Addressing the Psychosocial Needs of Youth with Neurofibromatosis:  
A Family-Centered Approach to Fostering Self Regulation and Learned Optimism  
A Research Paper  
Presented to  
The Faculty of the Adler Graduate School  

In Partial Fulfillment of the Requirements for  
The Degree of Master of Arts in  
Adlerian Counseling and Psychotherapy  

By:  
Carol Elizabeth McCartan  
July 2011
Abstract

Neurofibromatosis Type 1 (NF1) is the most prevalent genetic disorder of the central and peripheral nervous systems, affecting about one in 3,500 people. It is a progressive, unpredictable, and variable disorder that has no known cure. In addition to physical and cognitive manifestations, studies also found children with NF1 tend to internalize problems and struggle socially. This paper examines factors that may contribute to social and emotional difficulty for adolescents with NF1 and offers suggestions for intervention.
Outline

Addressing the Psychosocial Needs of Youth with Neurofibromatosis:
A Family Centered Approach to Fostering Executive Self Regulation and Learned Optimism

Introduction

NF1: A Snapshot

Physical Manifestations

Neuropsychological profile

Intelligence

Learning and Executive Functions

Social-emotional profile

Psychosocial Needs of Youth

Executive Self Regulation

Social information processing

Social problem solving

Learned helplessness

Designing relevant support

Learned Optimism

Pennsylvania Resilience Program

Acceptance and Commitment Therapy

Considerations regarding Intervention

Why Teens with NF?

Why Parents of teens with NF?

Proposed Group Intervention
NF Teen Talk Program

Overview

Session #1-3 Acceptance and Commitment Training

Sessions #4,5 Resilience Training

Session #6 Review and Celebration

Parent Support Group

Overview

Session #1 Executive Self Regulation

Session #2-4 Acceptance and Commitment Training

Session #5 Learned Optimism

Session #6 Review and Celebration

Conclusion
FOSTERING SELF REGULATION

Addressing the Psychosocial needs of Youth with Neurofibromatosis Type 1:
A Family-Centered Approach to Fostering Executive Self-Regulation and Optimism

Neurofibromatosis impacts a child's social and emotional development in a myriad of ways and the relative contributions of biological and environmental variables toward overall psychosocial functioning are difficult to determine. A wide body of literature, however, has increasingly identified effective self-regulation and optimism as key contributors to success in social, educational, and vocational pursuits (Ylvisaker et al., 2002). The goal of this paper is to summarize, integrate, and introduce themes in literature on executive self-regulation, learned helplessness, Neurofibromatosis, and research-based interventions designed to facilitate psychosocial wellbeing in populations with similar needs.

NF1: A Snapshot

Neurofibromatosis is an umbrella term for three distinct genetic disorders: Neurofibromatosis type 1 (NF1), Neurofibromatosis Type 2 (NF2), and Schwannomatosis. The main manifestation shared by all three is the growth of tumors in the tissues that surround nerves. Although each disorder may carry similar psychosocial challenges, this paper focuses on literature related to the most prevalent of the three, NF1.

Physical Manifestations

The most prominent physical manifestations of NF-1 are neurofibromas (tumor growths along nerve sheaths), and multiple café-au-lait spots (patches of hyper-pigmentation). The tumors and café-au-lait spots can be highly visible and disfiguring in some cases, while barely detectable in others. Although NF1 varies in both degree and type of manifestation, individuals with NF-1 tend to be shorter in stature and may have a larger than typical head size. In addition, individuals with NF1 may encounter any number of the following issues: delays in motor
development, endocrine deficiencies, bone abnormalities, seizures, cardiovascular issues, and neurological impairments (Friedman, Gutmann, MacCollin, & Riccardi, 1999).

**Neuropsychological Profile**

Generally speaking, neuropsychological functioning addresses a combination of information related to the development of a child's intelligence, learning abilities, executive functioning, and social competence. Common neuropsychological issues related to NF1 include learning disabilities, visuospatial deficits, language deficits, attention and organization problems, social information processing difficulties, and metacognitive difficulty (North et al. 2002; Dilts et al. 1996; Huijbregts et al. 2010). Similar to the physical manifestations, however, neuropsychological profiles of children with NF1 vary greatly from person to person.

