11 days of September, Minerva attacked others on 6 out of the 11 days prior to her being institutionalized for respite care. She returned home on October 10th at which time intervention was begun. During the following 21 days in October, Minerva only attacked others on four days – or for an approximate 19% of the days of that month. The following graph shows the frequency of Minerva’s aggression over the next five months. (Figure 2.)

Minerva – Aggression* Toward Others (*Hitting, biting, kicking, scratching and pushing)

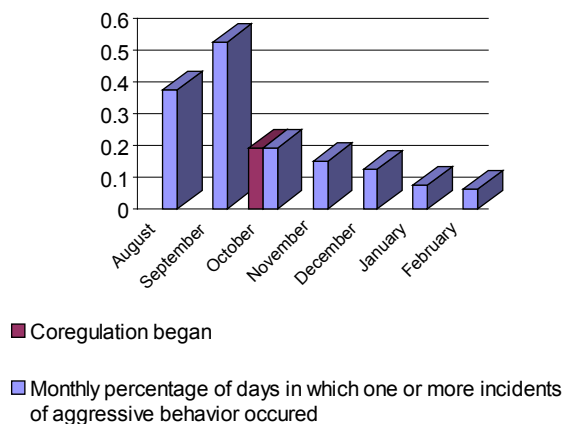


Figure 2. Minerva – Aggression Toward Others

Minerva also enjoyed a range of food preferences that staff would help her prepare. As with Henry, violating expectations and appearing not to remember how to do something was used to assist Minerva in doing more of the food preparation and to increase her intentionality. Also, Minerva loved tossing balls, beanbags, or other small items. Staff used this as a way of beginning interaction then experimented with tossing the ball in various places and using Minerva’s habit of throwing the ball in a direction away from her partner to elicit choices such as “should I go get it or should you?” This also served as a way of eliciting a yes/no choice from Minerva. Despite the diagnosis of severe autism and no history of having followed or used finger-pointing, Minerva began to spontaneously point at the ball on the floor in an imperious gesture, telling the staff person to get the ball.

Implications and Conclusions

Both of these individuals seemed to show significant improvement in their production of targeted problem behaviors as the result of adapted *Floortime* interventions. In the case of Minerva,

it is difficult to sort out the impact of medication changes that were made during her brief institutionalization from the impact of adapted *Floortime*. Variables of this kind are difficult to control in community services. However, it is certain that pronounced improvements in both the frequency and severity of aggression did occur. Two factors suggest that the intentional interaction may have been a significant contributor to the reduction in problem behaviors. One factor is the steady decline in aggression that continued after Minerva's return home. Despite the medication changes, Minerva returned home with a continuing habit of attacking others. The second factor that suggests a strong impact from the interaction was the fact that Minerva's main staff person – who did a significant part of the co-regulatory interaction with her – had to leave employment during March of 2002. In April, her aggression increased to the same level it had been in October¹, the first month of intervention, and only began to decrease again as the replacement staff was also trained in the adapted *Floortime* interaction. (This is a naturalistic equivalent of an A-B-A research design, where the “treatment” (A) occurs, is removed (B) and is reinstated (A). When the target behavior is reduced under treatment conditions, and recurs when the treatment is stopped (B), more confidence can be given to the treatment's efficacy.)

The picture is less equivocal in the case of Henry. He maintained at least two core staff over the next fourteen months and, although the staff person to whom he was closest left just five months after intervention began, Henry's aggression remained low as the two remaining core staff continued the interaction on a regular basis. During the follow-up period, Henry's aggression remained under control despite a range of dysregulating factors. After about a year, he moved with all of his staff and housemates. An additional roommate moved into the home and there was turnover in virtually all staff except for the core two who were already mentioned. The consistent element was ongoing training in the adapted *Floortime* techniques.

