A Trauma-Informed Toolkit for Providers in the

Field of Intellectual & Developmental Disabilities

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Healthy Environments and Relationships That Support

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Preface by Ed Bartz

This Toolkit is especially important to me, because of my background and my experience with many people with developmental disabilities. While I may not by a typical Adverse Child Experiences (ACEs) survivor, I am a survivor of adverse experiences. I am the youngest of six siblings and was born in the early 60's. At this time diagnosing my cerebral palsy took some time. My parents were told not to expect a lot from me cognitively. Mom and Dad disregarded this advice. I was acknowledging my name and knew all five siblings by name. Six children was a lot to attend to so I was placed in an institution. This was an adverse environment for my emotional and intellectual advancement. Thankfully I was only exposed to this environment for four years. I was moved to a rehabilitation hospital where my brain was exercised. This was an enlightening experience for everybody.

My time at Helen Hayes Hospital was spent on learning how to speak, eat and asking for help to go to the bathroom. These are tasks usually reserved three to four year olds. I was seven and eight when I moved to Helen Hayes Hospital. My potential was tapped and given a chance to grow. This all sounds great but I wanted to be home with my family. Yes, I had people who cared about me but they were not Mom and Dad. The older I got the more friends I accumulated. I became outgoing and people gravitated toward me. Still, regardless of how many friends I made I longed to be with family. Yes, staff at Helen Hayes considered me part of their family but I knew the difference. I would be invited to employees' homes to meet their families. This served two purposes, I got out of the hospital for a while and the children of the employee were exposed to a person with a disability. These experiences helped me realize that I had something to contribute to society.

Today I contribute to society be being an editor for an on-line magazine, Capability, writing about people and their accomplishments. Often I am asked to speak at local colleges on different aspects of my life. In the recent past, the University at Albany's School of Social Welfare, as part of the MARC grant, enlisted me as a "policy entrepreneur." As the editor and a writer for Capability magazine, I have developed skills that will be helpful in this regard. With the advancement of communication and technology I am able to keep in close contact with my four sisters and their children. My family may be spread throughout the country but we are all just an e-mail or a Facebook message away.

Through my writing, I will be advocating for people with developmental disabilities and a history of adverse experiences. This will enable me to showcase my writing skills while educating others about ACES.

There Is Nothing So Stable As Change   Bob Dylan, Nobel Laureate

Preface by Dan Tomasulo

Over the past 35 years the field of intellectual disabilities has evolved significantly with exceptional developments in treatment, medicine, programming and expansion of services. Yet, for all these advances, the struggle to initiate and maintain these advances has been problematic. Funding for staff and services has remained a perpetual effort—often as a matter of survival rather than thriving. The result is continual issues with staff turnover, compassion fatigue, and lowered productivity.

The approach to these issues has been to try and problem-solve them. This method follows a well-known pattern: we identify a problem, conduct a root cause analysis, brainstorm solutions, analyze them—then develop a treatment or action plan as an intervention. By definition if something is broken and we fix it—we have restored the condition back to zero. This is deficit-based change. We've done this for so long (and often under the gun) that we haven't stopped to ask if there is a better way to tackle our needs. Not just to fix things—but to take a situation and make it thrive and flourish.

To do this we need another approach—one that enhances our problem-solving method by coming at the issue from a completely different angle: strengths-based innovation. Hundreds of studies have now confirmed that investing in agency and employee well-being in a proactive way helps in the delivery of services. But these studies have been slow to come into practice. In the field of intellectual disabilities finding low cost, effective ways to bring these new methods to fruition is happening—yet is in its infancy. *Developmental and Intellectual Disabilities and Trauma: An Agency Toolkit* goes to the very heart of the concern. Agencies and staff are at significant risk when working with people with intellectual disabilities because they have a disproportionally high incidence of trauma related disorders. Witnessing, hearing about, or experiencing traumatic events is a daily possibility for our workforce. While other professions, such as first responders or the police, might be able to say the same—our exposure and mission is different. We are in the relationship with an individual for the long haul. The healing elements of our interventions have more to do with us than the technique we are using. If we aren't in a good place what we do won't be nearly as effective.

This toolkit offers what is essential as we move forward as practitioners in the field. Problem solving has gotten us here—but it won't get us to where we want to go. Taking deliberate steps toward increasing the well-being and self-care of agencies and their staff is the next necessary frontier. It is time for a change.

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Introduction

Research has shown that people with intellectual/developmental disabilities (IDD) are at significantly more risk of abuse and neglect than is the general population. Intellectual Disability has been defined as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior- which includes everyday social and practical skills. This disability originates before the age of 18 by most definitions. The term Developmental Disability is broader term, and includes both intellectual and some physical disabilities that usually are present from early childhood, and also occurs by the age of 18. Child abuse and neglect have been defined as "any act or series of acts of commission or omission by a parent or other caregiver (e.g., clergy, coach, teacher) that results in harm, potential for harm, or threat of harm to a child" (Centers for Disease Control and Prevention, n.d.). For our purpose, this definition of abuse and neglect is also applied to adults who may be vulnerable due to a developmental disability. Reviews of the literature on prevalence of abuse and neglect demonstrate that risks for children with disabilities are increased as compared to the rates reported for the general population (Sullivan, 2009; Sullivan and Knutson, 2009; Horner-Johnson & Drum, 2006; Govindshenoy & Spencer, 2006).

The causes for increased risk of maltreatment in children with IDD have been noted to include: that they may have more difficulty reporting abuse, be considered less credible, and that more empathy may be offered to caregivers than in children without disabilities (Manders & Stoneman, 2009). Additionally, it appears that increased parental stress and the vulnerability of this population contribute to increased risk. Wald (2003), for example found that children with disabilities likelihood of being subjected to corporal punishment increased based on the severity of their disability.

Martha Davis, of the Robert Wood Johnson Foundation, recently spoke to groups from around the US participating in the Mobilizing Action for Resilient Communities grants (presentation at MARC conference, November 9, 2015). Ms. Davis poignantly stated that we need to "develop a culture of power…we can create a unified voice for how to prevent the predictable. We are builders; brick by brick, we are linking systems together and denying trauma." Given the reviews of the literature cited above on prevalence of maltreatment in children with IDD, it is reasonable to conclude that this population is particularly at risk of experiencing Adverse Childhood Experiences (ACEs), and that we in the field of developmental disabilities had better start mixing the mortar for building our system's strength in this regard. As such we need to take steps toward increasing the knowledge base of providers, address prevention, and offer trauma/resilience-informed care when needed. The good news is that great work is happening all around us in the field of IDD. This groundbreaking work is being done by people like Karyn Harvey who addresses the issues associated with developing behavioral interventions (Harvey, 2012). Nancy Razza and Dan Tomasulo, who developed a group treatment program for people with IDD who have a trauma history (Razza & Tomasulo, 2005), and Tamsin Cottis in the UK, who discussed a wide range of topics associated with treatment of this group (Cottis, 2009).

Work to help improve self-care for staff serving people with IDD is being advanced by Stephen Noone and Richard Hastings in their work designed to build resilience in direct support professionals (Noone & Hastings, 2009). Singh and colleagues have also

addressed training direct support professionals in approaches to address their self-care (Singh, Lancioni, Karazsia, & Myers, 2016).   Both of these groups have begun to establish evidence based approaches to training staff; and their work supports such training as it reduces turnover, injuries and subsequent trauma to individuals served and staff, and is cost-effective.

The National Association for the Dually Diagnosed (NADD) under the able leadership of Robert Fletcher, has gone as far as rethinking the Diagnostic and Statistical Manual-V for people with ID (Fletcher, Barnhill, & Cooper, (Eds.), 2016). There is also great work being done to advance psychology in a larger context, which can inform our work. In particular, positive psychology as explained by Seligman (2011), has multiple applications. Another relatively new innovation is the Copeland Center's "Wellness and Recovery Action Plan" training, which can inform our work with individuals with IDD and in self-care of staff (Copeland, 2012; Copeland, 2014).

At the Center for Disability Services (CFDS), we have adopted a new model for Therapeutic Support Plans. We strive to develop treatment approaches that go beyond simplistic behavioral interventions, are written so they are clear to staff, and are informed by a deeper understanding of the individual; this is no small challenge particularly when regulatory requirements stipulate items that *must* be included. Harvey (2011) has described a similar approach with her suggestion for a more encompassing Mental Health Plan for people with IDD. The approaches taken by CFDS and Harvey (2011) are intended to go beyond the old style "behavior plan," offering new and trauma-informed ways to understand and support the individual towards a better quality of life. These approaches are consistent with the Restorative Integral Support (RIS) model (Larkin & Records, 2011; Larkin, Beckos & Shields, 2012; Larkin & MacFarland, 2012).
The purpose of this *Toolkit* is to integrate some of the best practices that can be applied to the work we do with people with IDD who have experienced trauma. As the reader, upon reading this document, you will have what we hope is a tool for the future, guidance and inspiration for your work, and direction for your reading and research.

A person who has experienced trauma, but fails to get the needed supports, suffers further damage. In the general population, trauma experienced during childhood is linked to the ten leading causes of early morbidity (Felliti et al., 1998). This is due to psychological stress, the physical impacts of stress, and to the increased likelihood of the person using coping strategies that are toxic– like drinking, drugging, smoking, and excessive eating. People with developmental disabilities may also engage in coping strategies that are potentially harmful, and these may be manifested in the same or different ways– for example, aggressive behavior may develop due to feeling unsafe, when access to the effects of maladaptive coping strategies is curtailed. The consequences of aggressive behavior and other behavioral problems frequently perpetuates the trauma. Being physically taken down by another person is a re-traumatization for a person with a history of physical abuse, and a new trauma for one without such a history. Intense, emotionally charged, interaction with others, including assuming physical risk, is often traumatic for staff. Given these impacts, the increasing interest in addressing these problems in the United States and internationally is critically needed and welcomed.

The responsibilities of those in a range of functions working in the field of IDD give impetus for shared concern, or even alarm. Quality Improvement departments are focused on reducing untoward incidents at their agencies. Evidence shows that well trained staff, and staff who have been taught self-care, are much less likely to resort to physical intervention, and less physical restraint translates to fewer episodes of trauma for individuals with IDD and staff (Singh, Lancioni, Karazsia, and Myers, 2016). Regulatory bodies look for evidence that care is taken to minimize abuse, and also to minimize the use of physical restraints and other restrictive interventions. Human Resource departments must concern themselves with the human and capital costs of high turnover. Administrators have a stake as well, for all the above reasons, and to ensure that agencies have policies and practices that best serve the people we support. Behavior Specialists, Social Workers, Mental Health Counselors, Psychologists, and Psychiatrists in the field need to be aware of methods that work to treat this group of valuable, but vulnerable people, who are even more likely to have had adverse experiences than others.

The focus of the toolkit is on areas other than psychotherapy, although the principals and information discussed here are critical for therapists. The following references, are representative, but by no means exhaustive, and are provided for the reader seeking specific information on therapy for people with IDD and a trauma history: Bedard (2013), Cotis (2009), Fernando, K. and Medlicott, L. (2009), Haydon-Laurelut M.and Nunkoosing, K. (2010), Mevissen, L., Lievegoed, R., Seubert, A., de Jongh, A. (2011), andPeckham, Howlett, Corbett (2006), and Razza and Tomasulo (2003). The full references may be found in the reference section of this toolkit.

Chapter 1 offers information and a guide for direct support professionals to enhance their wellness and resiliency. Research has shown that self-care is critical, and can positively impact the quality of care, reduce use of restrictive interventions, and reduce turnover. Self-care for Direct Support and other professionals serving people with trauma and IDD is critical, but often given too little attention. This chapter offers suggestions and resources for staff who may come to the work with their own trauma history, suffer from direct trauma in their work, or suffer from vicarious trauma as they hear the stories of those who have suffered direct trauma. The Chapter may also be used for staff training.

Chapter 2 provides background information as to the problem of ACEs and the evidence that the problem is magnified further in the field of IDD. Adverse childhood experiences and later trauma in people with IDD is a problem worthy of attention in its own right.

Chapter 3 provides guidance for trauma informed behavioral planning. Functional Behavioral Analysis for people with a trauma history requires special understanding. We know that a person's behavior may serve a function such as "escape" or "gaining attention", but knowing that a behavior may be manifested by an individual due to a trauma history, leads to potentially different interventions. In fact, the behavior may not serve a purpose or function at all; it may be an anxious response devoid of purpose, but requiring understanding. Critical elements needed in planning for people with a trauma history are delineated. A sample "trauma-informed" support plan is included to provide guidance in this area.

Chapter 4 is geared at offering direction for planning for agency administrators, quality assurance staff, and interested others. Agencies serving people with IDD are responsible for: minimizing restrictive interventions like physical restraints, interviewing victims of possible abuse, providing training to staff sensitizing them to trauma related care needs, and overseeing the care provided by direct support professionals and clinicians.

"Love yourself first, and everything else falls in line. You really have to love yourself to get anything done in this world." ---Lucille Ball

CHAPTER 1

Wellness and Resiliency for People Who Help People with Intellectual and Developmental Disabilities

Note: This chapter can be used by an individual staff member, but we recommend organizing an initial staff training facilitated by a mental health professional who could guide providers through the exercises and reflection questions. How this training is organized is left to the discretion of the trainer(s). Whether used individually or in a group, the chapter is ultimately geared to the development of a personal wellness plan, which appears at the end of the chapter. As the chapter is read, or the material covered in a group, individuals are encouraged to take notes about what commitment they can make to themselves to take care of themselves.

Being trauma-informed means understanding how trauma affects a person, and knowing effective ways to respond to someone who has experienced it. This background can help you develop empathy. But even with this background, many of us sometimes neglect our own needs as care providers. If you are drained, you need to know when it's time to stop and "refill your tank."

You can think of this chapter as a go-to guide on self-care for yourself and other helping professionals working in the field of intellectual and developmental disabilities (IDD). Research shows that the ways in which direct care providers cope with demands of the job can make or break their sense of satisfaction with the work they do. Among direct care providers in the IDD field, wishful thinking, or hoping things will get better without acting, commonly leads to emotional exhaustion. Problem-focused coping, on the other hand, leads to a sense of personal accomplishment, which may help prevent burnout (Devereux, Hastings, Noone, Firth, & Totsika, 2009). Further evidence suggests that teaching direct care staff mindfulness and other techniques can reduce the use of physical restraints, improve staff satisfaction, as well as reduce staff turnover rates while improving overall quality of care (Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, A. N., Adkins, A. D., & Singh, J. (2009).

In this chapter, you'll find self-care tools and resources that can be used at home or the workplace. We begin by introducing how to assess your stress levels and wellness needs. Multiple exercises are then offered, both in the chapter and in Appendix 1, geared at improving your wellness and resiliency. It is the authors' sincere hope that this chapter speaks to you and motivates you to develop a self-care plan or supplement the one you already have.

This chapter and Appendix 1 include:
- A brief overview of wellness and resiliency, including self-care
- Self-assessment tools to help providers determine their own wellness needs
- Several self-care exercises for individual use and/or training purposes
- Additional resources providers can use to develop their self-care practice- including how to develop a personal Wellness and Resilience Plan.

Wellness: Starting with You First

You can think of wellness activities as a kind of prep work we can engage in to protect ourselves from the stress that may comes along with the demands of doing "people work." Wellness is geared toward resiliency, or our ability to bounce back from adversity. While direct care can be very fulfilling and enjoyable work, it may not always be all rainbows and sunshine. At times we're faced with situations on the job that force us out of our comfort zones, sometimes with little thanks or reward for the hard work we put in. Some of these demands, like de-escalating an agitated individual for what seems like the thousandth time, are part of the job. It's demands like these that might leave you feeling frustrated or make you think that you're powerless to change the people you care for. If you have ever felt this way, don't worry, you're not alone!

Plenty of people in the field (including the authors of this toolkit) have felt frustrated or annoyed with the people under their care at some point in their career. Feeling this way can mean that you really care deeply about the people you look after and, after all, caring is what we're here to do! However, this very commitment to care that we all share, can place a heavy burden on us if we become too invested in *changing* the people we serve.

A story from one of the authors (Steve Marcal) may serve to illustrate this. When Steve started in the field of IDD an early experience involved a woman who resided at one of the agency's group homes. She was very agitated on the bus. Assuming (perhaps wrongly) that the behavior was attention seeking, Steve proceeded to gently tell the other folks not to react as the bus brought them to their sheltered workshop. These conversations went well enough until one particular individual was approached. He felt that others were being blamed for the person's behavior. He proceeded to curse Steve out- and once Steve learned the back story, that was understandable. Steve felt misunderstood, at first. But later learned that the person who got angry at him was really the one who was misunderstood. The person who was upset had a history of abuse in institutions where, he told Steve in a calmer moment, "the staff would hit you first, and talk to you later." You will make mistakes too; we are human after all. But we hope this chapter helps you reflect on things and gives you tools you need to recover quickly.