**Intelligence.** The intellectual functioning of children with NF-1 is not significantly different than that of the general population. The prevalence of mental retardation (5%-11%) in children with NF-1 is slightly higher than the general population and the distribution of full scale IQ is shifted slightly to the left, falling between the range of 88 and 99 (North et al., 1997).

**Learning and executive function.** The prevalence rate for learning disabilities (LD) and attention deficit/hyperactivity disorder (ADHD) among children with NF-1 is approximately 40-60% (Mautner et al., 2002). In addition, children with NF1 and a co-morbid condition, such as ADHD or a learning disability (LD), have also been found to have social skills deficits, particularly in the area of social problem solving skills (Barton & North, 2004).

A recent study indicates, however, that social information processing difficulties may be present in children with NF1 who do not have an additional diagnosis of LD or ADHD (Huijbregts et al., 2010). Results from various face recognition tasks found the children with NF-1 only, did poorly on measures of cognitive control and bottom-up processing of social signals.
Social-emotional profile. Several studies indicate children with NF1 tend to struggle socially (Benjamin et al., 1993, North et al., 1995, Dilts et al., 1996, Gresham et al., 2001). In one study, questionnaires were given to children with NF-1, unaffected siblings, parents, and teachers in order to compare experiences and observations of children with NF-1 in social endeavors. Children with NF-1 reported being teased and often rejected by peers. In comparison to their unaffected siblings, they had greater difficulty forming friendships and they maintained fewer friendships than their unaffected siblings (North et al., 1995). An additional study found internalizing behaviors such as somatic complaints, social withdrawal, anxiety, and depression to have a higher prevalence in children with NF-1 than their unaffected sibling (Johnson et al., 1999).

A study examining the neuropsychological, academic and social-emotional profiles of children with NF-1 found differences in the level of agreement between the child with NF-1 and his or her parent and teacher. For example, scores related to problems with peers indicated teachers and children with NF-1 were most in agreement. Parents were most in agreement with the teacher and child when scoring externalizing behavior (Deschemeekaeker et al., 2005). In addition, this research also found that scores on internalizing and/or externalizing problem scales did not vary significantly between children with NF1 only and children with NF1 and learning problems.

Psychosocial Needs of Youth

In a broad sense, psychosocial needs refer to psychological, social, and behavioral supports necessary for healthy development. The term is used in medical, educational, rehabilitative, and other venues and psychosocial care can be provided through social workers or other trained service providers.
The following statement, however, indicates that it may be common for children with NF1 and their caregivers to be involved in each of these settings yet miss opportunities to obtain valuable support.

"The emotional impact of NF1 is proving to be more challenging than the medical aspect. Knowing that most of the medical symptoms of NF1 can be managed, I think we can handle anything that comes medically. It's the emotional part of the day-to-day challenges for Julie that is so difficult. The problems making friends, the struggling in school, problems learning—that's what is so hard." - Diane D., mother of a child with NF-1 (Korf & Rubenstein, 2005).

For the purpose of providing a framework of elements pertinent to NF1, literature in the areas of executive self-regulation, social information processing and social problem solving are explored. In addition, learned helplessness, which can be an underlying barrier, is explored.

**Executive Self Regulation**

Many frameworks have been proposed for the purpose of defining a set of human functions which are paramount to success in educational, vocational, and social pursuits. Models ranging from the fields of cognitive psychology, developmental psychology, educational psychology and pediatric rehabilitation, seek to define and articulate approaches for fostering a set of skills variably referred to as executive function, self regulation, self-determination, and other similar terms. Ylvisaker & Feeney integrate insights from each of these perspectives and propose a holistic and practical view of these functions. Within this perspective, they propose executive self regulation to include (a) self-awareness along with understanding of the difficulty level of a task (b) ability to set appropriate goals (c) ability to initiate action toward achieving a set goal and inhibit actions incompatible with achieving the goal (d) ability to monitor progress
toward goals, while accepting responsibility for achieving them (e) ability to revise plans and form strategies to solve problems in the face of difficulty (p.53).

Studies regarding normal development of executive functions indicate these skills begin a developmental trajectory from early infancy, on. They involve cognitive functions and social behavior and are influenced by both biologic and environmental factors. In addition, motivational, contextual, and cultural factors can be powerful variables in the development of the executive functions (Bronson, 2000).