These data, as well as my clinical experience with a range of other people and other problem behaviors, suggest that adapted *Floortime* interaction, maintained in a sufficient dosage over time, may be a promising intervention for reducing aggressive behavior in adults with severe and profound cognitive delays. Further research is

indeed warranted. Such research should include better controls of significant life variables, such as medication, and more careful tracking of the amount of time spent in intentional interaction as well as better tracking of the relative skills in “adult *Floortime*” used by the particular staff conducting the intervention.

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¹ Minerva was aggressive on 6 out of 30 days in April (20%)

Neuroscience Reviews

Is There More Bipolar Disorder Than Meets the Eye

Jarrett Barnhill, M.D., DFAPA, FAACAP

Bipolar Disorder. (2009). In J.I. Hunt & D.P. Dickstein (Eds). *Child and Adolescent Psychiatric Clinics of North America*, 18(2).

This volume updates our understanding of the genetics and bio-psycho-sociology of Prepubertal Bipolar Disorder (PBD). This developmental approach to BD can also enhance our understanding of BD in individuals with IDD. The next several articles will take up this challenge.

Currently we rely on a descriptive model of BD (*Diagnostic Manual- Intellectual Disability*) that is based on adapted *DSM-IV-TR* criteria. This approach minimizes etiology and unfortunately does not address multiple psychobiological systems malfunctioning in this syndrome. These manifestations include: disruptions in mood state-regulation and emotional perception; dysregulation of reward pathways; increased-risk taking social behavior, impaired cognition, executive dysfunctions, impulse control, and disturbances in circadian rhythms. PBD also ramps up many externalizing behaviors.

Unfortunately these changes are also common in individuals with ID without BD. This should remind us that simply quantifying challenging behaviors or providing a diagnosis does not capture the complexity of either mood disorder or developmental disability. For example, measuring increases in stereotypies, risk taking behaviors, or inappropriate social behaviors during a manic episode does not explain how and why mania affects this particular pattern of challenging behavior rather than some other. If we limit our level of analysis to measuring challenging behaviors during mania (baseline exaggeration), we do not reach a deeper understanding into how these events shape and are shaped by this particular form of intellectual disability.

For individuals with IDD, gene-environmental interactions affect temperament as well as severity of ID; comorbid neurological disorders; executive function/adaptive behaviors and language and communication skills. Genes can indirectly shape family, social-emotional functioning and capacity to learn from life experiences. These reciprocal interactions make it difficult to make cause-effect statements or predict outcome with

a high degree of certainty. For most, the forces leading to BD are in play long before its clinical onset. In this sense the emergence of BD is one stage in a developmental process that is constantly modified by life events, social experiences, and various modes of treatment.

So let us begin with these basic findings:

1. Genetics: BD displays a complex pattern of inheritance. Current research suggests that rather than simple Mendelian genetics, BD involves modification of multiple gene components (e.g. single nucleotide polymorphisms or SNPs) spread across severe gene groupings. Yet these polygenetic influences do not cause BD. Instead they influence individual vulnerability; the expression of this vulnerability is the end result of interactions between the vulnerability genes and learning and life experiences. Once the syndrome develops gene-environment interactions continue to shape the course, severity, and treatment of BD.
2. Neuropharmacology: BD involves multiple neurotransmitter systems (GABA, DA, NE, serotonin, hormones, neuropeptides, and the immune system). Recent research points to downstream changes beyond the receptor site as critical to adequate treatment. Many of these intracellular pathways also play key roles in brain development and function, learning, and neuroplasticity. Some years ago most treatments were directed at specific neurotransmitters; most of today's work focuses within the cell at drugs effects on metabolism, gene regulation, and neuronal function.
3. Functional neuroanatomy: Changes are present in the orbital and medial prefrontal cortex, inferior temporal cortex, and amygdala (processing of social-emotional cues); responsiveness of motivation/reward; top down regulation by prefrontal and other cortical regions and self monitoring/executive functioning. Repeated episodes of BD adversely affect these functional pathways in a process similar to kindling or what Robert Post has aptly called "episode sensitization."
4. Neuroethologically: Disruptions in reward pathways, impulse control, circadian and ultradian rhythms increased appetitive-exploratory

behaviors, regulation of behavioral inhibition networks, executive networks, and social behaviors. BD involves a co-ordination of these systems and may help differentiate these from mood disturbances or impulse dyscontrol seen in other brain disorders.