It may seem to go against our basic instincts as helping professionals to embrace the idea that we're not here to change the people we're paid to take care of—but it's true. No matter how hard we try, we cannot change others; all we can hope to do is plant the seed of change and mindfully support its growth. Whether that seed sprouts is beyond our control. What we can change, is our response. We can do this by first making sure that we take proper care of ourselves.

"Taking care of you, first" is not selfish; it does *not* mean putting the people who depend on you for support second to your own needs at work. Rather, it means increasing awareness of yourself when you start each day at work, and adding simple activities to your life before you jump in to support another person in living their life. This idea of taking care of you first is really a key part of wellness and resiliency. Once you incorporate this concept in your thinking, and put it into practice, we think you will reap both professional *and* personal benefits.

In our work we are asked to put others *before* ourselves (rather than the other way around). This selfless calling to help people who, due to physical and/or intellectual disability, often cannot readily help themselves without support is truly admirable and worthy of praise. So, take a second to acknowledge this—*pat yourself on the back*—The work you do means a lot to the people you take care of. At the same time, however, we must not lose sight of our own needs, as neglecting our own wellness leaves us vulnerable to harmful stress, which reduces our resilience and puts us at greater risk of burning out.

Stress and Burnout

Stress affects each and every one of us. Basically, it's our bodies' natural, physical response to a perceived threat or demand placed on us. This response could be activated, for example, from the immediate fear of being attacked by an agitated individual under your care, from an upcoming performance evaluation, or a high workload.

A survey of staff in the IDD field showed that nearly 33% experienced high levels of stress (Hatton, Emerson et al., 1999). Too much stress, or stress induced by adverse events, like physical aggression, can do a lot of harm to our physical and mental health. When stress becomes chronic, it can seriously threaten not only our wellbeing but also the quality of care we provide for the people who depend on our support (Farrell & Turpin, 2003; Palm, Polusny, & Follette, 2004). If we're not careful this kind of stress overload can result in conditions known as "compassion fatigue" and "burnout."

Some common signs and symptoms of stress to watch out for:

- Constant worrying or feeling anxious
- Racing heart
- Increased frustration or irritability
- Feeling lightheaded, faint, dizzy
- Thinking the worst about nearly everything that comes your way
- Overreacting to minor events
- Aches and pains such as headaches or neck aches
- Not performing as well at work

Burnout and Compassion Fatigue

Burnout and compassion fatigue are two different stress-related conditions, however, there is quite a bit of overlap between them. Compassion fatigue is often what happens when we put our all into caring but don't take the time to care for ourselves. It's when we deplete our reserve of empathy (the ability to put yourself in another's shoes) after helping people who have suffered a lot. Empathy is, of course, a good thing and is essential to the care provider role. When we help others go through a challenge in life, we often put ourselves in their shoes, and literally feel their pain; that's empathy, a natural and normal response. However, when we constantly see and hear about the hardships of others over a period of time, or even a single case that just really hits us hard, we may become vulnerable to compassion fatigue.

Burnout, on the other hand, is built up over a period of time and is brought on by strictly work-related factors such as handling an increased workload or feeling underappreciated. A direct care worker can have burnout and compassion fatigue simultaneously. That's why it's so important to know yourself (what sets you off, what's working, and what isn't working for you). This includes recognizing the signs and symptoms of stress, burnout, and compassion fatigue and then taking proactive steps to prevent them from taking over your work and life (we'll go over some of these steps soon).

Take a look at some of the warning signs of compassion fatigue and burnout (adapted from Stamm, B. H. & Figley, C. R., 1996) below and consider if you have ever experienced any of them:

Compassion Fatigue—depletion of empathy reserve that can arise from helping other people.

• Feeling "on edge" and easy to startle • Feeling hopeless, as if nothing will ever go right • Feeling angry or irritable without any obvious reason • Just not caring anymore, "fed up!" • Avoiding certain thoughts or feelings because they remind you of some frightening experience	• Avoiding certain situations or activities because they remind you of some frightening experience • Avoiding or ignoring people you help • Feeling disconnected from others • Loss of sleep • Feeling "drained"

Burnout—stress-related condition built up over a period of time by work-related factors such as high workload or feeling underappreciated.

• Feeling anxious or irritable • Feeling depressed • Feeling tired most days even after resting • Loss of sleep • Difficulty concentrating	• Getting sick more often • Changes in appetite • Disconnecting from others • Reduced work productivity • Just not caring anymore, "fed up!"

Compassion Satisfaction

While it's important to recognize the symptoms of burnout and compassion fatigue, it's just as important to acknowledge when things are going right, when you're at ease with yourself and your work as a helping professional. Attaining this bced state known as compassion satisfaction is one of our ultimate self-care goals.

Look over the following characteristics of compassion satisfaction and see if   which of these attributes you already have (adapted from Stamm, B. H. & Figley, C. R. , 1996) :

<u>Compassion Satisfaction</u>—the positive state of feeling happy and at ease in your role as a helping professional.
- Feeling happy
- Believing in yourself and your abilities
- Finding life satisfying
- Finding yourself learning new things from the people you care for
- Feeling connected to others
- Having a good bce between work and free time
- Feeling calm and at ease with your work
- Feeling satisfied from working with those you help
- Having happy thoughts about those you help and how you could help them

Reflection Questions

1. If you've ever experienced burn out, what did it feel like and what factors led to it?
2. Have you ever experienced compassion fatigue? If so, what symptoms did you have and what factors led up to it?
3. When you experience compassion satisfaction, what is it like?

Adverse Childhood Experiences

It goes without saying that the folks we take care of undergo stress too. And when the individuals we serve experience major life challenges, such as the loss of a loved one, and go through trauma in the wake of a crisis, we're the ones there to help lift them up. We would do well to remind ourselves that such adverse experiences are likely but one of many others the folks we help have faced, beginning in childhood.

As touched on in the introduction to the toolkit, individuals with IDD tend to have higher rates of adverse childhood experiences (ACEs) than the general population. The evidence for this increased rate of adverse experiences is reviewed in Chapter 2. But, knowing of these risks, we recommend the following while at work:

- **Keeping in mind** how stress from ACEs, built up over time, and can influence the physical and mental health of the people we help.
- **Becoming more aware** of ACEs in the people we help could give us a clearer perspective on what they've been through in the past and what they're going through in the present.
- **Increasing our understanding through ACE awareness on the job** and hence our understanding of the causes of some individuals who experience emotional and behavioral difficulties.

Take a moment and do the questionnaire yourself (below).. For some, this may bring up potentially upsetting memories from the past, so try it only if you feel comfortable. Taking the ACE Questionnaire could turn out to be a meaningful learning opportunity and give you more reason to stick to a plan to build up resilience. A high ACE score does not directly result in negative outcomes, and many people develop post-traumatic strengths. Actually, there's a lot of research showing how health-promoting activities can help to prevent negative long-term consequences of ACEs. Practicing self-care gives you the power to lead a healthier life going into the future.

ACE Questionnaire

Prior to your 18th birthday:

Prior to your 18th birthday:
1. Did a parent or other adult in the household often or very often…
    Swear at you, insult you, put you down, or humiliate you?
        or
    Act in a way that made you afraid that you might be physically hurt?
        Yes   No   If yes enter 1   _____

2. Did a parent or other adult in the household often or very often…
    Push, grab, slap, or throw something at you?
        or
    Ever hit you so hard that you had marks or were injured?
        Yes   No   If yes enter 1   _____

3. Did an adult or person at least 5 years older than you ever…
    Touch or fondle you or have you touch their body in a sexual way?
        or
    Attempt or actually have oral, anal, or vaginal intercourse with you?
        Yes   No   If yes enter 1   _____

4. Did you often or very often feel that …
    No one in your family loved you or thought you were important or special?
        or
    Your family didn't look out for each other, feel close to each other, or support each other?
        Yes   No   If yes enter 1   _____

5. Did you often or very often feel that …
    You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you?
        or
    Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?
        Yes   No   If yes enter 1   _____

6. Was a biological parent ever lost to you through divorce, abandonment, or other reason ?
        Yes   No   If yes enter 1   _____

7. Was your mother or stepmother:
    Often or very often pushed, grabbed, slapped, or had something thrown at her?
        or
    Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something hard?
        or
    Ever repeatedly hit over at least a few minutes or threatened with a gun or knife?
        Yes   No   If yes enter 1   _____

Continues on next page
8. Did you live with anyone who was a problem drinker or alcoholic or who used street drugs?
        Yes   No   If yes enter 1   _____

9. Was a household member depressed or mentally ill or did a household member attempt suicide?
        Yes   No   If yes enter 1   _____

10. Did a household member go to prison?
        Yes   No   If yes enter 1   _____

Now add up your "Yes" answers: _____   This is your ACE Score

See Appendix 1, Exercise 1 for an example of a staff person coping with ACEs.

Checking Yourself

We mentioned earlier that we sometimes we get so caught up in helping others that we lose touch with ourselves. This is not necessarily a "bad" thing as the very nature of the work we do requires a level of selflessness. When an individual needs our help, for example, it's our duty to drop our personal needs and wants at that moment and jump in to help. But, then again, this does not mean that we should ignore ourselves entirely. If you know you're just *wiped out* and desperately in need of a break you can ask a coworker to take over—that is, of course, assuming that there is enough staff to do so and that there is a culture of mutual support among staff (which is not always the case).

Whatever the case may be, setting time aside to check in with ourselves is a must. You may have heard the saying: "you can't serve from an empty vessel." If you're running on "E," if you're totally drained and ready to snap at the drop of a hat, it's probably your body telling you "hey, buddy, time out already!" So, get in touch with *your* body by listening to its warnings and finding the time to practice the **3 R's of Recharging: Rest, Reflect and Regroup.**

The 3 R's of Recharging

1. **Rest**—Find a safe place where you can settle down for a moment and…

   - Close your eyes for a couple seconds.

   - Take a few deep breaths.

   - Think of something that makes you happy.

2. **Reflect**—Ask yourself:

   - "Am I stressed out?"

   - "What's stressing me out?"

- ■ "Is it something I can control?"

  - ■ If it is, what can you do about it?

  - ■ If it isn't, just let it go.

3. Regroup—Get yourself ready before going back to work:

- ■ Take a few more deep breaths in and out.

- ■ Write a "To-Do List."

- ■ Seek out a co-worker for support.

It is a good self-care skill to have a level of awareness about when our "battery" needs to be recharged. **See Appendix 1, Exercise 2 for more about recharging.**

Whole Self Wellness
"What am I doing for myself?" We owe it to ourselves, and to those we help, to stop and ask ourselves this basic question every now and then. Doing so can help us begin to better understand what we're doing right and what we may need to improve on in order to lead healthier and happier lives. We can begin by asking ourselves these basic questions:

- ◆ **How am I feeling *right now*?**
- ◆ **What makes me get out of bed in the morning?**
- ◆ **What are 3 things that make me happy?**
- ◆ **What are 3 things I'm doing in my life to help better myself?**

What are some of the things you do to take care of yourself? Maybe you play sports, go on hikes, or read books; maybe you hang out with friends or listen to your favorite music and just chill out after a long day at work. We've all developed our own personal ways of coping with the stress in our lives. Some of the coping strategies we engage in are better for us in the long run, while others can hold us back from achieving our true potential. Self-care involves identifying and practicing those strategies that help us to live well.

You may not even realize it, but many of the activities you already engage in every day are part of your wellness practice. Going to the gym, hanging out with friends, and relaxing on the beach are just a few examples of activities you may already be doing to improve your overall wellbeing. These activities give us the much needed time to de-stress, relax and work on ourselves, so we can be at the top of our game when the time comes to help others. To feel good and be at our best we must not forget any part of our self because each part plays a critical role in the wellness of our *whole self*. An effective wellness practice addresses all dimensions of the self, including the physical, the psychological, the emotional, the spiritual, as well as the professional.

Resiliency

Not only do you feel good when you take care of yourself, but you 're also actively

building resiliency against stress. Resiliency, put simply, is someone's ability to keep calm and carry on through life's rough spots—relationship challenges, problems at work, you name it. That's not to say, of course, that resilient people don't ever feel bad or have a negative thought. They do, it's just that they've learned helpful ways of coping with stress. In a word, people who are more resilient have just mastered a wellness practice that works for them. Anyone who's motivated enough can do this too! What it comes down to is whether a person is ready to push themselves a little and stick with it. If so, it does pay off in the long run!

Training your mind to produce helpful thoughts

Get in touch with how you're feeling

How you're taking care of your body

Your satisfaction with the work you do

Your meaning and purpose in life
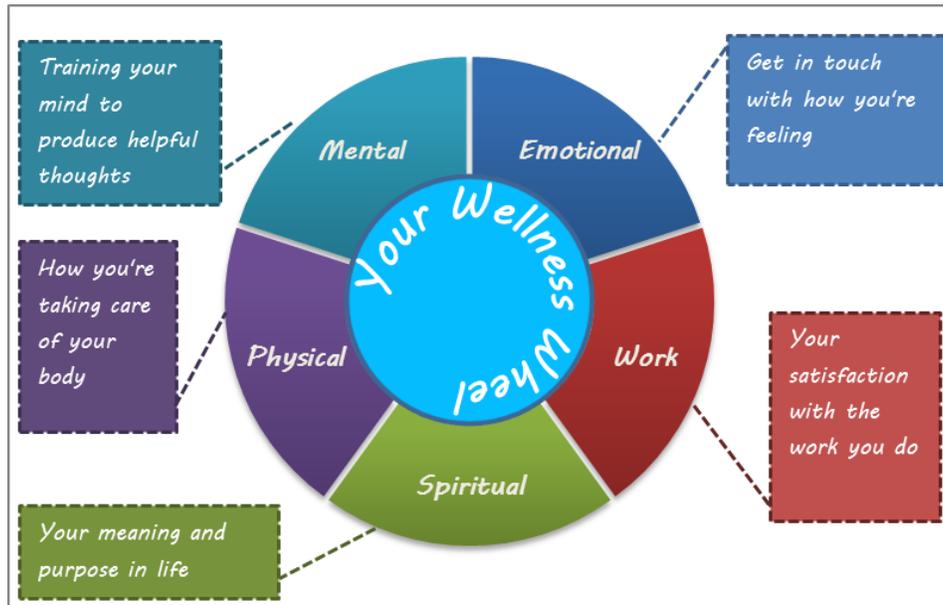
Your Wellness Wheel

After you review your wellness wheel (above) consider all the parts of your whole self wellness by filling in the dashed boxes corresponding to each of the parts in the wheel below. In each of the boxes, write just a few words that reflect one way you take care of that part of your whole self. In the box pointing to "work," for example, you might add "talk to co-workers for support."

*Now, take a look at **Your Wheel of Wellness**, at the top of the next page, to see what we mean by whole self wellness and its different parts. You can think of these parts as the focus areas of your self-care practice. When you're done looking over the wellness wheel try filling in your own personalized wellness wheel in the box directly below.*
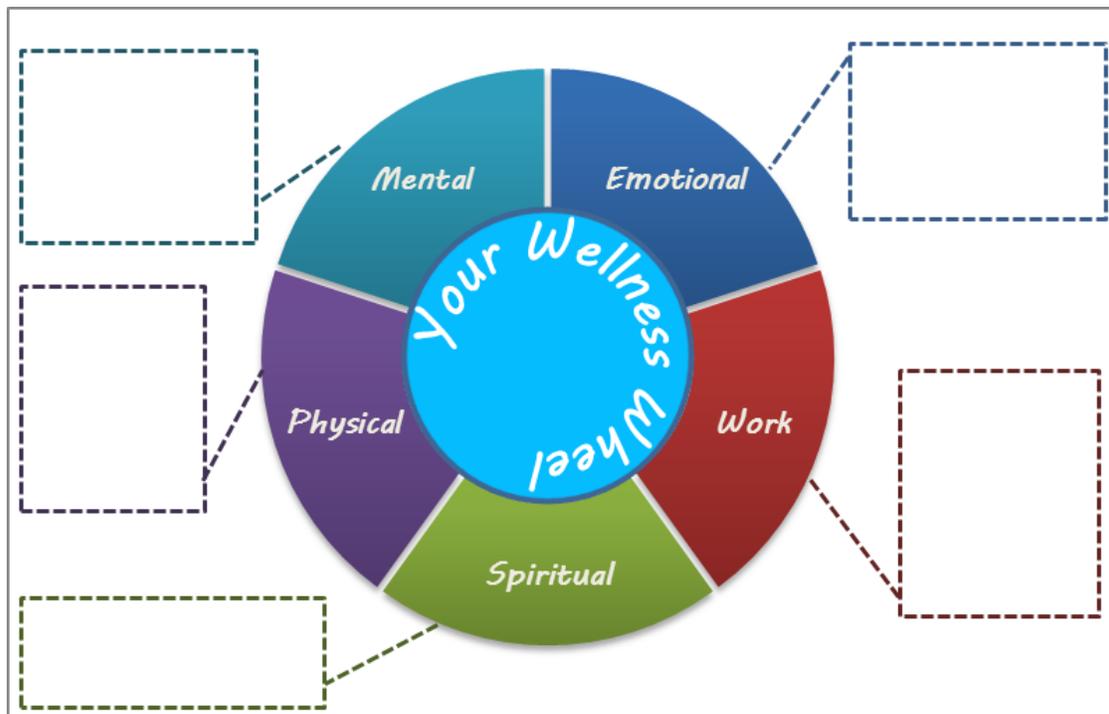
When you have filled in your personal information in your Wellness Wheel turn to
Appendix 1, Exercise 3, for a more in depth self-assessment.