**Social information processing.** In light of recent research which indicates children with NF-1 may struggle with bottom-up processing of social signals (Huijbregts, 2010), skills targeting more adaptive cue interpretation for ambiguous peer experiences may be particularly helpful for children with NF1. Social-cognitive models, such as Crick and Dodge's (1994) social information processing model, help to explain how transactions between a person's social environment and his or her individual interpretations may contribute to psychological function or distress. Social information processing studies explore the tendency for children to have biased interpretations of ambiguous social events. This model suggests that children may derive a number of intent and causal attributions from encoded social cues among their peers. Causal attributions, such as self-referent attributions, may have implications, particularly for internalizing symptoms (Crick & Dodge, 1994). For example, children may draw conclusions about themselves when considering various causes of a social event (e.g., "They didn't invite me because I am a boring child."). A consistent tendency for a child to derive negative self evaluations has been proposed to influence the child's perception of competence as well as his or her self-schemas. In addition, these cue interpretations have been found to impact mood, social
goals, behavior among peers, and, most notably, the child's potential for socially rewarding peer-interactions (Goetz & Dweck, 1980; Quiggle, Garber, Panak, & Dodge, 1992).

**Social problem solving.** In addition to developing skills in cue interpretation, children with NF1 may need additional guidance in social problem solving. Maydeu-Olivares and D'Zurilla (1996) identified five dimensions to the social problem solving process: (1) positive problem orientation, (2) negative problem orientation, (3) rational problem solving, (4) impulsivity/carelessness style, and (5) avoidance style. Although research regarding the social problem solving process of children with NF1 does not refer to these dimensions, they provide insight for fostering skills toward the more productive dimensions of problem solving.

In a study examining the relationship between social problem solving and coping, D'Zurilla and Chang (1995), found that problem-solving ability was strongly related to a positive problem orientation and rational problem solving. In addition, dysfunctional problem-solving dimensions related to the use of avoidant or disengagement coping strategies. Given this correlation, one may argue the benefits of skills training which fosters a positive problem orientation and engagement in rational problem solving.

**Learned helplessness.** Along with the development of increased cognitive and social skills comes an increased desire for mastery. Children who have self awareness and an optimistic approach to challenging tasks are more likely to put forth the sustained effort required for meeting their goals. Each new challenge met creates for the child, a sense of efficacy. Executive self regulation processes, as well as environmental factors, such as parental cues and cultural expectation, make powerful contributions to a child's developing sense of efficacy.

In general, helplessness stems from a belief that one has no control over adversity. Decades of research on learned helplessness points to the fact that aspects of a child’s attribution
creates the amount of helplessness to follow (Cole & Turner, 1993). Negative attributions which are stable, global, and internal, have been shown to contribute to a sense of helplessness. The degree and to which neurological and environmental factors contribute to executive self regulatory impairment for children with NF-1 remains unclear. However, literature on learned helplessness in neurologically stable, at-risk children offers insight into the issue.

**Designing Relevant Support**

The benefit of identifying these contributing factors lies in the hope of developing ways to foster and strengthen particular skills for children with NF-1. Skills training and interventions should target the child with NF-1 as well as his or her parental figure. The programs should aim to strengthen factors involved in self regulation, such as social information processing and social problem solving, as well as learned optimism.

**Learned Optimism**

The wealth of information gleaned from decades of research on learned helplessness laid the grounds for the field of study known as Positive psychology. Positive psychology, in contrast to psychological models focused on pathology, seeks to identify positive experiences, traits, and institutions which support and facilitate health and well-being (Seligman & Csikszentmihalyi, 2000). The initial research on learned helplessness, therefore served as a base for identifying elements which support learned optimism. Rather than a focus on experiences, both internal and external, which foster helplessness, the focus is on experiences which foster resilience. The emphasis is on prevention and education, with a focus on building character strengths and interpersonal skills. This approach fits well with the NF-1 population, as youth with NF1 may not feel they warrant intensive intervention, but could benefit from support.
Pennsylvania Resilience Program

The Pennsylvania Resilience Program (PRP) was developed for youth at risk for depression (Stark & Boswell, 2000). PRP is a group intervention for adolescent youth that teaches cognitive-behavioral techniques geared toward developing a flexible mindset, realist attribution styles, and social problem-solving skills based on accurate attributions. The program targets traits and skills which facilitate adjustment to adversity and is based largely on research from positive psychology, as well as social information processing and social problem solving.