Each of these phenomena follows a developmental trajectory that continues throughout the life cycle. The developmental course of BD is intertwined with that of the developmental trajectory of IDD. This mosaic of interactions raises several questions:

1. How do we integrate noncyclical irritability, explosive-impulsive aggression, and impulsivity into our schema for BD?

2. How do we deal with the high rates of neuropsychiatric comorbidity associated with childhood onset BD?
3. How do we integrate the developmental changes associated with the many subtypes of IDD with the evolution of BD as a syndrome?
4. How does BD affect brain development in children with IDD?
5. How do these developmental issues affect BD in adults with IDD?

In future articles we will use the work of Dickstein and others to make a stab at answering these questions.

US Public Policy Update

The United States v the State of Georgia 2010 Olmstead Settlement Agreement: U.S. Public Policy Implications

Joan B. Beasley, Ph.D., Associate Research Professor, University of New Hampshire, Institute on Disability, UCED

In 1999, the United States Supreme Court ruled that the Americans with Disabilities Act requires people with disabilities receive care in the most integrated setting possible. This led to the consideration of a major change in the practices of the State of Georgia, where what is now called the "Olmstead" decision was made. The precedent-setting decision affected policies and practices throughout the United States. Unfortunately, progress in Georgia was found to be lagging at best. In September of 2010, after many months of investigation and deliberation, the most recent Olmstead settlement agreement was signed by the Federal Government and the State of Georgia to comply with the Americans with Disabilities Act.

This Public Policy Update will highlight some of the most significant elements in the decision for people with intellectual disabilities and mental health needs. However it is recommended that stakeholders study the details, due to the great significance of this important settlement.

While the focus of the first Olmstead decision was on active treatment in the institution and discharge planning, and this is still required, the most recent interpretation broadened the focus

to prevent institutional care. It clearly states that the responsibility of the states to provide for adequate community infrastructure is part of the mandate for equal protection under the law. The Georgia decision indicates that the state is clearly responsible for quality of services offered to prevent the need for congregate care or the use of congregate care due to inadequate alternatives. Money is not a reasonable excuse for this to not be in place.

The decision states that "The expansion of community opportunities is critical to protecting the civil rights of individuals under Olmstead." *The findings indicated that the lack of community resources undermined Georgia's ability to comply with Olmstead.*

Following are some points to consider based on this landmark settlement.

1. Each State must be accountable to insure quality management of all services, needs to review data, assess services, and enforce standards.
2. The Georgia decision cited specific models, evidence based practices found to be effective in the community for SPMI (ACT, CSP, CST, case management, etc.) and infrastructure that is supported by models (like START). Ad-

equates resources are emphasized so that it requires expansion of some services to meet the need of the population (while there are some ACT services for example, more are required).

3. The decision requires a policy where there will soon be no more admissions for people with ID in state hospitals and fewer for people with SP-MI. It acknowledges that this cannot be accomplished without a remedy in the community.
4. The decision clearly prohibits the transfer from one institution to another, including a nursing home, unless the person needs these services based on clear criteria.
5. Active treatment is still essential while in-patient or in ID facility to include continuous look at discharge criteria.
6. People should not be admitted to institutions due to lack of resources in the community when there is evidence that this should be available.
7. Reporting and data collection are essential.
8. The Olmstead plan must have reasonable timelines with resources to meet needs.
9. Acute /crisis services should be provided in the community-based settings.
10. Large congregate facilities should play a very specific and limited role.