It's the Simple Things

Sometimes it's the simplest things that are the easiest to overlook when we're caught up
in the busyness of work. Such everyday, routine activities as taking time for lunch seem
inconsequential but they really do add up over time. Whether we recognize it or not, it's
these basic activities that help us build up our resilience to the stress that can add up in
our lives. We believe you will find that it is in your best interest to take note of each
activity you take part in (no matter how simple it is) as part and parcel of your wellness
practice. Remember: No single part of you is more or less important than another—your
wellness includes *every* part of the wheel. To be a more resilient person for yourself *and*
others, it's important that you clearly see how you're taking care of each part of the
whole.

Ways to Take Care of Yourself

There are lots of healthy ways to cope with stress and take care of yourself, which when practiced regularly help to keep you at the top of your game. You saw some of these helpful ways of taking care when you completed the Self-Assessment Tool (Appendix 1, Exercise 3). Hopefully going through the assessment tool helped you gain a better sense of all the things that you're doing, and might need to do, in order to make yourself a healthier, happier person and a more bced, effective care provider.

Some causes of stress, like dealing with traffic, are beyond our control. These kinds of stressors, because they are unavoidable, may call for more emotion-focused methods of coping (like mindfulness or for some, prayer) that help us to keep calm and carry on. Sometimes on the job we might employ unhelpful emotion-focused coping strategies like "wishful thinking" to help us feel more in control of a frustrating situation but without ever actually fixing the problem. And not only do these unhelpful strategies like "wishful thinking" not fix anything but they also can make us feel worse by draining us emotionally over time.

Other sources of stress are more or less under our control (despite how overwhelmed we might feel about them). In such cases problem-focused coping strategies can be particularly useful. Through problem-focused coping we tackle the roots of stress head on. A few examples include managing your time wisely, problem solving, and getting support from coworkers.

A number of mindfulness exercises are included in this chapter and Appendix 1. In case you aren't familiar, mindfulness is basically just the art of being aware in the present moment—that's it, really. However, much like painting, drawing, or playing an instrument, being mindful (that is, the state of simply being aware of things in the present moment) is an art and, like any other art, it takes some time and patience to fully master and get results. Just like when you go to the gym to try and lose a few pounds, results aren't always instant. To get the most out of it, regular practice is a must. Whether you're a regular practitioner or not, though, simple mindfulness practices like breath awareness or deep breathing can be great ways to de-stress and relax.

Our thoughts, feelings, and actions are all interconnected. Making sense of how they relate to each other can be a challenge but breaking them down can help put complex situations into perspective. **Turn to Appendix 1, Exercise 4 to see how you can apply the Thought, Feeling, Action Triangle.**

Problem-Focused Coping

Some sources of stress are more or less under our control (despite how overwhelmed we might feel about them). What is called "problem-focused coping" can be particularly useful at these challenging moments in our lives. Using problem-focused coping basically allows us to tackle the roots of stress head on. A few examples of this include managing your time wisely, problem solving, and getting support from coworkers.

There are times at work when we might employ unhelpful emotion-focused coping strategies like wishful thinking to help us feel like we're more in control over a frustrating situation. But

while we might feel more in control at the moment, we actually never really fix the problem. And not only do these unhelpful strategies like wishful thinking not really fix anything they also can make us feel worse in the long run by draining us emotionally over time.

Think of something within your sphere of influence that personally causes you stress at work. Begin to take control over the problem by going through the following problem-solving steps:

1. Identify the problem

2. Make a list of possible solutions

3. Choose the one you think is most likely to effectively solve the problem

4. Try your first choice

5. Evaluate your success and repeat the cycle if needed.

See Appendix 1, Exercise 5 for more problem-solving support.

Thoughts and more about what we can do about them:

Cognitive behavioral psychology teaches us that our feelings are affected by our thoughts. By changing our thoughts we can help our emotions to follow. Our thoughts can shape our reality. Sometimes we get so wrapped up in our own thoughts that we lose touch with the things going on all around us. Furthermore, as you learned in Activity 1, unhelpful thoughts can affect how we feel and influence our behavior. That's why it's so important to be mindful of what we're thinking, to recognize the unhelpful thought patterns and not let them get the best of us. Thoughts we can watch out for are:

Demanding: If we mentally insist that something be a certain way, and it isn't, that often leads to unhealthy emotions. Earlier in this chapter we referred to this as "wishful thinking." For example, saying, "this person shouldn't behave this way" is not helpful and may lead to poor frustration tolerance or even anger for the person who thinks it. Thinking something like, "it would be better if they didn't behave this way, but that's what they sometimes do" is more likely to lead to healthy emotions on your part- and solutions to the problem. The take-away is to **change demanding thoughts, or wishful thinking, into preferences.**

Exaggerating badness: When we make something out to be worse than it is, that also leads to unhealthy negative emotions. When you catch yourself thinking this is awful, horrible etc., that's a red flag. You can challenge those kinds of thoughts by asking yourself "is it really *that* bad?" **If you are honest with yourself, you will often realize that you are making whatever it is worse than it really is (like all of us sometimes do).**

Rating ourselves and others: It is typically not helpful to negatively rate or judge ourselves or others. **Exercise 6 in Appendix 1** provides a means of approaching this sometimes difficult challenge with humor. **Try to avoid rating people and recognize that coworkers and the people we're supporting all have value.**

<u>Additional exercises that appear in Appendix 1:</u>

Exercise 7: Thoughts on a Screen- Designed to increase awareness of thoughts.. .

Exercise 8: Three Funny Things- Designed to help you use your sense of humor to cope with difficult things.

Exercise 9: Mindful Living- Learning how mindfulness in your life can help you enjoy even the boring stuff.

Exercise 10: Mindfulness Before Work- To help you get ready to approach your work each day.

Exercise 11: Body Scan- Combines mindfulness with progressive muscle relaxation- this is something you may want to add to your wellness and resilience plan.

Exercise 13: Recognizing the Challenge- The work we do is rewarding and difficult. Janet Harrison and Stephen Noone have develop a great training program geared at helping us recognize and accept that the work really is challenging, and hence, we need to have a plan to cope with that rather than using strategies to avoid or distance ourselves from the challenges. One of their exercises, designed to do in a group, is very effective. Folks are asked about both the qualities they bring to their work, and the challenges they face. The result is often bitter-sweet humor, when presented as it is here.

Developing a Wellness Plan
Once you have completed this chapter and the exercises in Appendix 1, you will be ready to develop a personal Wellness and Resilience Plan. Below, we go back to the Wellness Wheel you've seen earlier in the chapter. But now is your chance to make it right for you. You know best what is important to you and what you can realistically commit to. If you are feeling too stressed and do something about it, you can make a positive difference in the areas that are important to you. If you do nothing different, well…nothing is likely to change.

My Self-Care Plan

My self-care goal:

Things I'm going to do for my mental, physical, emotional, occupational & spiritual wellness to accomplish my goal:
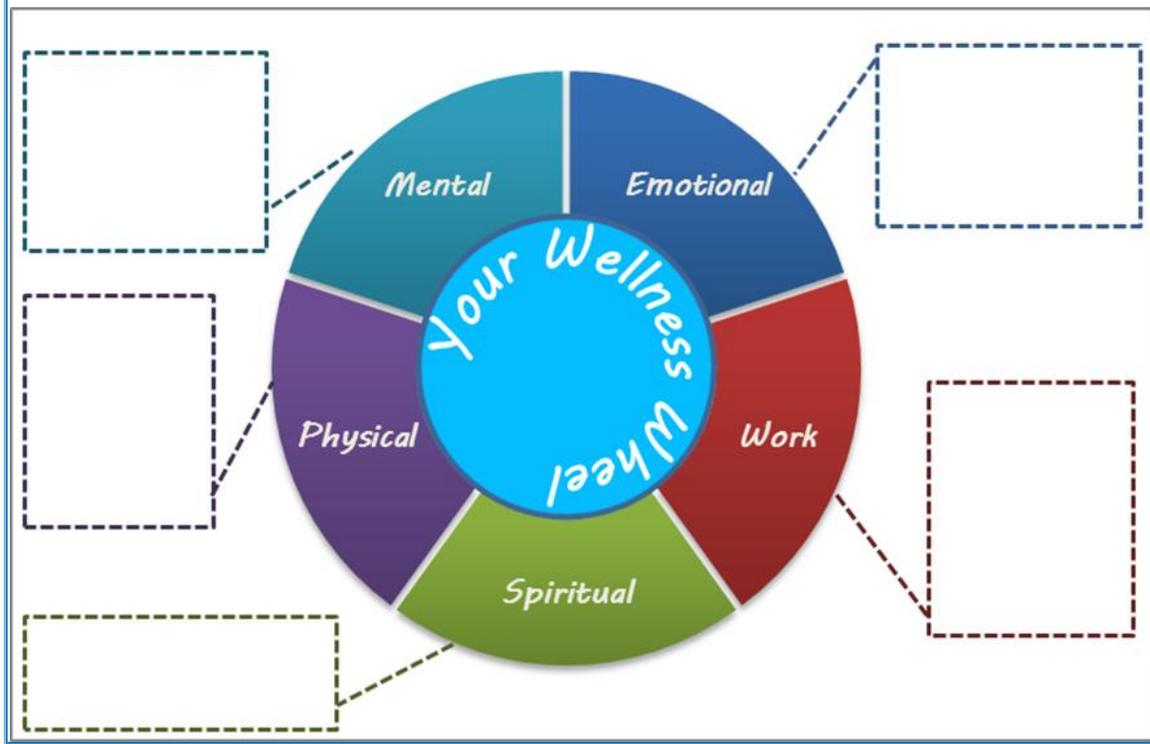
Your Wellness and Resilience Isn't Only About You

Whether we're Direct Support Professionals, Social Workers, Behavior Specialists, Psychologists, other Clinicians, or supervisors, we commit a large part of our own lives to enhancing the lives of others in need. Regardless of our degrees or credentials, we're all in this field to help people, people who happen to live with intellectual and developmental disabilities (IDD). Helping people is what we do and ensuring the welfare of those we look after is always our number one priority. Self-care practice is discussed too little, yet an integral part of our work. Without it we just wouldn't be able to offer the high quality of care that the people we help need and deserve. So, remember to take good care of yourself, not only for you, but for your coworkers, family, friends, and of course the people you help at work, too.

> *"I've got to keep breathing. It'll be my worst*
> *business mistake if I don't."*
> *—Steve Martin*

Additional Self-Care Resources

Books

Grise-Owens, E., Miller, J., Eaves, M. (2016). *The A-to-Z self-care handbook for social workers and other helping professionals*. The New Social Worker Press.

Seligman, M. E. (2012). *Flourish: A visionary new understanding of happiness and well-being*. Simon and Schuster.

Websites
- ACE Response: www.aceresponse.org
- Compassion Fatigue Awareness Project: http://www.compassionfatigue.org/
- Self Care Magazine: http://myselfcaremagazine.com/
- A Free Mindfulness Based Stress Reduction Course www.palousemindfulness.com
- Dr. Dan Tomasulo's Website: http://www.dare2behappy.com

Self-Care Mobile Apps
- SuperBetter: https://www.superbetter.com/
- Calm: https://www.calm.com/
- Breathe2Relax: http://t2health.dcoe.mil/apps/breathe2relax

CHAPTER 2

The ACE Study and Intellectual and Developmental Disabilities

If you are reading this document you must believe that it is important for those of us working in the field of intellectual and developmental disabilities (IDD) to know how people with IDD are impacted by trauma, and what we can do about it. We have already learned in Chapter 1, that taking care of ourselves is an important component. In this chapter, literature is reviewed to offer background and support the need for such a toolkit..

The Adverse Childhood Experiences Study (Felitti et al., 1998) is the largest study of its kind which examines the impacts of adverse childhood experiences (ACEs) in the general population over the lifespan (See-The ACE Questionnaire in Chapter 1). These experiences can have a significant negative impact on the individual during childhood and throughout the lifespan; emotional and physical health problems increase dramatically with ACEs- especially when they are untreated. ACEs are common and are strong predictors of adult health risks. They are implicated in the 10 leading causes of early morbidity in the United States. Furthermore, it has been well established that there can be harmful neurobiological changes in people who have suffered trauma (Anda et al., 2006).

In the original ACEs study, Felitti et al., (1998) assessed the impact of Adverse Childhood Experiences (ACEs) with patients at a large HMO in Southern California. The ACEs questionnaire was responded to by 9508 patients, representing 70.5% of those surveyed. The number of categories endorsed by individuals was compared to measures of adult risk behavior, health status, and disease. More than half reported experiencing at least one category, and 25% reported experiencing at least two categories. A relationship was found between the number of categories endorsed and number of adult risk behaviors and diseases reported. Those who experienced four or more categories had a four to 12 fold increase in risk for: alcohol abuse, depression, drug abuse, and suicide attempts, as compared to those with zero categories. Two to four fold increases were seen in smoking, poor self-rated health, having a history of 50 or more sexual intercourse partners, and sexually transmitted disease. Many other risk factors were also present at lower levels.

The negative impacts of ACEs in the general population are well established. But our experience working with people with developmental disabilities caused us to believe that the people we serve at the Center for Disability Services (CFDS) might be at greater risk than the general population, and that the impacts may be different. This was especially the case in our outpatient behavioral health services where many of the people referred have a trauma history. We wondered if there was generally an increased risk, and looked at the literature to see if that was true in people with IDD– perhaps we were biased in this regard. After all, perhaps people with a trauma history referred for counseling and psychiatric services are probably over-represented in our outpatient behavioral health service. We believed, in fact, that we do see more people with a trauma history in our

Health Service Division than is generally the case for non-referred people with IDD…
but we still wondered, "Is the risk of ACEs higher for people with developmental
disabilities?" We undertook a literature review to explore this, and began to verify the
linkage between ACEs in the general population, and ACEs in the people we serve. This
also lead to exploration of related issues. The literature review was originally presented
by one of the authors, Steve Marcal, at the National Association for People with Dual
Diagnoses (NADD) International Congress in Miami, in June of 2014, and a version of
the remainder of this chapter appears in the proceedings for that conference. We felt it
important to include, in revised form, parts of that document in this chapter, as
understanding the scope of the problem is a critical component in the "*call to action*" that
this toolkit suggests is needed.

THE PREVELANCE OF ADVERSE CHILDHOOD EXPERIENCES
IN PEOPLE WITH DEVELOPMENTAL DISABILITIES

A review of 40,000 school records in the Omaha public schools found that children with
disabilities were more likely to be maltreated than peers without disabilities by the
following multipliers: Neglect: 3.76, Physical Abuse: 3.79, and Sexual Abuse: 3.14
(Sullivan & Knutson, 2000). Data collected from 1997 to 2000 through the national
evaluation of the Comprehensive Community Mental Health Services for Children and
their Families Program, on 156 children with autism found that, in a clinic sample, 18.5%
had been physically abused and 16.6% had been sexually abused (Mandell, Walrath,
Manteuffel, Sgro, & Pinto-Martinet, 2005). A review of population based studies
(Govindshenoy & Spencer, 2006) concluded that children with conduct and learning
disorders are at greater risk of maltreatment, and stated that children with some disabling
conditions are at increased risk of abuse and neglect. A review of 18 studies published
between 1995 and 2005 in which maltreatment of people with Intellectual Disabilities
(ID) was the focus, concluded that although the literature is limited, it is clear that the
prevalence of maltreatment is higher among people with IDD and other disabilities
relative to no disabilities (Horner-Johnson & Drum, 2006). A review of 50 relevant
studies published between 2000 and 2008 (Sullivan, 2009) concluded that sufficient
evidence exists that children and youth with disabilities are at increased risk to be victims
of violence, that this effect was consistent across studies conducted in medical, child-
protective, law enforcement and school settings, and that the effects are cross-cultural.

The prevalence of children with disabilities in the child welfare system in Minnesota was
examined (Lightfoot, Hill & LaLiberte, 2011). More than a fifth of children with
substantiated maltreatment were labeled in administrative records as having a disability.
The most common type of disability among children with substantiated maltreatment was
emotional disturbance, while other common disabilities included intellectual and
developmental disabilities and learning disabilities. Using logistic regression, this study
found that children with substantiated maltreatment who had disabilities were about twice
as likely to be in out of home placement as children with substantiated maltreatment
without disabilities. Clearly, "out of home placement", even when the best available
alternative, is likely to add new traumas to the child's history.