Acceptance and Commitment Therapy

In an effort to facilitate cognitive, emotional, and behavioral self regulation we may also consult literature in cognitive behavioral therapy. Acceptance and Commitment Therapy (ACT) is based on the premise that common cognitive processes often enhance or distort experiences of unpleasant emotions, which leads people to engage in unproductive or harmful behavior as a means to avoid the unpleasant emotions. ACT utilizes basic behavioral techniques and focuses on effecting behavior change by changing the context, rather than the content, of thoughts and feelings (Hayes et al., 2004).

ACT has been applied successfully with adults and children dealing with a broad range of mental health challenges such as depression, anxiety, chronic pain, substance abuse, eating disorders and thought disorders (Hayes et al. 2006). In addition, ACT has been successfully used to help parents of children with Autism (Blackledge & Hayes, 2006). ACT may be particularly helpful for teens with NF-1 as it serves to strengthen metacognitive skills, addresses both internal and external influences on behavior, and offers a clear focus on valued direction. As stated by Greco & Eifert, "ACT focuses on personal responsibility, values, and choice- all of which reflect
important developmental tasks such as identity formation and the pursuit of autonomy and independence" (p.307).

ACT, which is based on a theory of language and cognition labeled relational frame theory, proposes that psychological suffering originates from language processes that create psychological inflexibility (Hayes et al., 1999). According to Hayes and colleagues, cognitive fusion is a common, yet problematic process. "Cognitive fusion" refers to the tendency for people to become attached to the content of internal events and, in turn, respond to these internal experiences as if they were actually true. Experiential avoidance occurs when a person is unwilling to remain connected to difficult private experiences (e.g. emotions, thoughts, memories, physical pain) and takes measures to change the events and the associated contexts.

A key goal of ACT is to foster psychological flexibility. Psychological flexibility is encouraged through the use of metaphors and experiential exercises. These aim to help clients remain in contact with the present as well as improve their ability to decide about values-consistent behavior (Hayes et al., 1999). ACT uses difficult private experiences as targets for exposure and focuses on the process of responding in a way that is in line with valued life directions.

**Additional Considerations**

**Targeting adolescents with NF**

In light of the vast amounts of research indicating that executive self regulation begins at birth and develops slowly, one may question an intervention designed for teens. Ideally, parents of children with NF would receive this information at the time the child is diagnosed. This intervention was designed for teens with NF1 based mainly on needs expressed by a local NF Clinic.
In addition, issue of cosmetic disfiguration can be particularly troublesome for teens with NF-1. Typically, body dissatisfaction begins to intensify and is most strongly associated with perceived self-worth during adolescence (Bearman et al. 2006). Unfortunately, the number and severity of the café au lait spots and tumors often increase during times of hormonal change (i.e. adolescents and pregnancy). In essence, adolescents with NF-1 are likely to develop more physical symptoms during developmental periods when there is a heightened sensitivity to their appearance (Counterman, 1995). Ablon (1999) also found that adults with NF1 attributed cosmetic disfiguration in childhood, as well as frequent absences from school due to medical needs, as main the factors in their difficulty in forming and maintaining friendships.

**Targeting Parents of Teens with NF**

The family's response to NF1 majorly impacts the child's functioning, access to resources, as well as the child's perception of efficacy in the face of the disorder. As primary advocates for their child, parents must employ or develop concrete skills in fact-gathering, problem-solving and organization, as well as model optimism and executive self regulation in the face of adversity. Even though parents are often naturally geared to nurture self-regulation in their children, there is evidence that these skills are often neglected in the case of children with visible or cognitive differences. Unfortunately, research indicates that the children most in need of extra practice in problem solving and strategic thinking tend to get fewer experiences than typically developing children (Levine, 1993).

On a more positive note, optimism in both children and caregivers has been found to result in improved adjustment to traumatic events. One study, involving parents of children with an acquired traumatic brain injury (TBI), found parents who were able to identify meaning in the
face of the traumatic event, were active problem solvers, and sought social support, also
experienced improved adjustment in the long term. (Davis et al., 1991).