11. Emphasizes increased supports to families who meet eligibility but who may not receive any other waiver services.

The 2010 Georgia Olmstead Agreement is important and must be considered by all policy makers as they plan ahead. During these times of very limited resources, it is essential that states plan carefully, assess how to improve upon their services, and focus on the development of an effective community-based system of care. There are some locations where this is already taking place. An opportunity to share information, funding to assess outcomes through research, and forums to help states problem solve and meet the challenges they face is required.

For further information, contact Dr. Beasley at Joan.Beasley@unh.edu.

The "U.S. Public Policy Update" is an ongoing column in The NADD Bulletin. We welcome your comments and submissions for this column. To learn more or to contribute to this column you may contact Joan Beasley, Editor of the U.S. Public Policy Update, at joan.beasley@unh.edu.

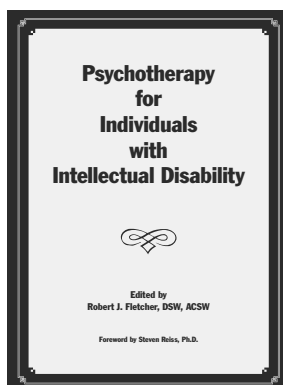
Psychotherapy for Individuals with Intellectual Disability

Edited by

Robert J. Fletcher, DSW, ACSW

This book provides the reader with insightful and useful ways to provide psychotherapy treatment for individuals who have intellectual disability (ID). It brings together all three modalities (individual, couple, and group), and a variety of theoretical models and techniques are discussed. The first section, Individual Therapy, offers a variety of approaches and techniques including dialectical behavioral therapy, positive psychology, mindfulness-based practice, and relaxation training. Also included in this section are chapters on specialty populations including victims of abuse, people who have Autism Spectrum Disorder, and people in mourning. The second section is a chapter on group therapy addressing trauma

"The most comprehensive discussion of psychotherapies with this population ever published"
Steven Reiss, Ph.D.



issues. The third section is on family and couple therapy. The fourth section covers chapters on research, ethics, and training. The individual authors are respected authorities in the field of providing psychotherapy treatment for persons with ID and all have contributed to the professional literature.

This book is a major contribution to the effort to make psychotherapy available to individuals who have ID and should serve to further stimulate interest in the provision of psychotherapy treatment for individuals who have ID co-occurring with significant mental health problems.

Price: NADD Member - \$49.95 • Non-Member - \$54.95

Visit the NADD Online Store at www.thenadd.org to order.

*DSP Interests and Concerns***Practical Support Strategies for Day-to-Day Interaction: Schizophrenia***Kathleen Olson, Ph.D., Kansas University Center on Developmental Disabilities*

Direct Support Professionals working with individuals with a dual diagnosis often support people with schizophrenia. The symptoms of schizophrenia may vary from day-to-day or from month-to-month. Treatment decisions are made by the individual and their team and may include medications, environmental support, and other therapies. Although each individual is different, the following practical suggestions for day-to-day interaction have been effective in helping the individual make sense of the environment and to sort out reality from psychosis.

When the individual talks about hallucinations (hearing, seeing, smelling, tasting or feeling things that are not there) or delusions (firmly held false beliefs):

- Be neutral and non-judgmental. Never make fun of hallucinations or delusions.
- If the individual is frightened or concerned about a hallucination respond calmly and truthfully. To “I see rats in the shower” you might respond by saying “I know you think you see rats, but I don’t see any. Your brain is playing tricks on you.”
- Encourage the individual to talk privately, rather than publicly, about delusions or hallucinations.
- Stay calm.
- Do not give undo attention for talking about hallucinations or delusions. You may unintentionally reinforce such talk. If possible, ignore statements about hallucinations or delusions.
- Do not try to convince the individual that hallucinations or delusions are unreal. Arguing will do no good.
- If asked if you experience these same hallucinations or delusions be truthful and say “no.”

Minimize the impact of delusions by encouraging the individual to control the environment. This will vary for individuals. Some examples are:

If they believe food is poisoned, encourage them to prepare own food.

