

DOWN SYNDROME

INCLUSIVENESS

“ Sam’s mannerisms of saying “Hi” to everyone, hugging often, smiling and laughing through even the worst of times, his purity and innocence and his lack of worry, anxiety, stress and doubt seem like something we should all strive for....We have so much to learn from these individuals if we allow ourselves to see.”

(Susan Mayen)

The Aim of Scouting is to promote the development of individuals, enabling them to grow and take their place in society as active citizens. As we move forward with the Canadian Path we are much more aware of each individual’s personal progression, inclusive of their varying abilities. This inclusiveness within Scouting uniquely positions us to play an important role in modifying community attitudes and behaviour towards individuals with identified needs; it starts with Scouts.

Please use this guide for a better understanding of youth with Down Syndrome; how as Scouters, we can make a difference through simple interventions, program modifications and knowing where to get help when needed.

DESCRIPTION

Down Syndrome (DS), is a term used to describe the unique medical and physical characteristics seen in individuals born with a specific chromosomal abnormality.

CHARACTERISTICS/BEHAVIOURS

- Most Youth with Down Syndrome learn to read and write and are able to lead fulfilling and independent lives
- Youth with Down Syndrome have the same physical and emotional needs as everyone else
- Have dreams, aspirations, perceptions and fears just as everyone else
- Youth with Down Syndrome have more ‘standard’ characteristics than they have unique, medical and physical characteristics
- Many Youth with Down Syndrome are prone to colds and infection.
- There are over 50 characteristics that can be found in people with Down Syndrome
- The number of unique physical characteristics present does not have any influence on mental ability or vice versa
- Youth may have a delay in reaching developmental milestones (e.g., sitting, talking, etc.)
- 40% of youth with Down Syndrome have congenital heart defects, which have been repaired; most youth will be able to participate without restrictions
- Will work hard when motivated and take pride in work and achievements
- Like to be treated respectfully
- Will be capable adults if treated as capable youth

IN A SCOUTING SITUATION

Scouters need to keep in mind that youth with Down Syndrome may:

- Have increased risk for some medical conditions
- Have possible hearing and vision impairment
- Have possible intellectual impairment or limited achievement
- Have difficulty communicating needs
- Have difficulty with co-ordination and fine motor skills
- Prefer the company of youth younger than themselves



- Have difficulty in chewing food and may need extra time to finish meals
- Need time to process and practice new things
- Need help some of the time but don't need help all the time.
- Have difficulty expressing how they feel, or why, but know what they are feeling

Further:

- It is important for Scouters to find out about the youth's medical needs, physical condition, cognitive abilities and view of the world
- To avoid an inappropriate situation or one that could be perceived as inappropriate, Scouters should be cognisant of physical contact (i.e., "cuddles" wanted by Youth with Down Syndrome); sensitive discouragement is required.
- Scouters should also be aware that obvious benefits will accrue from keeping in close contact with the family and keeping them informed of the young person's progress
- Know that youth ask not to be judged on everything they can and cannot do, based on their Down Syndrome

PROGRAM MODIFICATION SUGGESTIONS

- It is vital to ensure instructions are given clearly, simply and face to face and allow time to respond
- Patience is required to ensure that there is no discouragement from attempting to speak
- Gauge the level of difficulty of activities to ensure equal opportunity for success
- Again, liaise with the parents or care givers who will know what is essential to do
- Learn from the individual with Down Syndrome by being with them and together you will be able to bring out their best

- Jumping, hopping, skipping and running may be difficult, but youth should not be discouraged from joining in games and activities
- Provide opportunities for non-competitive games and activities
- Engage in activities to develop self esteem
- Use verbal cues when teaching (e.g., mantras, key words, repetitive phrases etc.)
- Use visual supports (e.g., photos, colour codes, diagrams)
- Break tasks into small steps and define each step.
- Expect and model respectful behaviour
- Create opportunities in the group, that ensures everyone works toward a common goal; the jobs may be different, but the goal is the same

FURTHER ASSISTANCE

This Info Sheet is a resource guide only and is not intended to be therapeutic, diagnostic, medical, or legal advice. Our best source of assistance for youth with identified needs is the youth's parents or caregivers; the information provided is designed to support the relationship that exists between a youth and his/her parents or healthcare providers and the Scouters involved with the youth.

SOURCES

Material adapted and used by permission of The Scout Association (UK), Scouts Australia, and Scouting Ireland.