Perhaps the most compelling argument for empowering parents of children with NF1 involves the fact that such efforts have been shown to produce improved outcomes for the child. A research study in Brazil compared outcomes between children with TBI who received rehabilitation services by rehabilitation professionals in the clinical setting and children with TBI who received rehabilitation services indirectly through their parents who were trained to deliver contextualized rehabilitation services in the context of daily life. The results from this study indicated children provided rehabilitation services by parents, in the context of the home, had better outcomes than those served by a specialist in a clinical setting. (Braga et al., 2005)

Proposed Program

NF Teen Talk Program and Parent Support Group

Overview

The proposed NF Teen Talk Program is a 6-week program designed to increase self-acceptance, decrease internalizing symptoms, and enhance social skills among teens between the ages of 12 and 19 with various forms of Neurofibromatosis (NF1, NF2, and Schwannomatosis). Parents and caregivers of the teens participate in a concurrent support group. Weekly sessions last 90 minutes and are facilitated by therapists who are knowledgeable about issues related to NF. The program consists of a core curriculum based upon the Acceptance and Commitment Therapy Clinical Model (Hayes, 1999), and the Penn Resilience Program (Seligman, 2007).

Portions of the parent support group content parallels the NF Teen Talk material, as this facilitates parental modeling and reinforcement of targeted social skills for daily use.
Description of NF Teen Talk Sessions

Session #1

Process:

The facilitator devotes time to establishing a sense of safety, rapport, and group cohesion. He or she provides a warm welcome, greeting each participant by name. Each participant is given a folder containing a name card, outline of the program, group guidelines, a pen, and written materials for the first session.

Content:

The initial portion of session one is devoted to introducing participants to the program. The facilitator explains the difference between a class, a support group, and the goals of NF Teen Talk. Participants are invited to share thoughts, feelings, and perceptions about the program. The facilitator models acceptance of all responses.

Once parameters of the program are established, a metaphor of a "swamp before the castle" is used to describe the, at times, uncomfortable process of looking at one's own thoughts and behaviors. Participants are asked to draw a large circle on a blank piece of paper provided. As they fill the circle with internal and external experiences, the participants are asked to pay attention to the difference between internal experiences and external experiences. Participants are then relieved of the responsibility to manage, control or fix the internal experiences. They are encouraged to see that their "response-ability" lies in their response to the outside world. The facilitator normalizes uncomfortable internal experiences. Participants are reminded that positive and negative internal experience will come and go throughout their lives, but they only have direct control over their overt behavior.
FOSTERING SELF REGULATION

The facilitator provides examples of ways people typically try to manage internal experiences. A mindfulness exercise is introduced as a way to pay attention to internal and external experiences in a way that is nonattached, compassionate, and accepting (Kabat-Zinn, 1998). Participants are encouraged to picture thoughts as leaves floating down a river. They are encouraged to allow the leaves to come, and then float by. After the exercise is complete, participants are invited to share their experience of having distance from thoughts. Participants may (or may not) find that the distance from internal experiences helps them get in touch with what they truly value. The facilitator briefly explains the link between session 1 exercises and session 2 related to clarifying values.

**Life exercise:**

Homework is introduced as "life exercises" as a way of encouraging participants to continue working with concepts between sessions. The first life exercise invites participants to pay attention and record their own control strategies for managing internal experiences. Participants also record the consequences (short-term and long-term) for each control strategy.

**Session #2**

**Process:**

Facilitator re-establishes safety of group members via interaction with individual members and modeling respect and acceptance. Facilitator gauges each participant's willingness to engage, modeling acceptance at various levels of engagement.

**Content:**

This session focuses on weakening the fusion between the participant and his or her thought content, and identifying valued direction. A metaphor of a city bus driver is used. Participants are encouraged to see themselves as the driver. The driver has a clear destination,
but must stop to pick-up passengers along the way. While some thoughts and feelings can be very annoying "passengers", engaging with them could interfere with the driver's ability to reach the destination. Using their life exercises work, participants are invited to share ways they engaged with or resisted engagement with passengers/ internal experiences throughout the previous week. The group discusses consequences (short-term and long-term) for attempts to control internal experiences (i.e. engage with passengers). Control measures are written inside blank shields and masks. Participants are asked to look at their passengers and shields with compassion. Although misguided, they were designed to protect what is valued. Participants are offered examples of values and are asked to place their own values in the bull's eye of a target. Participants then place various coping mechanisms around the outer rings of the target, placing more effective coping mechanisms closer to the bull's eye. The facilitator introduces skills that will be covered in future sessions. The skills are designed to help participants take actions that will move them toward their values and goals.

Life Exercise:

Participants are asked to identify coping mechanisms or skills they would like to improve or learn as a way to help them act according to their values (i.e. assertiveness skills, relaxation techniques, conversation skills).