If they believe people are looking in the windows, remove curtains.

If they believe others are talking about them, involve them in conversation.

If they believe others are stealing

items, provide them with a safe place to store items.

Encourage the individual to sit where he or she can hear others.

Simplify the environment.

- Individuals with schizophrenia may be more sensitive to visual and auditory stimuli. Reduce these as possible.
- Minimize clutter to minimize distractions.
- Avoid shiny surfaces to minimize visual hallucinations.
- Provide good lighting.

When hallucinations, delusions, or disorganized thinking limit the ability to focus on a conversation or activity:

- Keep conversation or directions simple and focused.
- Get the individual’s attention before speaking.
- Speak in a soft, calm, reassuring voice.
- Be simple and truthful.
- Present information in small bits. Be brief.
- Repeat as necessary.
- Allow time for the person to comprehend and respond to what you are saying.
- Ask questions to gauge comprehension and thought processes.
- Only one person should speak at a time.

To remain focused and get things done at work or home:

- Assign meaningful tasks.
- Establish a set routine to help the person understand what is going on.
- Assign repetitive work tasks. They may be easier than those requiring continual change.
- Break tasks into small components.
- Give directions simply, giving one step at a time.
- Be consistent in training.
- Provide visual and verbal prompts.
- Use graphic charts as reminders.
- Provide frequent prompts and reinforcement.
- Minimize clutter.
- Have person think aloud to monitor thought processes.
- Narrow down choices when the individual has difficulty in making decisions.
- Have individual write concerns in a journal for discussion as appropriate.

Stress and tension make symptoms worse, thus minimize stress or teach coping strategies:

- Establish a predictable way to handle reoccurring concerns.
 - Help individual learn alternatives when over stimulated.
 - Allow person to withdraw and be alone when he or she is overwhelmed by stimuli or upset.
 - Reinforce positive performance and behaviors.
 - Teach skills to handle situations in a socially appropriate manner.
 - Teach person to plan ahead.
 - Make expectations clear. Assure that expectations are realistic.
 - Set limits on how much abnormal behavior is acceptable.
- In a crisis:
- Remain calm.
 - Decrease distractions (e.g., turn off TV, CD player).
 - Talk in turns, one at a time.
 - Speak in a slow, clear, normal voice. Don't shout.
 - Repeat questions or statements. Avoid rephrasing them.
 - Decrease number of people present (while assuring safety).
 - Don't argue with others who are present.
 - Try saying "Let's sit down and talk" or "Let's sit and be quiet."

- Talk in terms of behaviors, not personality. Say, "You are upset. Let's talk about it," not "You're acting like a child."
 - Allow personal space.
 - Avoid continuous eye contact.
 - Don't challenge the individual into acting out.
- Other:
- Encourage the individual to take medications regularly.
 - Meet with the psychiatrist to discuss alternatives when noncompliance with medication is related to side effects.
 - Minimize consumption of alcohol and avoid use of illicit drugs.
 - Minimize cigarette use (or at least make use consistent).
 - Encourage sound and regular eating habits and exercise.
 - Build a support network.

For further information, contact Dr. Olson at kolson@ku.edu.

DSP Interests and Concerns is an ongoing column in The NADD Bulletin. We welcome your comments, suggestions, and submissions for this column. To learn more or to contribute to this column, you may contact Kathleen Olson, Editor of DSP Interests and Concerns, at kolson@ku.edu.

DSW Resource Center

The National Direct Service Workforce (DSW) Resource Center (www.dswresourcecenter.org) is a useful website for anyone concerned with issues related to direct support professionals. This extensive resource database can be used to access information, resources, and research on training, recruitment, retention, wages, supervision, consumer di-

rected services, and other topics. Covering the full range of DSW consumer populations, resources include web-based clearinghouses, technical experts, training tools, and more. Funding and support for the Resource Center come from the Centers for Medicare and Medicaid Services, U.S. Department for Health and Human Services.