

## RECRUITING DIVERSE MARKETS: SPEAKING WITH PARENTS OF CHILDREN WITH DISABILITIES

The Foundation for Jewish camp aims to reach Jewish children of all backgrounds, ethnicities and all abilities. In response to an overwhelming need expressed by families of children with disabilities and disabilities advocacy groups, and verified by research it conducted in 2012-13, FJC is currently working to secure funding for a significant program to enhance services to children with disabilities at non-profit Jewish residential camps across North America. Fourteen – 20% of Jewish children have a disability and many are denied access to a Jewish camp experience. FJC's current vision, based on what we learned about the current state of disabilities programs now offered by the field of Jewish camp, is that we should focus on three distinct but overlapping areas:

- Staffing and Training
- Physical Accessibility
- Vocational and Life Skills Training Programs

Our overarching goal is to ensure that campers with disabilities and their families experience camp as fully and completely as their typical peers. In our first effort to increase accessibility, our intent is that by 2020, 5% of the total Jewish camp population be children with disabilities. Our current focus is on staff training and awareness.

FJC is working directly with interested camps to provide the tools and resources to best serve campers with disabilities through direct training, webinars and consultations. We are also collecting information to create a database of which camps can meet the needs of children with disabilities to make that information more readily available to parents and to professionals in the field.

FJC has a growing number of programs to serve children with disabilities and we would like to ensure that families can properly access them.

As One Happy Camper partners, we hope you will join us on this journey of making Jewish camp a reality for all children.

## BE PREPARED

### TERMINOLOGY: Disabilities vs. Special Needs

If in conversation, a parent shows a preference for one of these terms over another, take their lead. It is the practice FJC to use the word “**disabilities**”, yet we recognize that some parents are more comfortable using the words “**special needs**” when referring to their child.

An individual with a **disability** is defined by the Americans with Disabilities Act (ADA) as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.

The term “special needs” tends to be linked to a child’s eligibility for services from the Department of Education. **Special needs** is a term used in clinical diagnostic and functional development to describe individuals who require assistance for disabilities that may be medical, mental, or psychological.

*FJC defines a camper with a disability as a child with such disabilities as (but not limited to) Down Syndrome, blindness, hearing impairments, Autism, Asperger’s, challenging behaviors, seizures, intellectual or developmental disabilities and physical impairments.*

### KNOW YOUR CAMPS

To be prepared to talk to parents of children with disabilities familiarize yourself with the camps in your areas ability to accommodate this population.

Different camps in your area are able to accommodate different types of disabilities. Their abilities may change from year to year. Speak to the camp directors in your catchment area to inquire if they are open to talking to parents of children with disabilities and if there are specific disabilities they are better able to accommodate.

*Different types of opportunities a camp may be able to offer:*

- **Inclusion** refers to a camp setting that campers with and without disabilities live in the same cabins together and attend all of the same activities.
- **Camp within a camp** would mean that campers with disabilities live in cabins with other campers with disabilities and attend programs specially geared towards campers with disabilities. They usually spend some percentage of their day interacting with campers without disabilities.
- **Camp for children with disabilities** is a camp program where all of the children at camp have a disability and have been determined to need extra supports at camp.
- **Vocational training program** is usually a job coaching program at for teens over the age of 16.

## THE PHONE CALL

Most parents who call in search of a camp for their child who has a disability will specify that desire up front, but others will not.

### What are the things that you should do when you receive this call?

**Listen!** Ask the parent to tell you about their child and then just listen. Your primary goal here should be to learn enough about the child and family to help them find a Jewish camp. The only advice that they are looking for at this point is about camp. As helpful as you would like to be, please try not to offer them advice about how to care for their child.

**Acknowledge.** If a parent expresses feelings about their child that you do not agree with simply acknowledge their feelings and listen. We are not in a position to make assumptions about what they are sharing. Acknowledge and affirm. Examples of things to say: “Wow that sounds hard” or “I hate that it’s so difficult for you.”

**Soliciting information.** When trying to get more information on the child, do not focus on the disability. Ask the same questions you would of any potential camper - age, where they go to school and what if any accommodations they receive there. Ask the parent/guardian to describe their child and their interests. You can also inquire about what activities the child finds difficult or unappealing.

### Questions that you might ask in order to make a more accurate referral to a camp or camps.

1. Why are you looking for a camp serving children with disabilities?
2. Tell me about your child (interests, dislikes, school, interactions with peers and adults).
3. What would you hope that your child will gain from a camp experience?
4. Are there any supports that the camp would need to provide so that your child’s experience would be most successful?

**Use people first language.** Take care in how you describe people with disabilities – *the words that you choose matters.*

- Avoid outdated, derogatory terms like "crippled," "retarded," and "handicapped."
- Put the emphasis on the person and not the disability. For example, use language like "the child who is autistic" versus "that autistic child."
- Avoid referring to nondisabled kids as "normal," since it implies abnormality or a defect in others.
- Choose language like – “a camp that works for children with autism” instead of “camp that works with autistic children”. “Your child will live in a bunk with peers without disabilities” instead of “your child will live in a cabin with normal or typical campers.”

### Things to be careful not to say or do

1. Do not contradict or judge the parent.
2. Try not to say things like “God only gives us what we can handle.”
3. Do not pretend to be knowledgeable about a topic if you are not.
4. Do not promise the parent that a camp will accept their child.

