## **SCOUTS-L**

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## DOWN'S SYNDROME

Date: 28 Nov 1996 21:43:15 -0800

From: "Chris Siegl" <Chris.Siegl@nsc.com>

To: DScruggs@concentric.net> (Return requested),

jambo97 <jambo97@hoplite.org> (Return requested)

Subject: JAMBO97 Re: Down's Syndrome

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Reply-To: jambo97@hoplite.org

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## Hello Donald,

Great to hear you are able to mainstream a Downs Syndrome boy, I think it adds

much to the scouting experience for all the participants in the Troop (leaders,

parents as well as boys) when everyone has a good attitude. I have two handicapped boys in my current Troop, but boy do I hate that stereo type "handicapped" or "Downs Syndrome", "Disadvantaged etc. I Never use them around

the boys or even with parents except in abstract discussions like this, seems

like no getting away from it here.

I like to think of us all as handicapped, but functioning by adapting to them.

I am myself "handicapped" in that I wear glass, or I don't see, I am slightly club footed, so I often fall when running. As we get older everything hurts more etc. Do we consider ourselves handicapped? NO!!! Not if we are out there

"being everything we can be". Attitude has very much to do with what we can do.

My experience with Troop 451 dates back twenty years when I was in College,

the boys in that troop were 10 to 20 years older than I was, Scouting takes away the 18 year old age restriction with mental handicaps. I got involved because the parents, who had been running the troop themselves, no longer felt

that they could physically keep up with them, but these parents had made a big

sacrifice to keep these boys out of the mental institutions, so were very committed to working with the boys. I did have one boy who made it to Star rank

at that time. My memory is a bit faded right now on the details, we had frequent problems with seizures and self control, but the parents taught me a

lot and made me comfortable that if something happened they were there to help.

In my current troop I have an Autistic boy and a visually handicapped boy. The

first boy came through the Pack while I was Cubmaster, we also had a couple of

other handicapped boys in the Pack including one who needed a walker to walk

and another who probably had Downs syndrome or something similar.

Now with that as background, let me try to answer your question, remember that

with any of these afflictions there is a broad range of capabilities, both from

the degree of handicap to the "attitude" of the boy and the availability of program help. I have seen some amazing developments from shear determination by

parents, teachers and the boy. Boys Scouts recently clarified the "Alternate Requirements for Tenderfoot, Second Class and First Class Ranks" see page 6 in

"1995-97 Boy Scout requirements". The main points being, the physical or mental

disability must be permanent, and certified by medical or educational authority, and alternate "requirements" must be defined with the scout completing as much of the regular requirements as his ability permits. The Candidate is expected to "do his best in developing himself to the limit of his

resources." The council Advancement committee must approve the request before

the alternate requirements can be implemented. You and the parents may have to

educate the Council Advancement Committee, work with them to find the experts.

The scouting enthusiasm and scouting contacts may make the difference in

finding alternate programs to assist the scout and his family, be careful though, the family may not see things quite as you do, you must be a team with

them to find the right Road to Advancement for their boy.

I am going through this right now with regard to the swimming requirement for

First Class, the important thing to keep in mind is that we are working to help

the boy "do his best in developing himself to the limit of his resources." I think the most important thing is to keep it positive, so much of a boys development is predicated by his attitude always remember when things slow down

or back slide, how much progress the boy has made while he had his current

attitude and enthusiasm. I remember little things from my 451 days of loving

relationship between boys and parents and their responsive enthusiasm to the

"little" advances, which were major milestones to these boys.

As far as merit badges are concerned, the requirements regarding alternate

merit badges are in a footnote on page 8. The boy should complete as many of

the required merit bodges as he can. Just council the Merit Badge Councillors

that these boys will need more time, they must complete all the requirements,

but check these requirements out with the medical and educational authorities

before the boy becomes so frustrated tat he wants to quit scouts, don't push

too hard, be a team with the parents, doctor and school teachers and ask for

help, then document.

One final word, every boy is different, Downs Syndrome severity varies all over

the place, if the boy is getting frustrated, talk to your team, ask for help, don't let if fester. Tell the boy, "we will find a way to work it with you", give the boy plenty of time, remember, no 18 year age limitation. Make up some

special awards for him if he needs interim recognition. Also emphasis to your

patrol leaders that you judge them on "how the patrol does its best to operate

within the limits of its resources", don't let your "special" scout become a handicap to how you reward your patrols/junior leaders, this is not always easy.

Good Luck, I reposted your message as I think others may have interest in this

subject, feel free to reply with specific issues, I may be slow at times in responding, but will try my best. My wife is a Pharmacologist and often helps

me understand the medical stuff. I talked her into taking up the sister Girl Scout troop to Troop 451 while I was in College, we did the Scoutmaster / Girlscout leader bit together for 3 years until we got married. I got to know my wife through scouting, she was the Girl Scout Representative to the Explorer

Board in Philadelphia when I was elected Co-Chairman of the explorer board, I

gave her rides to the meetings. Today we have 3 boys ages 7, 10 and 14.

Anyway, it is way after midnight and I have to quite,

YIS, Chris Siegl chris.siegl@nsc.com

DScruggs @ concentric.net 11/27/96 03:46 PM

To: Chris Siegl

cc:

**Subject: Down's Syndrome** 

> Former Scoutmaster and Asst. Scoutmaster Troop 451 Philadelphia > Council

(mentally handicapped, sponsored by PARC Pennsylvania Assoc. > for Retarded Citizens).

Chris,

Maybe you can help me. I have a new boy in my troop who has Down's Syndrome. I am not totally unfamiliar with the handicap as I once worked administratively for the ARC in the Washington Area. In many ways I have more help than many other leaders in this situation might. Firstly, the boy (Will) has a father who is active and willing to be there most if not all the time. Secondly, most of the new boys in Will's patrol were in Cub Scouts for several years with Will and are quite used to him. Lastly, Will has as much if not more fun than anyone in the troop. My problem is that I am uncomfortable with his advancement. I feel that we should not use the "did his best" Cub Scout criteria in Boy Scouts. I think, however, that some slack has to be cut. I am just not sure how much.

I really don't want some cut and dried rule or policy on this. If possible I'd like to have a feel for how to handle this. Maybe, some examples on specific Tenderfoot through First Class requirements would be helpful. Also how do I, or SHOULD I approach MB counselors about this.

YiS Donald Scruggs