The increased risk of girls with disabilities or illness was investigated (Alriksson-
Schmidt, Armour, and Thibadeau, 2010). The study evaluated whether US adolescent

girls with a physical disability or long-term health problem were more likely to report having been physically forced to have sexual intercourse than other girls. Using regression analysis to study data from the 2005 National Youth Risk Behavior Survey, the study found that reports of being forced to have sexual intercourse were about twice as high (19.6% vs. 9.4%) in the disabled/health-problem group than in the group without disability/health problems.

It appears that the risk of maltreatment increases with the severity of the disability. Lower scores on the Vineland Adaptive Behavior (VABS) Composite were associated with increased probability that parents would endorse physical punishment as an initial response to child behavior problems (Wald, 2004). Use of physical discipline was more likely in parents of children with more significant disabilities, as measured on the VABS. There was more family stress and social isolation in parents of children with disabilities. Increased levels of disability led to increased levels of family stress. Finally, increased disability level resulted in a negative impact on attachment.

IMPACT OF ADVERSE CHILDHOOD EXPERIENCES
IN PEOPLE WITH DEVELOPMENTAL DISABILITIES

Research regarding the impact of adverse childhood experiences on individuals with IDD is limited. The impact of sexual abuse history on the functioning of 54 people with ID in the UK was investigated (Sequeira, Howlin, & Hollins, 2003). The sexually abused group of people with ID was matched with other individuals for IQ, but who had no sexual abuse history. The subjects ranged in level of ID; 16 in each group were people with severe or profound ID, 14 had moderate ID, and 24 had mild ID. Individuals with ID who had experienced abuse had more severe behavioral problems than the matched comparison group. The individuals who had suffered abuse were more likely to have aggressive and agitated behaviors, self-injury, temper outbursts, sudden changes of mood, social withdrawal, inappropriate sexual behavior, and hyperactivity. The proportion of people meeting the criteria for Posttraumatic Stress Disorder ((PTSD) was significantly higher in the abused group. The abused group had significantly more symptoms of depression, anxiety and hypersomnia than the non-abused group.

The psychological impact of abuse in men and women with severe ID was studied in a UK sample (Rowsell, Clare, & Murphy, 2013). Interviews were conducted with family members or caregivers of 18 victims of abuse as to their functioning in the three months prior to the abuse, three months after the abuse occurred, and at the time of their study. In many cases the victims suffered multiple forms of abuse over an extended period of time. The study found marked increases in frequency and severity of a range of emotional, physiological, and behavioral symptoms of psychological distress following alleged abuse. Victims showed very limited recovery at the last interview, conducted at least two years after the last instance of abuse.

Psychiatric disorders and characteristics of abuse in sexually abused children and adolescents with and without ID was studied in Turkey (Soylu, 2013). The study compared 102 children with ID with 154 who did not have ID, all aged six to 16, with regard to the psychological impact of sexual abuse. The children with ID were representative of a range of IDs: mild (87%), moderate (11.8%) and severe (1%). Some

important differences were found between the two groups: It was determined that sexual abuse types involving penetration and contact were higher in the group with ID; they were exposed to more frequent repeated abuses, the abuses were revealed with their own reports at a later period and at lower rates, and pregnancies after abuse developed more frequently. In the ID group, compared to the group without ID, it was determined that the abuser was less likely to be familiar person and/or a family member, and instances of more than one abuser were encountered more frequently. While no difference was determined between the two groups in terms of post-abuse Posttraumatic Stress Disorder (PTSD) and Major Depressive Disorder (MDD) frequency, conduct disorder was observed more frequently in the group with ID.   This fits with our experience that people with IDD may have mental health problem overshadowed by their developmental disability- so they may not get a diagnosis even when warranted. Also, it is noteworthy that in some cases people with IDD may have limited access alcohol and illegal drugs, and so may manifest overt behavioral expression of the emotional consequences of trauma because other maladaptive responses are less available.

Web-based resources:
- National Child Trauma Stress Network (search for developmental disabilities on the site): nctsn.org
- An Association for Persons with Developmental Disabilities and Mental Health Needs: thenadd.org

CONCLUSION

This chapter and the chapters to come address a range of issues to provide a broad overview of topics associated with trauma in people with IDD. The overview presented so far, covered the impacts we learned about from the original ACE study, and the prevalence and impact of ACEs in IDD we learned about from our literature review. Given the increased risks demonstrated by the literature review, and the negative consequences that have been shown in the literature as well as through our many years of experience in the field of mental health and IDD, the groundwork has been laid for the remainder of this toolkit to take on the importance we know it deserves in your hearts and minds, and in your work. You have read this far, so you are motivated and have demonstrated your willingness to make a positive difference in the lives of the people entrusted to your care. It is time to put the sordid history of abuse behind us, and to look to a new day. Deinstitutionalization was necessary, but *not* sufficient to enable this good work to happen. Action is still required. You can play a significant role, whether you are working as a direct support professional, an administrator, a clinician, or a person receiving services, we hope you find something in this Toolkit that you can put right to use in our shared mission- prevention and treatment of traumatization and re-traumatization of people with IDD.

CHAPTER 3

Trauma-Informed, Resilience-Supporting Intervention

At the Center for Disability Services we have worked for many years at devising a template and a "best practice" conceptualization to address emotional and behavioral difficulties.   As we have become increasingly attuned to the impacts of trauma, we have updated our approach accordingly. We will start with a discussion of the overarching concepts. Later in this chapter we'll share our most recent iteration of the template we introduced in May of 2016, and an example of a trauma informed plan. The reader is also referred to Karyn Harvey's book on the topic which was mentioned earlier (Harvey, 2012). In her book, Harvey has referenced a specific template for trauma informed care, and has a number of wonderful examples.

The field of IDD is permeated heavily with behavioral psychology. This is a good thing, as available training and certification opportunities have been enhanced over the last several years. Through a specific course of study including traditional coursework, supervision hours, and a certification exam, one can earn certification and have the designation -Board Certified Behavior Analyst (BCBA). Applied Behavior Analysis (ABA) is heavily emphasized in BCBA training. ABA involves a highly structured approach that is a good fit for children, especially in classrooms that are heavily staffed. These time-intensive approaches don't work as well with adults because **1)** rigidly applied behavioral approaches are seen by some as condescending when working with adults **2)** there are very real differences in staffing that we face in adult services for people with IDD that often render ABA impossible to deliver **3)** trauma histories may require going beyond traditional functional behavioral assessment (FBA) and towards a more "reasoned analysis" that subsumes and, we argue, extends beyond typical functional analysis and **4)** they may be difficult or even unethical to implement because of the constitutional rights adults hold in our society. New York State, for one, does not generally allow punishment procedures, and reinforcement procedures cannot involve things that adults would typically have access to without a reinforcement plan.

With both children and adults, a behavioral approach will only be effective if the trauma history of the individual is taken into account. Some have argued, and we agree, that there are all sorts of traumas, big and small, that people with IDD are at risk for. These aren't discussed in many general approaches to trauma because they don't apply. For example, the Adverse Childhood Experiences paradigm does not account for the traumas of being placed in a special class, of not being afforded the opportunity to get married or drive a car, not getting to go to college after witnessing siblings have that opportunity, being bullied or even called "retarded", and countless other indignities (or worse) faced by people with IDD. The toll of these apparently smaller adverse experiences can add up. For this reason, and because there may be trauma we don't know about due to

communication problems or withholding information, trauma informed approaches to care make sense for many, if not all people with intellectual disabilities.

The BCBA designation and other forms of similar training provide wonderful preparation in behavioral principles that can be applied in any work in behavioral health- if applied wisely. One criticism of that approach from our perspective is that the role of mental states is minimized. Mental states are the very thing that are altered in traumatized people, and an understanding of that is critical to quality treatment. An approach that denies or minimizes that aspect is flawed. Trauma informed care, and overall quality care require more than behavioral principles for a treatment plan to be successful. For that reason we have chosen to label our plans at the Center for Disability Services "Therapeutic Support Plans." For similar reasons, Karyn Harvey has chosen to call her plans "Mental Health Treatment Plans." We agree with criticisms of behavioral approaches when rigidly applied, but we feel that trauma informed care and behavioral psychology can be wedded intelligently.

Good planning involves a thorough understanding of the individual in the milieus that they live and spend their days. Behavioral interventions routinely start with a functional assessment as to why the behavior is occurring. The underlying principle of functional assessment is that behaviors occur to meet some need and therefore serve a purpose or function. Most routinely considered in such an analysis are: 1) escape- the person may be behaving to escape or avoid something unwanted 2) attention- the individual may be trying obtain attention of others 3) tangible- they may be trying to get something and 4) sensory- they may be meeting a sensory need – like rocking in people with autism spectrum disorders, for example. Once we determine the function, the theory goes, we design an intervention to address that aspect, by helping the person to meet their need in a manner that is not harmful to them or others.

It is widely (though certainly not always) recognized that many behavioral difficulties are a result of an undiagnosed medical problem- the person may be reacting to pain. The importance of investigating medical bases of problems, particularly in people who may not be able to tell us that they are in pain, or what hurts, has been noted (May & Kennedy, 2010). But, in addition to functional analysis and possible medical explanations for behavioral difficulties, trauma informed care means that we must also be cognizant of a trauma history as a possible cause of difficulties; in fact trauma history and medical difficulties can be considered a critical but often under evaluated part of functional assessment and analyses. In the case of trauma history, this is particularly relevant when we consider that the people with IDD are probably at least three to four times more likely than the general population to have suffered abuse or neglect (Marcal, 2014, Presentation at NADD). If we lack an understanding of the person's history- we may draw inaccurate conclusions when doing a functional analysis. Since the functional analysis is the driving force in designing interventions, we may be traveling down the wrong path, and at worst the intervention can cause further trauma.

We also need to acknowledge that a behavior that is a function of post-traumatic stress may serve NO useful function for the person. It may be a visceral reaction based on an altered stress-response system. There is evidence that brain structure and functions are

altered by trauma, especially during childhood (Anda et al., 2006). Our response must include the factors that address trauma-related impacts, or intervenions will not be effective.

A classic book on understanding trauma includes a discussion of essential aspects of recovery from trauma (Herman, 1992). These should be taken into account in designing interventions and will therefore be discussed here. Herman noted that the first stage required for recovery is safety, and the essential importance of providing a safe environment has become well accepted in trauma recovery work. Herman pointed out that the acutely traumatized person needs a safe refuge. Home should be an especially safe place. If that isn't the case at your agency, you are dealing with a problem that many of us are facing…but we must recognize and address it as best we can…or the folks we're serving may get worse instead of better.

Herman pointed out that the underlying experience of psychological trauma includes disempowerment and disconnection from others. As such, recovery requires the empowerment of the survivor and the creation of new connections. *These core aspects of recovery are often especially difficult for people with IDD to obtain.* Interactions with people we serve are often disempowering- people with IDD don't have a lot of choices in many cases. Can they really change where they live or work, for example? How many committees do the people we serve include the people we serve as members? It has been noted that many of the choices we offer are not real- so our plans to help people, whether they have a trauma history or not, need to include true choice (Harvey, 2012).

New connections can also be very challenging for people with IDD to establish. Many are dependent on staff or family for transportation. Often the opportunities for meeting new people are limited. We must go out of our way to make the opportunities possible. At the Center for Disability Services (CFDS) we are working towards building a "friends network"- to help people connect and develop relationships outside of paid staff or their housemates. At CFDS, we need to go further with our programming in this regard, but have recognized the need and are working towards easing relationship building challenges.

Do your intervention plans include **real choice making**, and do they include helping with relationship development? A traditional functional assessment might not lead us down these paths, but these aspects are essential for recovery from trauma, and important for everyone we serve. "Setting Events", a commonly used behavioral concept, most frequently refers to recent situational factors (onset of illness, for example). Trauma from long ago may be missed in many analyses. Understanding a person's trauma history can inform interventions because the interventions flow from what we know about helping a person feel safe, connected, and empowered. For example, when someone is re-experiencing a trauma, we need to understand that teaching alternative behaviors won't work. We typically understand that about current crises, but may miss this when intervening with traumatic memories, which for the individual may as well be happening in the present moment. Understanding a person's trauma history, for example may mean that having male staff toilet someone with a history of male perpetrated abuse is contraindicated. Or it may mean that staff turnover, prompts memories of abandonment, and is likely to trigger difficulties. **See Appendix 2 for the complete CFDS Therapeutic Support Template.**

Resilience, or the ability to recover from adversity, is a key component in any treatment model for trauma. Buse and Burker (2013) have outlined key components that foster resilience in people with developmental disabilities, each of which has research support. The table below lists the important characteristics, and the implication for our work.

Resilience Enhancing Component	Implication for Intervention
Self-enhancement	• Help people recognize and accept greater responsibility for their successes father than their failures. • Offer specific and positive feedback following any type of assessment (vocational, psychological, or otherwise).
Hardiness	• Help people establish a clear sense of their personal values that can serve as a guide for them in their behavior when faced with challenges (e.g., talk about what sort of person the individual wants to be, moving them from doing well to please others, or avoid "getting in trouble" to doing things, because they know they are the right thing based on their values). • Consider hardiness training (Khoshaba and Maddi, 2001)
Emotional Regulation	• Consider introducing mindfulness training in your program (one of the authors adapted the on-line mindfulness course mentioned in the self-care chapter for a group of individuals with IDD, some of whom have a trauma history. • Teach relaxation strategies such as deep breathing • Refer for Occupational Therapy evaluations as a sensory evaluation may provide useful strategies
Humor	• Use humor only after first employing listening carefully, and ensuring the individual knows they have been understood. • Be sure humor does not come across as putting the person down, and that it will not be perceived as being in bad taste. • Integrate humor in a kind manner, with low and soothing tones • Use self-deprecating and light-hearted humor to help people through difficult times.

Focht-New, Barol, Clements, and Milliken (2008) have suggested a number of practices to address a history of victimization in people with IDD. These are adapted in the table below:

Suggested Intervention	Brief Description
Biographical Timeline as Assessment and Intervention	• Life events are laid out on a time-line which allows for "respectful guesses to be made about life events, challenging behaviors, and interventions. Interventions can be designed to address gaps in development and/or experience. The timeline can support staff in assuming a therapeutic stance, and support resistance to

Supportive Intervention	• Planning should flow from the Biographical Timeline
	    o One key strategy is to establish an "anchor for safety" (we sometimes refer to this person at the Center for Disability Services as a "focus person." This is a trusted person who can be readily available.
	    o Another key strategy is establishing a "safety valve" which is a metaphor for coping strategies in the person's repertoire.

Socially Therapeutic Environment as Intervention/Educational Interventions	• Help staff to fully appreciate that people with IDD need support because they are "challenged with a neurological disability that affects their abilities to process information and communicate." • Ensure staff know about their own wellness, and encourage them to practice self-care to foster their ability to support a therapeutic environment.
Communication as Intervention	• Teach people to label and ventilate their feelings.
Psychiatric Care and Therapy	• We now know that quality psychiatric care and psychotherapy work with people with intellectual and developmental disabilities. Make referrals as needed, preferably to providers with experience with IDD. Providers lacking this experience may wrongly attribute a problem to the intellectual disability, rather than the trauma history and/or mental health problem.

A Therapeutic Support Plan

At your agency or school, you probably have a basic template from which to build behavioral plans. We want to share with you the latest version of our template at the Center for Disability Services, which you can adapt to meet your needs. You will see that our template has many parts and is complex. But, you will also see, that we have tried to make the plan as user-friendly for direct support professionals as we can, given the demands of their very difficult jobs. We try to carefully break down what staff can do at each juncture, including preventative and teaching strategies. We have moved the background to a Part II, not because it is less important, but so that staff can quickly reference "what to do". Also keep in mind that aspects of our template are designed to meet regulatory requirements in New York State. One of these requirements is that when a restrictive intervention, such as a physical intervention, medication, or a splint to prevent self-injury, are included, our Human Rights Committee must review the plan and the reasons it is being proposed. You must be familiar with requirements in your state to design such plans. We have listed only one "behavior or symptom" here for space purposes. Clearly many people have more than one thing to address- though the reader is cautioned to prioritize difficulties.