Session #3

Process:

Participants are given time to discuss their experiences doing the life exercise. The facilitator helps participants identify their values, skills, and ways they show willingness to experience discomfort in service to their goals.

Content:
The outcomes of this lesson are acceptance and use of cognitive skills as a way to move in a valued direction and meet goals. The facilitator points out the difference between accepting the fact that uncomfortable thoughts and experiences will happen, and accepting uncomfortable thoughts and experiences as true and permanent. The facilitator illustrates the difference with examples; pointing out that the former idea of acceptance allows us to pay closer attention to our values and resulting goals.

Participants are given large paper coins upon which they write something they highly value. On the reverse side, participants write possible pain or loss related to the value. Participants are encouraged to hold the coin in their hands and think about their willingness to experience various forms of pain and loss in order to keep the value.

The facilitator explains that while commitment is vital, it is equally important to have skills and effective tools for reaching goals. The facilitator introduces components of the Penn Prevention Program related to thinking styles. The group discusses optimistic versus pessimistic thinking styles with specific focus on realistic optimism. Participants share experiences related to permanence, pervasiveness, and personal explanatory styles. The facilitator emphasizes the importance of refraining from judging people for using a particular style. A guided imagery exercise is offered suggesting participants use images to represent pessimistic and optimistic explanatory styles (i.e., the over-protective soldier and the curious explorer). Participants are encouraged to speak with both images (i.e. thank their "soldier" for his or her dedication to protecting them, and tell the "curious explorer" that they will be listening to him or her). The goal of the exercise is to increase awareness of explanatory styles and teach the practice of choosing explanatory styles that are based on realistic optimism.
Life Exercise:

Participants are instructed to write about any experience during the week that caused them to use any of the explanatory styles. They are to identify the explanatory style used, whether or not they were aware of it at the time, and how different explanatory styles would change how they would respond to the situation in the future.

Session #4

Process:

Participants are encouraged to share their experiences, ask questions, and provide feedback and support to one another. The facilitator models goal-directed behavior by acknowledging and respecting all input, but giving particular attention to participants' pro-social, values-driven behavior.

Content:

This session focuses on reviewing explanatory styles and teaching the skill of generating alternative explanations. The facilitator tells a story using two fictional characters used in the Penn Prevention Program (Seligman, 1999): Sherlock Holmes, the good detective, and Merlock Worms, the hasty detective. The story illustrates the difference in outcomes when the detective takes his time gathering evidence. Participants break into small groups for a "File Game" activity. Each group is given a file containing information about a character, a stressful situation, and various forms of "evidence" the character can use to decide how to respond. Each group is responsible for evaluating the evidence, choosing their character's course of action, and role play their conclusions.
Life Exercise:

Participants and parents set time aside during the week to discuss how Sherlock Holmes and Merlock Worms have each played a part in their responses to Neurofibromatosis.

Session #5

Process:

Participants are given time to share their experiences. They discuss differences and similarities they found with their parents in relation to the life exercise. The facilitator models an accepting and non-judgmental stance toward all perspectives shared.

Content:

This session addresses the realities of being a teenager with Neurofibromatosis. The image of the bus passenger is re-introduced as a way of describing various ways NF is experienced by different participants. Participants are invited to quiet themselves and form a mental image of the type of passenger NF is for them currently. Participants are asked to picture themselves as the bus driver and imagine how they currently interact with the passenger, NF. Next, the participants are asked to imagine the possibility of interacting with NF, the passenger, in a way that allows them to continue driving toward their destination. A group discussion is held in which the facilitator and participants draw from material presented in previous sessions.

Life Exercise:

Participants are encouraged to gather one or several ideas, pictures, or objects. These represent something they value (i.e. a paint brush for creativity or an acorn for growth). Participants are told they will have an opportunity to share their items during the final session.
**Session #6**

**Process:**

The two-sided coin image is used to facilitate a discussion about the completion of the program. Participants are given the option to participate in activities at their own comfort level. Participants will later have the opportunity to share contact information with other participants. They are encouraged to attend "booster sessions", held on a quarterly basis throughout the year.

**Content:**

The final session focuses on celebrating each participant's willingness to experience discomfort in service to their stated values. The session begins with a "body-scan" mindfulness exercise. Participants are instructed to use the exercise as a way to get some space from the "passengers", or to clarify their "bull's-eye." Participants have an opportunity to give and accept validation while sharing their thoughts or presenting their life exercise work. Participants join the parent group for a shared meal and presentation of certificates. Participants and parents are asked to complete feedback forms and are given information regarding future booster sessions.