## GLOSSARY

Terms that you might hear and should be familiar with:

### TYPES OF DISABILITIES

**Every child is a unique individual and no two children with the same disability are alike. Disabilities display themselves very differently in each child.**

Following is a short list of some of the disabilities that you might come across in your conversations with parents.

**Autism** is a complex developmental disability that typically appears during the first three years of life. Autism impacts the normal development of the brain, the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

#### **Asperger's**

Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.

**Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)** (commonly referred to as atypical autism) a diagnosis of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.

**Bipolar disorder** (also known as manic-depression) is a serious but treatable medical illness. It is a disorder of the brain marked by extreme changes in mood, energy, and behavior. Symptoms may be present since infancy or early childhood, or may suddenly emerge in adolescence or adulthood. The more we learn about this disorder, the more prevalent it appears to be among children. Children usually have an ongoing, continuous mood disturbance that is a mix of mania and depression. This rapid and severe cycling between moods produces chronic irritability and few clear periods of wellness between episodes.

#### **Obsessive Compulsive disorder**

The brain gets stuck on a particular thought or urge and just can't let go. Worries, doubts and superstitious beliefs can become excessive such as hours of hand washing.

Normal worries, such as contamination fears, may increase during times of stress, such as when someone in the family is sick or dying. Only when symptoms persist, make no sense, cause much distress, or interfere with functioning do they need clinical attention. Obsessions are thoughts,

images, or impulses that occur over and over again and feel out of your control. The person does not want to have these ideas, finds them disturbing and intrusive, and usually recognizes that they don't really make sense. People with OCD typically try to make their obsessions go away by performing compulsions. Compulsions are acts the person performs over and over again, often according to certain "rules." People with an obsession about contamination may wash constantly to the point that their hands become raw and inflamed.

**Tourette syndrome** is an inherited, neurological disorder characterized by repeated involuntary movements and uncontrollable vocal (phonic) sounds called tics. In a few cases, such tics can include inappropriate words and phrases. Eye blinking is a common tic. However, facial tics can also include nose twitching or grimaces. With time, other motor tics may appear such as head jerking, neck stretching, foot stamping, or body twisting and bending. A person may also utter strange and unacceptable sounds, words, or phrases. It is not uncommon for a person with TS to continuously clear his or her throat, cough, sniff, grunt, yelp, bark, or shout.

**Epilepsy (Seizures)** - Epilepsy is a neurological disorder in which a person has repeated seizures (convulsions) over time. Seizures are episodes of disturbed brain activity that cause changes in attention or behavior. Episodes can vary from brief and nearly undetectable to long periods of vigorous shaking

**Dyspraxia** is a disorder that affects motor skill development. People with dyspraxia have trouble planning and completing fine motor tasks. This can vary from simple motor tasks such as waving goodbye to more complex tasks like brushing teeth. Individuals with dyspraxia often have language problems, and sometimes a degree of difficulty with thought and perception.

**Cerebral Palsy** is a group of disorders that can involve brain and nervous system functions, such as movement, learning, hearing, seeing, and thinking. It is a life-long physical disability due to damage of the developing brain. In most cases brain injuries occur during pregnancy. Motor disability can range from minimal to profound, depending on the individual and can range from weakness in one hand, to an almost complete lack of voluntary movement requiring 24 hour care. Children with cerebral palsy are likely to also have other impairments in addition to their motor disability. Spastic hemiplegia, where one half of the body has difficulty with voluntary movement, is the most common presentation of cerebral palsy.

**Muscular Dystrophy** is a group of inherited disorders that involve muscle weakness and loss of muscle tissue, which get worse over time. There are many different kinds of muscular dystrophy. Symptoms of the most common variety begin in childhood, primarily in boys. Other types of muscular dystrophy don't surface until adulthood. Most people diagnosed with MD will eventually need to use a wheelchair.

**Down Syndrome** is a chromosomal condition that is associated with intellectual disability, a characteristic facial appearance, and weak muscle tone (hypotonia) in infancy. All affected individuals experience cognitive delays, but the intellectual disability is usually mild to moderate. Individuals with Down syndrome often have distinct physical characteristics, unique health issues, and variability in cognitive development.

## OTHER WORDS TO BE AWARE OF

**Assistive communication device or technology** refer to any device that helps a person with hearing loss or a voice, speech, or language disorder to communicate. Examples can be as simple as highlighters, color coding files or drawers, books on cd, calculators or a different paper color or background color on a computer screen. Complex or high-tech, assistive technology devices include computers with print-recognition software that "read" text aloud or speech recognition systems that turn oral language into written text.

**ADA compliant (American with Disabilities Act)** – this usually means is the camp equipped for campers in wheelchairs and is within the regulations set forth by the American with Disabilities Act.

**Camper to staff ratio** – meaning how many staff are assigned to a bunk of children

**Shadow** – a counselor assigned to a child with a disability

**Gluten free diet** excludes the protein **gluten**. **Gluten** is found in grains such as wheat, barley, rye and triticale (a cross between wheat and rye). A **gluten-free diet** is used to treat celiac disease. **Gluten** causes inflammation in the small intestines of people with celiac disease.

**Celiac disease** is a condition that damages the lining of the small intestine and prevents it from absorbing parts of food that are important for staying healthy.