Here is an outline from CFDS with some minor modifications:

Outline of Therapeutic Support Plan Format at the Center for Disability Services

- Identifying information, date plan initiated, date of latest revision

Part I: Supports and Interventions

- Indications of what team(s)/individuals worked on the plan and dates
- Purpose for the plan, whether it requires review by our Human Rights Committee (HRC) and if so which restrictive interventions necessitate such a review
- Summary of what is in the plan, including: the behaviors/symptoms to be addressed in the plan, any attachments that must accompany the plan (e.g., PRN Protocol, protocol for any mechanical restraint (like a splint to prevent self injurious behavior), the most recent psychiatric consult, and how and where documentation will be done
- General Everyday/Proactive Approaches, with focus on teaching skills and developing preventive strategies-including trauma informed considerations (in the example below this section was incorporated into the intervention section for brevity)
- Tables for each behavior/symptom based on a functional analysis and history that includes:
  - One table indicating how the difficulty presents, when it is most likely to occur, when it is least likely to occur, and new skills to develop
  - A second, two columned table including- when a precursor, opportunity for prevention, or the difficulty occurs (where we list environmental triggers and times when most likely to occur) **and** for each of the items, what supports should be provided

**Part II: Functional/Reasoned Assessment Summary/Update
and Justification for Restrictive and Intrusive Interventions**

- Identifying information
- How the Functional/Reasoned Assessment was completed (direct observations, interview with _____, Review of clinical medical and environmental or other data, Use of specific assessment tools
- Background Information
    - Age, level of cognitive functioning, residential history including institutional history, trauma history, past vs current functioning, what has worked previously to end or reduce difficulties or restrictive interventions, and if the person is not involved in development of the plan a statement indicating why not (e.g., would not be able to comprehend due to limited verbal ability)
- For each Behavior/Symptom, specific history of the difficulty being addressed, contextual factors/contributing background info (cognitive, environmental, social, physical, medical, psychiatric conditions that may contribute to the difficulty, and trauma history if applicable), Antecedent Events, Hypothesized Function **OR** Reason for the behavior (Reasons may be different from functions, which imply the behavior serves a specific function – in the case of trauma, it may simply be reactive), Conditions that maintain the symptom/behavior, Baseline data for each program (e.g. day and residential)
- An indication of whether or not the plan (Part I) contains restrictive interventions like physical restraints, psychotropic medications may fall in this category (see your state regulations), mechanical restraining devices, and other rights restrictions (e.g., turning off a motorized wheelchair). If restrictive interventions are included a justification must be included here along with the frequency of its use for ongoing plans. If restrictive interventions are used we also must include a specific plan to fade, reduce, or eliminate their use.
- Areas in need of follow up (e.g., things that are covered that should also be included in program goals, follow up appointments that may be needed with psychiatry)
- The method of review including documentation details and a statement that the plan will be modified as needed and at least annually.
- Signatures of all parties (informed consent capacity for people receiving services is captured in another document).

This chapter will conclude with an example of a Therapeutic Support Plan, adapted to protect confidentiality, from the plan of one of the people receiving our services.

See Appendix 2 for the Center for Disabilities template for a Therapeutic Support Plan

SAMPLE THERAPEUTIC SUPPORT PLAN (Summarized)

BACKGROUND

Michael is a 71-year-old man diagnosed with Post Traumatic Stress Disorder (PTSD), profound intellectual disabilities, and Autism. According to the Vineland Adaptive Scale-Second Edition, Michael's communication skills are at the one year level. Michael also has a medical history significant for seasonal allergies. Based upon Michael's level of intellectual functioning and communication skill, he is unable to have direct input into the creation of his TSP. Behavioral observations, and analysis of Michael's communication through behavior, has enabled him to participate indirectly. He resided in institutional care from age five until 46 at several different locations; abuse and neglect are likely have occurred in those settings. Direct information about all that may have happened to Michael is not available, but we believe his ACE score is at least 5; this is based on what we know about his separation from his parents, and their histories. He currently lives in a group home called Barnett House, in Clifton Park, NY, and splits his time between two day programs at Sanderson Avenue in Troy, NY, and at Lyden Road, also in Troy.

> Note the long-term focus on relationship building.

Michael is seen by Dr. Douglass Belden-Hacker for psychiatric care. He often engages in ritualistic behaviors, similar to those commonly seen in people with autism, that are thought to be methods for coping with anxiety. These may include spinning a wide variety of items, pulling threads on his clothing, and opening the door, peering out, and closing the door (possibly a form of hyper-vigilance associated with trauma). Within the past few years, Michael has made progress with joining group activities at a large table at his day program. He has been able to achieve this due to the development of safe, positive relationships with staff and peers in the room.

> Note that we make every effort to remove restrictive interventions as we have done here with Michael- we know these are retraumatizing.

Michael has a long history of experiencing increased anxiety when he is not in his structured routine and surroundings. He responds to changes by going to a certain location, apparently to give him a view of anyone who might approach. At his residence, Michael continues to progress with using his room for coping activities (e.g. using recliner chair). Due to an overall improvement in behavior and staff not needing to utilize the SCIP-R 1-2 Person Escort and Strategies for Crisis Intervention and Prevention-Revised (SCIP-R) Standing Wrap for a period of 12 months, these interventions were removed from the plan in a 2008 revision. SCIP-R Standing Wrap, however, was restored in a 2009 revision to address Michael's increased aggression when his anxiety becomes overwhelming. Michael's TSP previously included unsafe transportation, but that behavior was removed from the plan.

From the Functional/Reasoned Analysis and Intervention Sections:

ANXIETY SYMPTOMS

How the difficulties present: Pacing or scanning the room, MIchael may appear sweaty and engage in ritualistic behaviors such as scratching his face with his hands, putting his hand down his pants, leaving the room and returning, carrying/moving large objects, urinary incontinence, taking off clothes , pulling threads from clothing, and tapping those around him.

History:	Displaying signs of anxiety is long-existing behavior for Michael.
Contextual Factors/ Background information:	Symptom of Post Traumatic Stress Disorder; environmental changes
Antecedent Events:	Michael shows signs of anxiety throughout the day, but unfamiliar places and people may be an antecedent to more severe behavior
Hypothesized Function/Reason:	Symptom of PTSD; some anxiety type behaviors (e.g., sitting behind the divider, ritualistic behaviors) may make him feel safer and help him control his anxiety
Conditions that maintain symptom/behavior:	Unfamiliar places and people, changes in routine; anxiety being reduced through ritualistic behaviors
Conditions that reduce, prevent, eliminate the symptom/behavior:	Presetting for changes in routine; time to process requests; positive interactions with staff; additional time in preferred activities (e.g., shower); relaxation techniques (e.g., sitting in recliner, music from the list he prefers); respecting Michael's personal boundaries
Baseline data:	Residence: Signs of anxiety occur daily. Intensity is monitored on a 5 point scale at the residence in the morning, afternoon, and evening. The daily average severity of anxiety observed by staff over the last 12 months is 1.91(previous average 2.21). Day Programs: Signs of anxiety occur daily. Intensity averages 2.66 with no clear patterns emerging and a similar frequency in each program.

When this occurs,	Provide the following supports:
Medical appointments; new locations	• While riding in vans (including to med appointments), if one staff is available to sit by Michael, they should do so and talk with him during the ride or he can sit up front in the passenger seat • Verbally reaffirm Michael's safety when in new or unfamiliar places • Use food reinforcers as needed
Michael pulls on a staff member's hand or attempts to pull away from an activity	• Acknowledge that Michael is communicating that he is feeling anxious and help him move to a different activity / help him leave the outing • Encourage Michael to take a break and give him personal space • Praise him when she uses a coping strategy and when she communicates that he is anxious.
Michael is pacing, taking off his clothes, or showing other signs of anxiety at residence	• Encourage Michael to communicate to staff when he is feeling anxious (through gestures, etc). Help him to use coping strategies such as taking a break or a walk Staff should try to sit near him and speak calmly to him, while trying to redirect him to an activity • Michael may also feel physically calmer if staff rub his head or hands.
Michael is	• Redirect him to an activity that requires the use of his hands, such as carrying

Note the emphasis on safety and helping Michael feel safe that permeates the approach. Note also the importance of connection with others, and not unnecessarily usurping Michael's control (don't thwart him from leaving the room).

putting his hands in his pants while engaging in ritualistic behaviors	something. If unable to do this, ask him if he would like to move to a private location (i.e., the bathroom or his bedroom). If unsuccessful, put up a mat or sheet to shield Michael for privacy (this is NOT a mat enclosure—he must be able to walk through or around the mat if he desires)
Michael attempts to leave the classroom at day program	• Attempt to redirect Michael back to a preferred activity. Use first, then pairing. Gently say, "First _____, then walk." • If verbal redirection is unsuccessful and Michael is persistent in leaving the classroom staff should allow him to do so while keeping with his level of supervision. Preventing Michael from leaving the classroom only heightens his anxiety and can escalate to self abuse, property abuse, and aggression.
If anxiety continues…	• Give Michael increased personal space and/or ask him: "show me what you want." • Monitor Michael for presence of other target behaviors (Aggression toward self or others, urinary incontinence)

<table>
<tr><td colspan="2" align="center"><u>AGGRESSION TOWARD SELF/OTHERS</u></td></tr>
<tr><td colspan="2">Banging his head. Attempting to hit or kick. Also includes property destruction (i.e., knocking over furniture and throwing small objects).</td></tr>
<tr><td align="right">History:
Contextual Factors/</td><td>These behaviors have occurred since before Michael moved into his current placement. Symptoms of PTSD; agitation; unexpected changes to routine/environment; anxiety symptoms</td></tr>
<tr><td align="right">Background information:</td><td></td></tr>
<tr><td align="right">Antecedent Events:</td><td>Request to perform a task, especially if not given enough time to process; prevented from engaging in ritualistic behaviors; disruption of routine/environment; negative interaction; in response to peer aggression</td></tr>
<tr><td align="right">Hypothesized Function/Reason:</td><td>A means of communicating "no;" a demonstration of frustration or agitation; means of avoiding tasks. Feeling unsafe or unsure of what to expect.</td></tr>
<tr><td align="right">Conditions that maintain symptom/behavior:</td><td>Avoidance of unwanted activities/tasks; sensory stimulation; being left alone</td></tr>
<tr><td>Conditions that reduce, prevent, eliminate the symptom/behavior</td><td>Presetting for changes in routine; time to process requests; positive interactions with staff; additional time in preferred activities (e.g., shower); relaxation techniques (e.g., lotion/nails, music); respecting Michael's personal boundaries</td></tr>
<tr><td align="right">Baseline data:</td><td>Residence: Self abuse occurred approximately 2-3x/month (previously 4-5x/month) and aggression occurred approximately 1-2x/month (previously 2x/month)
Day Programs: Self abuse 1-2x/month (previously 3-4x/month).
Aggression: 2x/month (previously 4x/month).</td></tr>
</table>

Note the understanding of trauma and its impact in the use of choice, positioning as he wishes, minimizing change, using calm tone, and this is especially noteworthy-accepting his gentle pushing of staff as a form of communication and not overreacting.

When this occurs,	Provide the following supports:
Transition from work to home	• Provide Michael with time to transition from work to home. • Give him the choice of taking his break first or having his snack first. • Michael should be allowed go to his room for a break or rest period to use his foot massager and/or to massage his hands with hand cream.
	• Michael prefers to sit with his back against the wall or in a corner. This is a position of safety for him. Encourage him to gradually move up to the table for group activity.

Transitions and changes to routine during day program	Allow him to move back to his "safe" position when she pushes his chair back from the group. • Provide him with choices daily (e.g., type and order of activities, food or beverage, schedule). • Prepare Michael in advance for the next activities: what, where, with whom, and when (pre-setting). • Changes to the daily routine should be kept to a minimum and explained thoroughly. Additions to him structured routine should be gradual.

Giving Michael a direction or making a request	• Approach him in a calm, quiet manner; use his name and remind him who is speaking to him.
	• Make the request (i.e., "Michael, this is Sally, it's time to go to Dunkin' Donuts, please put your shoes on") and allow him about a minute to process the request, move away from him and return about a minute later to request a second time.
	• If Michael has not responded at all, use a second person who is not normally in his environment on a regular basis, to make the request. Michelle generally complies with the request. If not, with both staff together, one will inform him that they will help him. Give him three seconds then begin helping him by using Strategies for Crisis Intervention and Prevention-Revised (SCIP-R) Touch and verbal prompts.
	• If Michael continues to push staff away:
	    o <u>Non-essential</u>: staff will respect this communication as a refusal. Staff will comply and leave him alone for 15 minutes, then return to offer another activity. When leaving, tell Michael "Okay Michael, you can refuse, but I will return in 15 minutes with another activity."
	    o <u>If essential</u> (i.e. incontinent and needs to be cleaned or any unsafe situation): staff will remain with him and state, "Michael, I am not leaving" and then repeat the request.
	        ▪ If he continues to be noncompliant, one staff will state, "Michael, we are going to help you with__ and this is how we are going to do it…" Then proceed in assisting him.
	• When Michael begins to engage in complying with the request, staff will gradually stop using physical prompts.
	• Reinforce him for complying by saying "Thank you for helping to …" (business-like but gentle tone).

Gently pushing people away; any indication that he is refusing an activity or outing	• When Michael gently pushes a person away, staff will respect this communication as a refusal for all non-essential demands (i.e., to engage in a task/activity, to choose between type of drink). • Staff will comply and leave him alone for 15 minutes, then return to offer another activity. When leaving, tell Michael "Ok Michael, you can refuse, but I will return in 15 minutes with another activity."
Michael crosses his arms and backs into a staff member while exhibiting minor agitation	• This is Michael's way of communicating that he needs support to deal with his anxiety. When he does this, do not physically restrain Michael. • Offer to give him a hug, provide positive attention (Michael enjoys high 5s), and redirect him to a calming activity (such as listening to music in a quiet area)
Michael is slapping himself,	• Staff should immediately get a mat (if available) or small pillow to put behind his chair, standing up by a wall/window or for the position he is in for his protection.

banging his head, attempting to hit, bite, head butt, or destroy property	• Use (SCIP-R) verbal calming techniques to prevent him from hurting himself
	    ○ Let him know who is there and how you are going to keep him safe
	    ○ It may be necessary to maintain a short distance from him rather than using touch to calm him.
	    ○ Tell him that if he can't stop, staff will help him because "we can't let you hurt yourself."
	• If necessary, use light touch to prevent injury or to redirect him to a less chaotic space.
	• If the above techniques were unsuccessful and she continues abuse herself, (and no environmental cause is determined), Michael may be in pain. If Michael communicates using the sign for pain, a PRN pain reliever may help reduce the self-abuse

If his behavior escalates and he becomes a danger to himself or others	• Remove items that could present a danger when thrown, remove others to a safer place, and get a mat (if available) for his protection • Staff may use *SCIP-R Standing Wrap.
SCIP-R Standing Wrap is used	➢ SCIP-R approved physical intervention techniques should only be used as **a last resort**; after all other methods listed in this plan have been unsuccessful. ➢ Michael must be released from any physical intervention when he is calm or at the end of 20 minutes. If there is a need for further physical intervention, staff may re-engage in the physical intervention technique. ➢ Follow (regulatory) reporting Procedures
Additional interventions used to maintain safety for this person or others:	➢ Complete Agency Events Form to document additional physical techniques ➢ Temporary Postponement of Community Activity Form if a planned activity is postponed

See Appendix 3 for examples of "Proactive everyday approaches" we have included in our plans at the Center for Disability Services. We have increasingly focused on this section of our plans recently, as we understand that by improving quality of life we can have a tremendous positive impact on the people we serve.

Discussion

In this chapter we have outlined some considerations for behavioral planning for people with intellectual disabilities who have a trauma history. Many people with IDD have such a history. It is also important to be aware of the many smaller traumas endured by people with disabilities, which can add up over time, and be very impactful. In planning for people we have taken into consideration that functional assessment has an important place…as long as we understand the functions and/or reasons in the context of trauma.

We presented an example of a trauma-sensitive plan, that of "Michael." Imagine if staff responding to Michael interpreted his light pushing as a form of aggression, or blocked his way when he wanted to leave a room. Neither of these possibilities is farfetched, when one lacks a trauma-sensitive perspective. And with those misguided interventions, we would no doubt see more symptoms of PTSD in Michael, and end up using restraints more. We realize that it is regrettable that we have not come up in every case with interventions to avoid holds and other restrictive procedures that may be retraumatizing, and we are always thinking about that. We regularly perform debriefing with staff and try to learn from our experiences- and hopefully our plan for Michael reflects the thoughtfulness of this ongoing process.

CHAPTER 4

Developing A Trauma/Resilience Informed Guiding Philosophy for Yourself and Your Agency

Application of the Restorative Integral Support Model to ACEs and Adult Trauma in People with IDD

The Restorative Integral Support (RIS) model was developed for social service agencies helping high ACE Score populations experiencing multiple problems. How RIS applies to the subject matter of this toolkit rests in its holistic approach, or meta-theoretical framework; the framework, when applied, ensures that providers and agency leaders touch on all the important aspects of the complex set of problems encountered in the IDD field. Larkin, Beckos, and Shields (2012) have noted that RIS acknowledges the role of early-life adversity, including developmental impact, to mobilize resilience and recovery efforts. The principle idea behind the RIS model is to develop a culture of recovery that fosters social connections. Building a culture of recovery in the work we do with people with IDD requires an enhanced focus on individual strength and resilience, empowering people we serve, maximizing their self-determination, enhancing their autonomy, and fostering their healing through community integration (Jacobson & Greenley 2001). Social affiliation shapes healthy interdependence on others-especially peers, strengthening individuals through inclusion and group connectedness. We know that many people with IDD and trauma histories struggle with these types of connections and need our support. Within social affiliations, people gain resources and opportunities to maximize personal efficacy (Zlotnick, Tam, & Robertson, 2003).