**Description of Parent Support Group**

**Session #1**

**Process:**

Parents are welcomed and offered simple refreshments. The room is arranged with comfort and ease of sharing in mind. Each parent is given a folder containing the program outline, notes related to the first session, and a list of resources. The facilitator provides structure by initiating introductions, explaining the program, and shaping group conversation. The facilitator emphasizes the parental role of “expert” in raising their child with neurofibromatosis,
and encourages parents to acknowledge the success and learning they have experienced along the way.

**Content:**

The first half of session one focuses on setting the framework for both programs (Teen Talk and Parent Support). The facilitator explains the basis for each teen session topic, and points out differences between the two groups. The parent group is told that they will determine the balance between content and support each session. Written resources are provided and are discussed during parent sessions, or they can use the time to process their experiences with the material. During introductions, parents are asked to talk briefly about their experience with NF and identify what they would like to gain from the group program.

**Session #2**

**Process:**

The facilitator seeks to insure each participant has an opportunity to share at his or her comfort level. The facilitator answers questions related to the program material, but avoids being cast in the role of "expert".

**Content:**

The facilitator offers to provide a brief overview of Acceptance and Commitment therapy (ACT), and explains the ACT-related material covered in the Teen Talk group. The facilitator points out the research-indicated benefits of ACT for parents of children with chronic condition. Parents are given time to discuss their understanding of cognitive fusion, acceptance, values-driven responses. A mindfulness exercise, (leaves in a stream) is offered at the closing.
Session #3

Process:

Parents are encouraged to view the material in relation to how it impacts their child, as well as how it could impact their parenting.

Content:

Parents are provided an outline of findings related to psychosocial adjustment of children and adults with Neurofibromatosis. ACT and Resilience Training materials are introduced in relation to the challenges faced by children and adults with neurofibromatosis.

Session #4

Process:

Parents are provided details about the material covered in this week's Teen Talk session. The facilitator gages the level of depth necessary for the group, based on their feedback and expressed interest.

Content:

The facilitator explains the material covered in the Teen Talk session, as teens and parents will be responsible for doing Life Exercises together. Parents are encouraged to share their own experiences with various explanatory styles and the generation of alternative explanations. They are also encouraged to share these experiences with their child.

Session #5

Process:

The facilitator insures time is given to each participant willing to share their experience with the Life Exercise. The facilitator models a non-judgmental and accepting stance toward each participant's experience. Experiences shared are not judged as good or bad. Rather, each
experience is viewed in relationship to the parent's valued direction (i.e. mutual respect, expression of caring in relationships).

**Content:**

Materials and resources are provided in relation to identifying valued direction. The facilitator encourages parents to listen for the value being expressed, when their teen appears caught up in a social dilemma. Parents are also encouraged to keep their parenting goals in mind when faced with their own parenting dilemmas (i.e. fostering my child's sense of self-efficacy). Parents are given two-sided paper coins. On one side of the coin they're asked to write a parenting value (i.e. my child's sense of self-efficacy). On the opposite side of the coin, parents are asked to identify possible risks or losses associated with the value (i.e. they may not need me as much and I could experience sadness). The facilitator asks parents to sit quietly with the coin in their hands as a way of gaining acceptance of the fact that there are risks associated with acting in the interest of their values and resulting goals.

**Session #6 (Review & Celebration)**

**Process:**

The initial portion of this session is used to process the conclusion of the parent support group. Teen Talk and parent support group combine during the second portion. The facilitators congratulate participants in both groups, and provide information regarding future sessions. Feedback forms are provided and participants are strongly encouraged to return the feedback information at the conclusion of the session.

**Content:**

Parents are asked to share a concept or exercise introduced during the program, that they found to be helpful. After each participant is given an opportunity to share, the facilitator
explains the feedback form, future booster sessions, and outline for the remainder of the final session. The teens join the parent group for a shared meal and presentation of certificates.

Summary

Supporting the social and emotional wellness of youth with NF1 requires a multifaceted approach. Interventions are needed for targeting executive self regulation skills, learned optimism, and identifying meaningful direction in the face of challenges. In addition, parents and caregivers need support in obtaining information and implementing techniques designed to facilitate executive self regulation and learned optimism.
References