Note. The following section was adapted, with permission, from:
http://aceresponse.org/get_help/Restoratative_Integral_Support_RIS__54_pg.htm

Integral Theory (Wilber, 2000) offers a comprehensive map, useful in considering various dimensions of complex social problems faced in the 21st century. Restorative Integral Support (RIS) applies Integral theory for a flexible, holistic model that brings attention to the way in which leadership, service systems, and collective contexts work together to build resilience and promote recovery from ACEs (Larkin & Records, 2007, 2011).

RIS applies the All Quadrants All Levels (AQAL) framework from Integral theory to human services. Basically, AQAL is a conceptual tool that helps map out the "whole picture" of any given problem. The framework consists of four distinct yet interconnected quadrants (see the graphics below).

The Four Quadrant Model of Restorative Integral Support

INDIVIDUAL

I **N** **T** **E** **R** **N** **A** **L**	**I** **IT** **WE** **ITS**	**E** **X** **T** **E** **R** **N** **A** **L**

GROUP
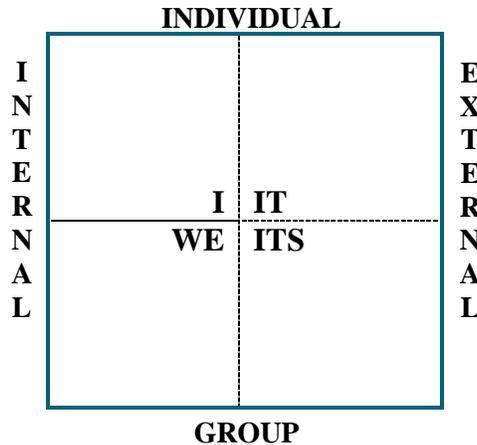
For our purpose this model is more easily accessible by considering the quadrants filled in as shown in the table below (items relevant to IDD services are listed as examples to clarify considerations that could go in each quadrant):

• Feelings • Strengths • Passions • Hopes • Dreams	• Behavioral supports • Physical supports • Job training • Personalized goal planning
• Community values • Social networks • Group treatment modalities • Social support between staff	• Policies and procedures of an agency • Government regulations • Committees that serve the system

The upper quadrants represent the individual level of thoughts and behaviors (**"I"** and **"IT"**), while the lower represent the collective level of communities and systems (**"WE"** and **"ITS").** Reference will be made to this model at various points in this chapter. For a more detailed discussion on the RIS model and its application to trauma-informed care, the reader is referred to:

http://www.posttraumawellness.net/files/9313/5941/5125/RestorativeIntegralSupportCPTW.pdf

The above referenced website contains a great deal of useful information, with regard to other links, and a discussion about evidence supported intervention and emerging

practices. As our focus in this document is on work with people with IDD we have kept our focus spotlighted on that, but much can be gleaned and applied from approaches that have more general application.

Things we can do within a systemic perspective are briefly reviewed below; this section applies the RIS model to the field of IDD and trauma/recovery:

We can raise staff awareness of ACE Score characteristics among those served. The first chapter of this toolkit contains information that can be shared in regular training with staff. A PowerPoint training covering this information and more is available at acesconnection.org, and you are welcome to use that. Make it your practice to ensure that all staff are trained to understand how the people they serve are impacted by trauma, and what they can do about it..

Draw upon knowledge of resilience and recovery to inform ACE response. Ensure that your Human Rights Committee (or equivalent committee that reviews behavioral interventions) is trained and reads intervention plans with an eye toward best practice with regard to trauma. Chapter 3 of this document discusses how trauma/resilience informed planning is critical to recovery.

Set a compassionate example and offer self-care support for staff who provide relationship-building and role modeling for the individuals they serve, to create a culture of recovery through safety, empowerment, and connection with others.

Involve staff to clarify the values and principles behind trauma/resilience-informed programs.

Implement policies that facilitate a recovery-oriented system and culture. For example, at the Center for Disability Services (CFDS), one of our sites serves people with difficult behavioral problems. When we regrettably use restrictive interventions, we acknowledge that these can be retraumatizing for both individuals we serve and staff. We provide debriefing sessions to discuss what happened and try our best to foster an atmosphere of understanding and growth. Without this, staff are reluctant to speak up for fear of being blamed.

Ensure that the support plans staff are asked to follow are understandable and written with their input. At the CFDS we have recently revised our template for behavioral intervention which is based on long standing evidence based behavioral approaches and new understandings of how trauma related issues must be taken into account- and what staff has to do in various circumstances is made as clear as possible.

Support staff training in evidence based approaches. At CFDS, for example, we brought in an expert on evidence based group treatment for people with IDD and a trauma history. Dr. Dan Tomasulo spent two days with our staff and others from agencies around the state, offering us insights into applications of positive psychology for self-care in addition to discussing the evidence based treatment model he co-developed called Interactive Behavioral Therapy (Razza and Tomasulo, 2005).

Engage the community, tapping local resources while addressing local needs. The participation of the authors of this Toolkit in our local group *Healing Environments and Relationships that Support* (HEARTS) is an example of supported group connectedness. The HEARTS initiative under the leadership of Heather Larkin, Ph.D., of the University at Albany, has made it possible for local agencies to band together in common cause. Support

of systemic movements in your area will make a difference. The HEARTS initiative made it possible for us to participate in the MARC grant, hence making it possible for development of this toolkit and many other initiatives in the region. The graphic at the end of this chapter shows how wide ranging and diverse this group is in the Capital District of New York State (insert current graphic).

Dr. Heather Larkin presented at a three day workshop in Washington State in 2011. There she asked participants a number of exercises designed to foster "Restorative Integral Thinking" to ensure thoughtful and comprehensive responding to the problem of ACEs, trauma, and recovery. The Substance Abuse and Mental Health Administration has subsequently turned these exercises into a handout. Dr. Larkin has graciously agreed to share these questions for this toolkit.   We encourage key personnel at agencies serving people with IDD to take the time to go through a process of answering questions designed to ensure they are looking at the full picture in terms of ACE/Trauma response. Going through this process will serve a number of functions for you and your agency, and should help you discover what your next steps will be. **See Appendix 4 for RIS Exercises.**

Conclusion

Adverse Childhood Experiences, are a societal problem, with momentum building in the United States and around the world. The Fourth Annual Symposium on ACES, hosted by the LaSalle Institute in Albany and the University at Albany, drew over 900 people on May 5, 2017-one day prior to the writing of this conclusion. This incredible turn out was facilitated by HEARTS, the local movement addressing ACES, and the recent grant supporting that effort, awarded by the Robert Wood Johnson Foundation's grant (MARC). In the field of Intellectual and Developmental Disabilities, we know that the risks of adverse experiences for this vulnerable population are at least three to four times greater than the risks the general population faces.

We have identified wellness and resilience in caregivers to be one important focus and have outlined many practices to help staff and potentially family members cope, and offer quality connections. We know these connections reduce risk of future trauma for them and those they provide care for. We also know that these connections foster recovery from past trauma.

In the field of IDD there has long been a practice of designing behavioral intervention plans, which we call therapeutic support plans (TSPs), to emphasize support rather than control. We have included a sample plan and examples of everyday approaches. With awareness of trauma or possible trauma histories, and a focus on happiness, resilience, and wellbeing, we join with others in our field in joining with the ACE-aware communities working with other populations. Plans that offer hope and connectedness are a key tool for our toolbox.

Restorative Integral Support (RIS) offers a model to help us look at the work with doing from all conceivable perspectives. By achieving this type of understanding of what we are doing, we offer a framework for developing philosophy and developing policies that are resilience informed.

A sturdy, resilient building requires careful planning and systemic understandings. The lives we serve through our care, but also our careful planning and development of effective systems, likewise require much thoughtful planning, and constant review. We hope you use all aspects of this toolkit, to facilitate your work in the endeavor of enhancing the lives of people we serve.

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# Appendix 1

Exercises from Chapter 1

Exercise 1

Case Example

Amy is a 28-year-old direct support professional working in a group home for people with mild to moderate intellectual disabilities (ID). She's been working in the field for 3 years and has always said how much she loves her work. She considers her workload "doable" and has always gotten along well with coworkers and management. Amy has an ACE score of 6, a busy home life, and doesn't do much to take care of herself.

Amy has always put her all into helping the individuals under her care but lately she's been feeling drained. Following an episode at work when an individual physically attacked her, Amy has started avoiding the individual. She's also feeling more on edge at work and easily gets irritated when an individual asks her for something. Overall, she feels numb, wonders if she just doesn't care anymore.

Reflection Questions

1. What stress-related condition is Amy most likely experiencing?
2. What could Amy do to overcome the stress in her life and restore satisfaction with the work she does?
3. How might knowledge of her own ACE score be helpful in restoring satisfaction with her work?

Exercise 2   Check Your Batteries

Is it time to recharge *your* batteries? The batteries illustrated below each show a different level of battery power. Think of these as visual indicators of your own energy levels, or "battery power," throughout the day. You might be at full battery power at the start of your day but by the end, or after a series of stressful events, you might feel that energy dip down. So, be aware and know when it's time to call a timeout and take a breather.
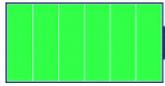
Feeling positive and full of energy.
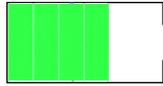
Feeling all right, just a little tired and getting slightly irritated about things.
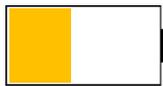
Feeling drained, having a hard time concentrating, finding little things more irritating than usual.

Feeling exhausted, can't concentrate, snapping at people, STRESSED OUT!

Fill in the batteries below, according to the above images, to track your own energy levels throughout your day and think about what you're doing to help yourself recharge:

Morning	Noon	Afternoon	Evening

Exercise 3 **Self-Assessment Tool: Self-Care**

The following is a checklist of self-care activities. You can use this as a self-reflection tool to help keep track of all the ways you take care of yourself.

How often do you do the following? (Rate, using the scale below):
5 = Frequently   4 = Sometimes   3 = Rarely   2 = Never   1 = It never even occurred to me

Physical Self-Care
☐Eat regularly (e.g. breakfast & lunch)
☐Eat healthfully
☐Exercise, or go to the gym
☐Lift weights
☐Practice martial arts
☐Get regular medical care for prevention
☐Get medical care when needed
☐Take time off when you're sick
☐Get massages or other body work
☐Do physical activity that is fun for you
☐Take time to be sexual
☐Get enough sleep
☐Wear clothes you like
☐Take vacations
☐Take day trips, or mini-vacations
☐Get away from stressful technology such as pagers, faxes, telephones, e-mail
☐Other:_____

Psychological Self-Care
☐Make time for self-reflection
☐Go to see a psychotherapist or counselor for yourself
☐Write in a journal
☐Read literature unrelated to work
☐Do something at which you are a beginner
☐Take a step to decrease stress in your life

☐Notice your inner experience—your dreams, thoughts, imagery, feelings
☐Take a step to decrease stress in your life aspects of you
☐Engage your intelligence in a new area—go to an art museum, performance, sports event, exhibit, or other cultural event
☐Practice receiving from others
☐Be curious
☐Say no to extra responsibilities sometimes
☐Spend time outdoors
☐Other:_____

Emotional Self-Care
☐Spend time with others whose company you enjoy
☐Stay in contact with important people in your life
☐Treat yourself kindly (supportive inner dialogue or self-talk)
☐Feel proud of yourself
☐Reread favorite books, review favorite movies
☐Identify and seek out comforting activities, objects, people, relationships, places
☐Allow yourself to cry
☐Find things that make you laugh
☐Express your outrage in a constructive way
☐Play with children
☐Other:_____

Exercise 3   **Self-Assessment Tool: Self-Care**   (*Continued*)

Spiritual Self-Care	**Workplace/Professional Self-Care**
☐Make time for prayer, meditation, reflection	☐Take time to eat lunch
☐Spend time in nature	☐Take time to chat with co-workers
☐Participate in a spiritual gathering, community or group	☐Make time to complete tasks
☐Be open to inspiration	☐Identity projects or tasks that are exciting, growth-promoting, and rewarding for you
☐Cherish your optimism and hope	☐Set limits with clients and colleagues
☐Be aware of nontangible (nonmaterial) aspects of life	☐Bce your caseload so no one day is "too much!"
☐Be open to mystery, to not knowing	☐Arrange your workspace so it is comfortable and comforting
☐Identify what is meaningful to you and notice its place in your life	☐Get regular supervision or consultation
☐Sing	☐Negotiate for your needs
☐Express gratitude	☐Have a peer support group
☐Celebrate milestones with rituals that are meaningful to you	☐Other:_____
☐Remember and memorialize loved ones who have died	
☐Nurture others	
☐Have awe-full experiences	
☐Contribute to or participate in causes you believe in	
☐Read inspirational literature	
☐Listen to inspiring music	
☐Other:_____	

Reflection Questions

1. Are there any areas of self-care you tend to focus on more than others?
2. Is there any one self-care area (physical, psychological, spiritual) that you could maybe work on more?
3. What's your plan for taking care of you?

Use this triangle to break down a situation at work that made you feel annoyed, frustrated, or upset (this could be a disagreement you had with a coworker or a particularly difficult interaction with a person under your care). What happened? What did you feel like when this happened? What thoughts were running through your head? What did you do?:

_____
_____

Feeling

What Happened

_____
_____
_____

Thinking   **Doing**

_____   _____
_____   _____
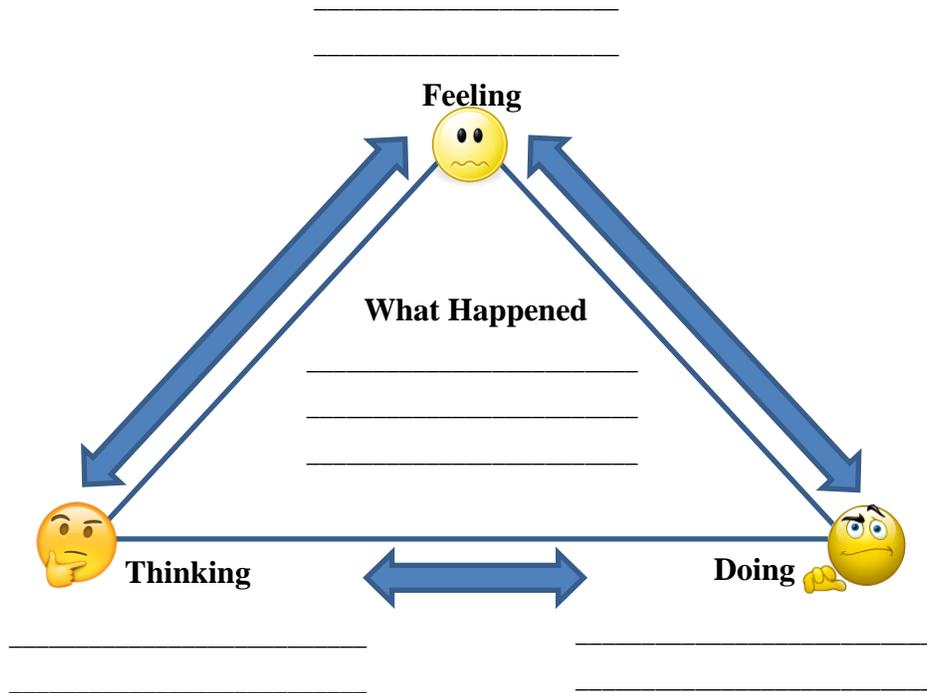
Reflection Questions

1. How did your thoughts influence how you felt in the situation you identified?
2. How did your feelings influence your actions?
3. What could you have done differently to improve the outcome of this situation?

Exercise 5: Problem solving- Use the problem solving steps from Chapter 1 to solve a work related problem.

1. Identify the problem.

The Problem Solving Loop

5. Evaluate the results.

2. Explore information and create ideas.

4. Build and test the idea.

3. Select the best idea.
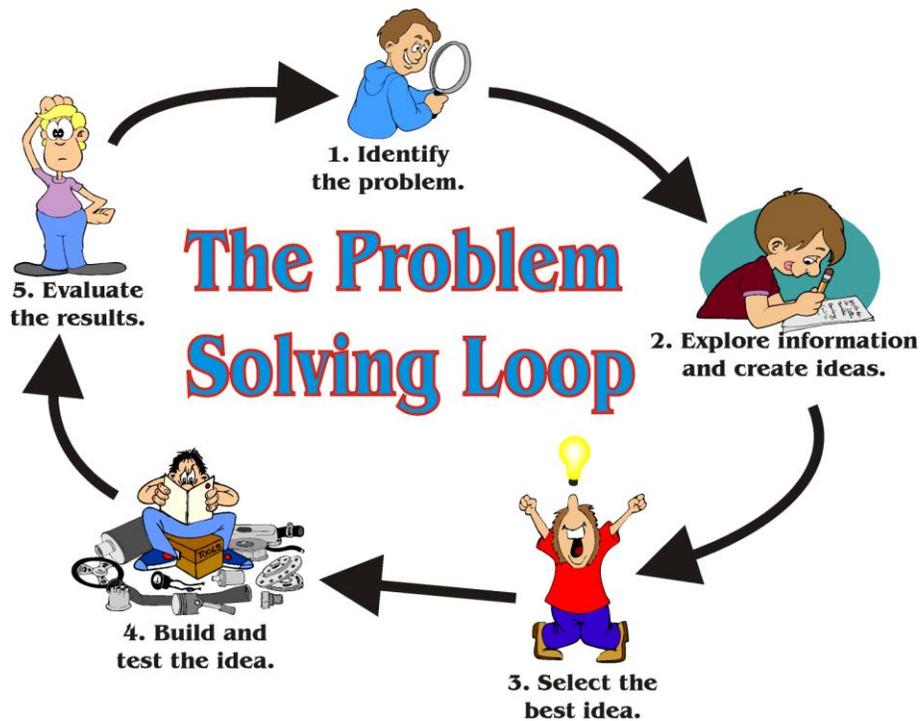
What is the problem:
List possible solutions:
Choose the one you think most likely to work and try it:
How did it work?
If more problem solving is needed repeat the cycle with a new possible solution?

Reflection Questions

1. Could you turn to coworkers or supervisors to gain support in working through this problem? If so, how would you reach out to coworkers, what would you say to them, and how could you work together?
2. Can you think of a time when you used the wrong strategy to solve a problem at work? What happened in the aftermath and what could you have done differently?

Exercise 6 **Cartoon Voices** (adapted from J. Harrison, personal communication, April 15, 2016)

Negative self talk—"I'm not good enough" or "I can't do this"— can hold you back from achieving true happiness in life. But you're not a helpless victim to your own mind. You may not always have the power to stop negative thoughts dead in their tracks, but you do have the power to change how you process these thoughts. This exercise shows you a way to cope with unhelpful self talk by asking you to actually repeat negative self talk to yourself in a cartoon voice or in the weirdest, most ridiculous sounding voice you can come up with.

1. Start by thinking up some unhelpful thought about yourself, like "I'm dumb" or "I can't do anything right!" and write it down in the space below

   Unhelpful thought:

   _____

2. Then, reflect on how the thought you wrote down makes you feel—sad, scared, angry— and any bodily sensations it brings up

3. Think of a whacky, ridiculous sounding voice (this could be the voice of a cartoon character or something you make up yourself—just make sure it's weird!)

4. Now close your eyes and experience the unhelpful thought you chose for a few moments but hear it again in the silly cartoon voice that you made up

5. Open your eyes and look at the written unhelpful thought and notice how you feel now.

Reflection Questions

1. How did you the unhelpful thought make you feel before you did the exercise?
2. How did you feel after you told yourself the unhelpful thought in a cartoon voice?
3. How might you apply this technique while at work? (discuss in groups)

Exercise 7

THOUGHTS ON A SCREEN (adapted from J. Harrison, personal
communication, April 15, 2016)
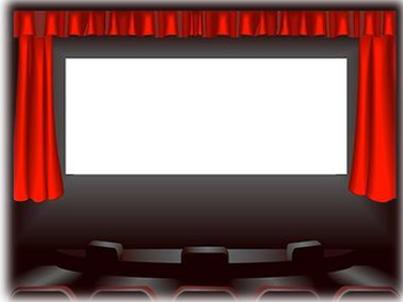
The point of this exercise is to let go of your feelings and just look at your thoughts as they are. Imagine yourself as a moviegoer at the local cinema, just sitting back, relaxing, and watching the motion picture of your own thoughts go by from scene to scene. Remember, you're not the film director; you're just the moviegoer for now, so no sense in trying to rewrite the script…

- Please start by closing your eyes and getting in touch with sensations in your body, feet, hands and stomach.

- Take the perspective of a moviegoer observing your thoughts on the "big screen." Practice watching your thoughts as they arise, as if they are being projected onto a blank screen of your awareness.

- Some thoughts will appear as words, others as images, some clear, some vague.

- No need to try and control any of your thoughts, just sit back and notice what your mind provides you with. The aim is just to catch a glimpse of your thoughts as they come and go in your awareness.

- Sometimes you will be sucked into your thinking and be pulled away from the perspective of observer. When that happens, just take a second to acknowledge what has happened then notice the next thought being projected on your screen.

- You may find you drift off in thoughts quite often—that's fine. As soon as you've noticed you have drifted off, reassume the role of an observer, aware of your thoughts coming and going.

- Just catch a glimpse of the thoughts as scenes coming and going in your awareness.

Reflection Questions

1. How did you feel during this exercise?
2. Did you have any nagging or unhelpful thoughts? If so, were you able to let them go? (if not, don't worry, that's perfectly normal—just keep at it!)
3. How might you apply what you've learned from this exercise to a challenging situation at work?

Exercise 8   **Three Funny Things**

What makes you laugh? Laughing can be stress relieving, and there's quite a bit of research out there to back it up (Craun & Bourke, 2014). For this exercise, list three funny things you can remember that made you laugh out loud. This could be a moment you shared with a co-worker, friend, a person under your care, or even a time when you laughed at yourself. Try to avoid listing instances of insulting or teasing humor and focus instead on good-natured humor.

1. _____
   _____

2. _____
   _____

3. _____
   _____

If you're in a group and feel comfortable sharing, tell the group the funniest thing you wrote down (make sure of course that it's work appropriate).

Reflection Questions

1. Have you ever shared a good laugh with co-workers? If so, how did everyone's attitude change afterwards? (discuss in groups)
2. Is humor common in your workplace? If not, think of some ways to lighten the mood a little and get people to at least crack a smile. (discuss in groups)

Exercise 9	Mindful Living

Most of us need to do chores at some point or other. They're not always exciting but, hey, they need to get done. So, why not bring a little mindfulness to them? This exercise involves focusing your attention on everyday tasks like doing the dishes, folding laundry, vacuuming the floor, or doing yard work. You can do this simple exercise at home, at work, or pretty much anywhere you see fit. All you have to do is be in the moment using your senses to pay full attention to the task at hand.

- If you're washing dishes, notice the gentle touch of the warm running water falling on your hands, feel the textures of each dish run under your fingertips, and be aware of the aroma of the soap. Take in all appropriate aspects of the experience. If your mind wanders, just focus on your breathing, then return to the task at hand and just be present.

- If you're folding laundry, notice the textures of the fresh linen brushing under your fingertips, be aware of the movements of each of your hands as you fold each individual item, pay attention to the colors of the linen and its fresh smell. Take in all appropriate aspects of the experience. If your mind wanders, just focus on your breathing, then return to the task at hand and just be present.

You get the idea: almost any task can be turned mindful. It just takes a little concentration and a slight shift of awareness to the present moment. So, the next time you're stuck doing the boring old dishes give this a try. What do you have to lose?

Reflection Questions

1. How did you feel before vs. after doing this activity?
2. Is this something you think you could easily do at work, or maybe at home? (discuss in groups)

| Activity 10	Mindfulness Before Work

Think about what you do right after you get up on an average work day. How much time do you give yourself before going to work? Do you wake up with plenty of time to take care of things before you go, or do you leave in a rush, with little or no time to spare? There's no judgment here, no right or wrong answers, just be honest with yourself. Just be mindful of the thoughts and feelings that come up and, without force, let them just roll on by.

This exercise asks you to be mindfully aware of your early pre-work routine and invites you to add something that may be a little new to it…nothing major, really, just a slight shift in perspective that you could find helpful. For now, you can imagine this scene which takes place in the morning, but going forward, it could become part of your daily routine.

- The alarm goes off and you open your eyes to the world around you

- Find a safe, quiet place where you feel at ease, with as few distractions as possible (this could be the place where you sleep, in your car, or outside somewhere)

- When you find the right place that works for you, take a seat somewhere, anywhere—a chair, a bed, the floor, even the toilet (after all, this may be the only place where you can actually get a little peace and quiet)

- Close your eyes and just sit in silence for a few seconds. Be aware of any thoughts or feelings that come up at this time and relax, letting go of any tension in your body

- Now take a **deep**, slow breath in, counting as you inhale…**1…2…3…4...5…**then, hold your breath and count….

- **1…2…3…4…5…**and slowly breathe out, counting on the out breath….

- **1…2…3…4…5…**until all the air is out of your lungs

- Now keep your eyes closed and just breathe normally for 5 minutes…Your mind will wander, that's natural and normal

- Notice each breath you take, notice how it feels when the air fills your lungs and then releases

- When you're ready, open your eyes and just remain seated where you are for a few seconds before getting up and starting your day

Reflection Questions

1. How did you feel during and after this exercise?
2. How might this deep breathing exercise help you at work?
3. Is there a place at work where you could do this exercise to recharge? If so, identify a location for yourself. (discuss in groups)

Exercise 11	Body Scan
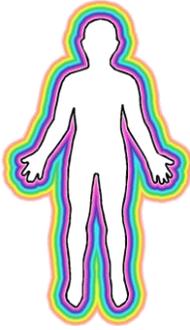
This exercise is a relaxation technique called progressive muscle relaxation. It involves tensing and relaxing different muscles in your body while drawing your awareness to those areas of your body (hence, "body scan"). Practicing this technique is not only a nice way to relax, it can also make your mind become more flexible and concentrated at the same time. This can be an especially useful method of getting your mind "unstuck" when, for example, you face chronic pain and you can't get your mind off of the pain. For now, though, just breathe and relax…

- Begin by sitting or lying down on your back, face up in a comfortable position. Feel free to change positions at any point through the exercise if you need to

- Now, breathe in deeply 1…2…3…4…hold it 1…2…3…4…and breathe out slowly, letting all the air out as you release tension [*repeat this 2 more times*]

- Bring mental awareness down to your feet, to the left and then to the right, then both together

- Tense all the muscles of your feet while breathing in and slowly breathe out as you release tension—notice how you relax

- Move awareness to your lower leg muscles, to the left and then to the right, then both together

- Tense all of your lower leg muscles while breathing in and then slowly breathe out as you release the tension—notice how you relax

- Now, place your awareness to the muscles of your upper legs, to the left leg then the right, and then both together

- Tense all of your upper leg muscles while you breathe in, hold breath, and then slowly breathe out, releasing all the tension—notice how you relax

- Repeat with torso, shoulders and chest muscles, neck, head, face, arms, and hands

- When finished, just stay relaxed where you are for a moment in the silence, with your breath…in…and…out…

Reflection Questions

1. How did you feel during and after the body scan exercise?
2. Which of the self-care practice areas (mental, physical, emotional, spiritual, work) would this exercise fall under?
3. Would you make this exercise part of your self-care practice? Why/why not?

Exercise 12 Where's my head at? (adapted from J. Harrison, personal communication, April15, 2016)

If done in a group, you will introduce your partner to the group after you have discussed the activity with your partner.

Please share the following information:
- Your first name
- What job you do and the department you currently work in
- **One activity** you personally perform while on "**autopilot**"- without being very aware of what you are doing as you are doing it.
- **One activity** you personally perform with more **psychological awareness**- activities that give you a sense of being more " in the moment"

| Automatic pilot | | Focusing on what is happening in the moment |
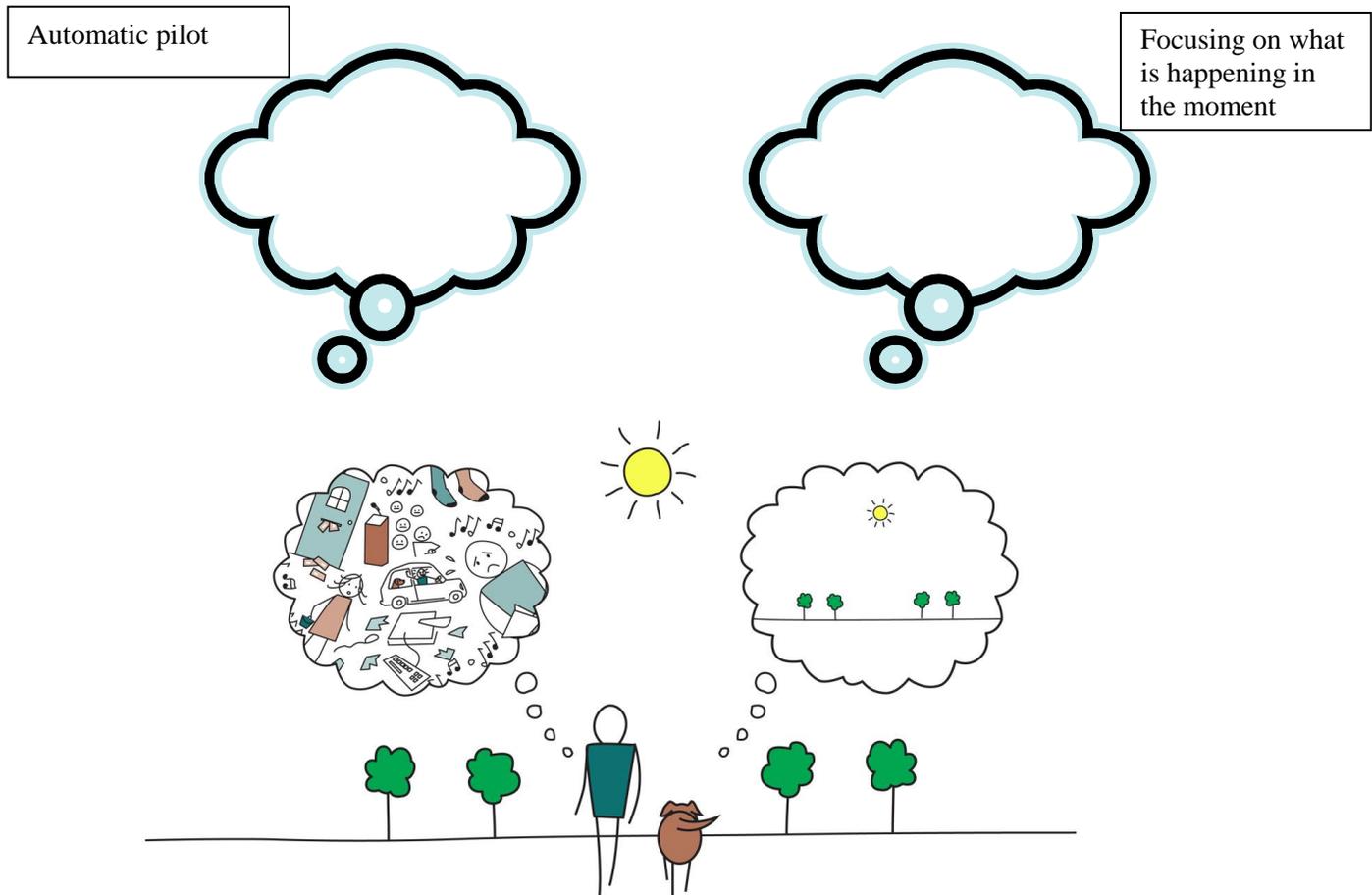
Mind Full, or Mindful?

Exercise 13: Recognizing the challenge (adapted from J. Harrison, personal communication, April15, 2016)

➧ Part I: Break into pairs and think about what you bring as individuals to your relationships with your folks (we're talking about your positive personal qualities (*not* things like training and experience); don't be shy about taking credit.   Items transferred to flip chart

➧ Part II: Whole group- Get people to shout out challenging behaviors and other aspects of their job they've had to face, and write them down on a flip chart next to the Part I flip chart. They should list every aspect of challenging situations. Then read back your ad to be placed in on a job-hunting site: We are looking for staff with the following qualities (insert Part I qualities) to work with people who will (insert challenges) finish with We are committed to maintaining a good work life balance and the successful applicant should have a clean driving record.

<div align="center">

Appendix 2

Template for Therapeutic Support Plans at

Center for Disability Services

</div>

Name:	Plan Start/Renewal Date:
Date of Birth:	Semi-annual review due:
Residence:	Next Renewal Date:
Day Program:	

<div align="center">

Part I: Supports & Interventions

</div>

Plan Formulation: This current therapeutic support plan was revised based on updated functional assessment information, in consultation with staff at residence on: and day program on: , and with (name) on:

Purpose for the Plan:

Requires Human Rights Committee (HRC) Review:

☐ Physical   ☐ Rights   ☐ Time-out   ☐ Mechanical   ☐ Medication   ☐ Other
Intervention   Limitation(s)   Restraint

Does NOT Require HRC Review/Medication Monitoring:
☐ "Protective" Physical   ☐ Medication for Co-Occurring Psychiatric Condition   ☐ Best Practice
Intervention

The current plan includes:
- ❖ General Everyday/Proactive Approaches
- ❖ Specific Interventions when encountering:
  - ➢ (Behavior/Symptom)
  - ➢ (Behavior/Symptom)
  - ➢ (Behavior/Symptom)

This plan also includes the following attachments:
  - ➢ PRN Protocol for:
  - ➢ Mechanical Restraint protocol, for:
  - ➢ Psychiatry Consult (last page with medication list/diagnosis)

Documentation:

Data regarding _____ will be documented on charts located at the residence and day program.
  - ➢ Updated Behavior/Symptom Documentation Sheet
  - ➢ Sleep Chart?
  - ➢ Other?

Medication to treat: __; *as of _____ consult; please refer to most recent consult for any changes to diagnosis.* Additional psychiatric conditions include: . Provider:

General Everyday/Proactive Approaches
(If a rights restriction is included here, its use needs to be justified by the FA and there should be a corresponding plan to teach an alternative/plan to eliminate its need in FA section)

Guidance for Developing
General Everyday/Proactive Approaches (use items that apply):

Orientation:
➢ What practices should be put in place at specific times to help the person with orientation
➢ Presets that will be helpful for specific activities
➢ Specific orientation practices for people with Traumatic Brain Injury or Dementia
➢ Structure and routine to allow for the highest level of independence

Choice:
➢ What types of choices should be encouraged for the person
➢ What choices should not be interfered with even if inconvenient (e.g. leaving for a break or to walk around the building when the person may feel unsafe)

Likes:
➢ What the person likes to do and how this can incorporated into their life more.
➢ What the person likes to talk about and how this can be incorporated into their life more.

Communication:
➢ What staff can do to communicate most clearly (e.g., giving the person adequate time if they process information slowly)
➢ What augmentative communication tools or devices should be used

Safety:
➢ What is required to maintain the persons' safety and prevent injury (also see trauma response prevention)

Independence:
➢ What can we do to promote independence
➢ When and how to offer choices to empower the person
➢ How to involve the person in making informed decisions

Happiness Procedure*
➢ What staff should do to assist the person to gain pleasure
➢ How staff should support the person in seeking engagement in activity
➢ How staff should assist fostering relationships and coaching social skills
➢ What achievements staff should help the person to acknowledge
➢ How staff should support activities that enhance meaning (such as arranging visits with a beloved grandparent)

Trauma Response Prevention* (Emotional Support)
  ➢ List of known triggers and how to prepare or address
  ➢ List of known difficult anniversaries and how to prepare or address
  ➢ List of people whom the person is connected to positively and how they can help
  ➢ List of factors required for this individual to feel/be safe

Positive Identity Development*
  ➢ Roles that are positive and important to this person
  ➢ Ways in which staff need to facilitate the development of self-esteem (including listening procedures)
  ➢ Ways in which staff need to facilitate the development of positive peer relations/relationships

*From: Harvey, K. (2012). *Trauma-informed behavioral interventions.* Washington D.C., American Association on Intellectual and Developmental Disabilities

TARGET 1 (MAY BE A BEHAVIOR OR EMOTIONAL STATE LIKE DEPRESSION)	
How it presents	
Times when most likely to occur	
Times when least likely to occur	
New Skills to Develop	

When this occurs,	Provide the following supports:
(Environmental trigger/times when most likely to occur)	(Specific prevention for targeted setting event/antecedent)
(When displaying positive coping skill)	(Reinforcement strategy to support development of new skill)
(Target behavior)	(ways to teach new coping skill/redirection etc)
(Target behavior)	(de-escalation strategies)
If (target behavior) continues,	(emergency procedures)
(Mechanical restraint) used:	➢ See protocol for time limits & required documentation
(Restrictive Physical Intervention) is used,	➢ (Time limit & Supervisory Notification) ➢ Follow RIA reporting Procedures
Additional interventions used to maintain safety for this person or others:	➢ Complete Agency Events Form to document additional physical techniques ➢ Temporary Postponement of Community Activity Form if a planned activity is postponed

Use the same format for additional target behaviors or emotional states.

Part II: Functional Assessment Summary/Update & Justification for Restrictive and Intrusive Interventions

Name:	Date of Birth:
Residence:	Day Program:

Based on data obtained through:

___ Direct Observations:

___ Interview with:

___ Review of available clinical, medical, environmental or other data

___ Use of assessment tool (e.g., Motivation Assessment Scale):

_____

Background Information/Contextual Factors:

Age

Level of cog functioning

Residential history – including any Willowbrook history

Past vs Current functioning

Any elimination of previous concerns or restrictive interventions

Any rationale on why person was not involved in plan development

<table>
<tr><td colspan="2" align="center"><u>PRESENTING SYMPTOM/BEHAVIOR FOR TARGET 1</u></td></tr>
<tr><td colspan="2" align="center">(description in observable and measurable terms/matches header on intervention pages)</td></tr>
<tr><td align="right">History:</td><td>Include severity of symptom/behavior(previous and current) to provide clinical justification of any restrictive techniques (rights restriction, mechanical, physical restraint).</td></tr>
<tr><td align="right">Contextual Factors/ Background information:</td><td>Cognitive, environmental, social, physical, medical and/or psychiatric conditions, that create or may contribute to the symptom/behavior</td></tr>
<tr><td align="right">Antecedent Events:</td><td>What triggers the presenting symptom/behavior?</td></tr>
<tr><td align="right">Hypothesized Function:</td><td>Why is the symptom/behavior occurring (what need is this filling for the person)? Should guide intervention strategies</td></tr>
<tr><td align="right">Conditions that maintain symptom/behavior:</td><td>What maintains the presenting symptom/behavior?</td></tr>
<tr><td align="right">Conditions that reduce the frequency:</td><td>This would guide preventative strategies. Examples: structured schedule, approach, sleep, consistent medication compliance, etc</td></tr>
<tr><td align="right">Baseline data:</td><td>Frequency, duration, intensity and/or latency across settings, activities, people, and times of day</td></tr>
</table>

There are no restrictive interventions associated with ___.
Or:
Justification for Intrusive Intervention/Rights Restriction:
_____

Why is this intervention needed?	
Why was this intervention selected over less restrictive options? (Describe other interventions tried that were not sufficiently successful)	
How often was this intervention used in the past 12 month period?	
What is the specific plan to reduce/fade/eliminate the intervention?	Intermittent use: The preventative, teaching of replacement skills, and de-escalation strategies outlined in the plan are specific to the person, based on functional analysis, and intended to reduce the frequency of use of this restrictive intervention. If the intervention has not been used in the previous 12 month period, it will be removed from the plan and no longer approved for use. Continued use: (fading plan must be specific to the person, a step-wise, gradual process with criteria for reversal, and criteria for completion) Medication: Reduction/elimination of medication will be discussed at least quarterly with the clinical team and at least 2x/year with the prescriber, including review of functioning through use of less restrictive methods, onset of adverse side effects, and determination to ensure that reduction/elimination would not be detrimental to functioning.

Areas in Need of Follow-up:
- ➤ **Psychiatry?**
- ➤ **Program Goals?**

Review:
- ➤ Documentation (including frequency, duration, and intensity of symptom/behavior and interventions used) and any necessary training will be reviewed at least semi-annually by the clinical team.
- ➤ Modifications of the plan will be made as needed by the clinician and the clinical team, at least annually.

Revised, with clinical team input, by:

_____

Residential Clinician, Credential

Administrator:

_____

Administrator of Residential Services

_____

(Person plan is written to support)
* Signature reflects participation in plan development. Informed consent is captured in another format.

Supervising Licensed Clinician:

_____

Day Program Clinician

Administrator:

_____

Director of Day Program Services

Supervising Licensed Clinician:

_____

Licensed Psychologist/Licensed Clinical Social Worker

Appendix 3

Examples of Proactive Everyday Approaches
Contained in CFDS Plans

Example 1:

Communication:

- Alan values his independence. It is important to respect Alan's choices, even if you disagree with them.
- Utilize Active Listening. This includes making eye contact with Alan, turning your body toward Alan so he knows that you are listening to him, and repeat back and summarize what you have heard to check for mutual understanding.
- All agreements made with Alan should be clear and specific. Whenever possible, have the information written down (such as on the calendar) for Alan to reference independently.
- When there is a need to prompt or redirect Alan, for example, getting his backpack ready, use the Sandwich approach
  - Start with a compliment/strength- *Alan, I heard that you were able to …….. I am proud of you.*
  - Provide the prompt- *It is almost 7:30, Why don't you start grabbing stuff you need for your bag?*
  - Finish with a positive remark- *You have been doing a great job remember all your things.*
- When Alan asks for something to be done, avoid saying "no" or "you can't." Address his request by first listening to his thoughts (*Tell me more about your thoughts*). Then involve him in problem solving (*One of the concerns I have is ……).*
- Alan will sometimes use humor/sarcasm to bring up a topic that is uncomfortable for him, often times in a self-deprecating manner. Help Alan clarify the feelings/thoughts he is trying to express.

Likes:

- Provide positive attention: Alan enjoys going to the movies, aquariums, festivals, and fairs. Engage Alan positively by planning fun outings with him and talking about things he enjoys.
- Support Alan in taking an active role in the residence in public space with things such as choosing music to play for his peers around meal time. Alan likes jazz and blues especially.

Independence:

- Help Alan to set up a routine or schedule that includes tasks that he is working on to become more independent (making his own lunch, laundry, cleaning his room, packing for each day). Having a routine reduces the amount of verbal prompts needed and decreases agitation.

Other:

- Alan continues to grieve for his Uncle Walt, whom he was very close to; Walt passed away in 2014. Alan will often bring up the subject during important events such as the holidays or when Alan is experiencing something he considers a significant event in his life. Validate his feelings of grief and encourage him to discuss with his clinician(s).
- Provide choices regularly throughout his day. Remind Alan of his goals and help motivate him.

Example 2:

Getting to know Carole:

- Carole appreciates a sense of humor and responds positively to an upbeat attitude.
- Topics of conversation that she enjoys include places she enjoys going, shopping, food, her friends, and tennis matches on TV.
- Carole really enjoys her friendships including those with people who don't reside with her. She enjoys having these friends and talking about their activities together.

To promote healthy relationships with staff:
➢ Model good energy and a positive attitude when working with Carole.
➢ Encourage and engage her when she is calm and happy.
➢ Use a positive tone of voice.
➢ Use encouraging words with Carole when she completes a task without hesitation.
➢ Get physically down on her level and ask her to make eye contact with you.
➢ Provide an explanation as to why you are asking her to do something instead of just giving a command.
➢ Engage with Carole and provide opportunities for her to talk about her day.
➢ Be engaged by asking questioning and using reflective listening.
➢ Provide choices as often as possible and avoid power struggles.

To promote healthy relationships with her family:
➢ Address any concerns/expectations she may have (ie: brother being at home) prior to her visit.
➢ Encourage expression of feelings around interactions/conversations with her family.
➢ Use reflective listening and validation.
➢ Offer to accompany Carole on family visits to provide support.
➢
➢ Remind Carole of coping strategies when visiting family (calling staff to pick her up, making a decision to leave a stressful visit, saying NO to a visit).
➢ Remind Carole to have a charged cell phone when going on family visits.

Orientation to the mornings:
➢ When Carole's mental health is decompensating, it is helpful to use the following guidelines in the evening and the mornings to support Carole in getting to work.
➢ Be clear, direct, using a neutral tone of voice while being polite
➢ Focus on her accomplishments during the morning routine and use praise often
   o **Evening before:**
      ✓ Assist Carole in choosing clothing for the next day
      ✓ Make sure it is a complete outfit and is laid out the night before for her to easily reach
      ✓ Assist Carole in setting her alarm for 6:30am
      ✓ Make sure the volume is turned up to a level that she will be able to hear
      ✓ Make sure the alarm is set so the volume gradually increases
   o **Morning of:**
      ✓ Enter Carole's room at 6:35 a.m. and greet her with a friendly tone.
      ✓ Let her know that you are now going to turn on the light.
      ✓ Proceed to Carole's bedside and let her know that you are going to slowly pull down her covers and assist her in getting up out of bed.
      ✓ Assist Carole with putting on her glasses.
      ✓ Focus on the positive aspects of her upcoming day
      ✓ Remind Carole of the exact time.
      ✓ Give Carole a few minutes to process your request of waking up
      ✓ Do not pull her up and move her without her understanding and assisting.
      ✓ Once Carole has opened her eyes, continue to address her in what the next step is.
      ✓ Once awake, let her know you are ready to help her get in the tram to transfer.
      ✓ Proceed with bathroom/breakfast routine.

Appendix 4

Restorative Integral Support (RIS) Exercises

The following Restorative Integral Support (RIS) exercises are designed to help you clarify your purpose, consider your influence and supports through your current job, provide RIS guidance for ACE Response and help you evaluate RIS impacts. For each exercise you'll go on a journey around the RIS quadrant model referenced in Chapter 4, starting each time in the upper left quadrant (what you think and feel).

Exercise 1: Exploring your life's purpose
This first exercise is designed to explore and identify your life's purpose, with the expectation that carrying out your life's purpose contributes to a satisfying life and fulfillment of your goals.

What you think and feel
What has made you feel happy in the past? What brings you joy?
As you look at what is going on in the world, what breaks your heart?
As you look at what is going on in the world, what makes you feel good?
What are you passionate about?
What is your life's purpose?

Your actions
What skills help you carry out your purpose?
What new behaviors might you develop to carry out your purpose?
What physical supports do you need to carry out your purpose?

Community
Does carrying out your purpose involve social networks? How?
What relationships support you in carrying out your purpose? How might you develop or enhance networks with others who share your values and support your purpose? Who do you admire? What leaders set an example for carrying out your purpose?

Systemic/structural supports
How do you interact with others when carrying out your purpose?
What systems or structures facilitate your ability to carry out your life's purpose? Are there systemic obstacles to overcome?
How do systems influence and reflect your community?

Exercise 2: Expressing through your job
This second exercise is designed to explore how your purpose can be expressed through your job, as well as how your job role and work community supports you to carry out your purpose. Answering these questions may help you discover the alignment of your job with your purpose.

What you think and feel

How do you express your passion and purpose in your job?
What unique strengths, talents, perspective, and skills do you bring with you to carry out your job?

Your actions
What is your job description?
What activities are involved in carrying out your job?
What physical supports help you to do your job?

Community
What resources within your work community, or the larger community, support you in carrying out your job?
What social networks strengthen your ability to do your job well?
Who do you admire in your job? What do you admire about them?
How do you contribute to or strengthen social networks within your workplace and community?

Systemic/structural supports
How does your job fit within your agency structure?
How does your agency support your work? Are there any obstacles to overcome?
Do you interact with other service structures? Which systems? What activities are involved?
Are there other community agencies or service systems that support your work?
How is your job influenced by societal, community, or agency policies? What helps you do your job and how do you remove obstacles?

Exercise 3: Guidance for carrying out "Restorative Integral Support" (RISing)
This exercise is designed to help you in RISing to the challenge of ACE Response by identifying inner and outer resources for support.

What you think and feel
What is your awareness and understanding of ACE and related research?
What is your purpose in regard to ACE Response?
How do you feel about engaging in ACE Response?
What capacities and gifts do you bring to ACE Response?

Your actions
How do you lead? How can you set a compassionate example?
What actions can you take to raise awareness of ACE consequences and the potential for recovery?
What can you do to engage others in ACE Response?
What physical supports do you need to carry out these activities?

Community
Who is engaged in ACE Response with you? What social networks support the development of a culture of recovery?

What are some ways to expand your ACE Response community? What resources would support you and others contributing to healthy social networks?
How can you involve staff or community coalition members in clarifying values and principles behind your ACE Response initiative? What is your shared vision?
Who sets a leadership example for you? What is it about this person that you admire? How does this leadership support ACE Response?

Systemic/structural supports
Does your agency support RISing? What other systems support ACE Response? What are some ways to remove obstacles?
How might the media facilitate sharing of ACE Response knowledge?
How can systems be brought together for comprehensive ACE Response? What existing best practices in the local community can be brought together on-site?
What societal, community, and/or agency policies help develop a recovery-oriented system and culture? Are there policies that could be changed?

Exercise 4: Determining RIS Impacts
The following exercise explores ways to reveal different types of data regarding RIS impact.

What you think and feel
How passionate and engaged are you? What have you learned?
Has your own level of awareness changed in any way? How?
Are you fulfilling your purpose? If anything is missing, what is it?
What are signs of change in yourself and others?

Your actions
What short and long-term results did you expect from your actions?
For each activity you have engaged in, can you list apparent outcomes?
Have others provided feedback about your activities? What do they say?

Community
Please describe the community capacity that has developed for ACE Response? What social networks mobilize resilience and recovery?
Has a shared vision emerged among community groups? What processes were involved to clarify a vision and identify shared values and principles for ACE Response?
What are others saying about their participation in ACE Response? What resources have been important? How has the application of those resources led to a culture of recovery? What other group processes have been involved in RISing?

Systemic/structural
What kinds of inter-agency relationships have developed through ACE response? Is there evidence that services have been brought together around ACE Response?
In your agency and others, are there any changes in agency structures, agency interactions, or how services are delivered? Are policy changes evident?
What community outcomes are directly related to ACE Response activities?
Do you have a structure for evaluation or how can you create one? How might your ACE Response group develop research partnerships?