**Supplement B: Free Response Comments from Participants**

Participant free response comments about the impact of NF1 on various factors of young adult life and the transition process.

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| **How has NF1 affected your education plans after high school?** |
| “Due to my intellectual disability related to NF, I am looking for a college program for individuals with ID/DD, as I want to go to college.” – Male, age 21 |
| “Trouble with test taking. Had lots of trouble passing the entrance exam.” – Female, age 25 |
| “Even though I try to deny having NF it has affected me socially, educationally and emotionally.” – Male, age 24 |
| “Currently not ready for further education but will be still living at home because of NF and choosing certain courses and school close by.” – Male, age 15 |
| “It has affected my high school education.” – Male, age 17 |
| “No plans after high school right now.” – Female, age 16 |
| “I have had to work my schedule and activities around symptoms of NF1. I have had to miss classes due to NF1. I have taken longer because of NF1.” – Female, age 24 |
| “I finished school and went to continue to study and then got cancer because of NF and had to have 2 years off.” – Female, age 26 |
| “I have to work with disability services for accommodations.” – Female, age 18 |
| “I have to be in high school for a fifth year in order to earn a diploma.” – Female age 18 |
| **How has NF1 affected your career or job choices?** |
| “My ID/DD related to NF is my biggest issue with not having a job. I am in a job-training program through my local school district.” – Male, age 21 |
| “My visual impairments have limited some career choices for me.” – Female, age 19 |
| “I think my NF was not addressed during my years at school by myself, my parents or school staff.” – Male, age 24 |
| “I have not been able to be hired because my NF1. (Or I like to think that is the reason. I have had several interviews and been trying for the past 6 years).” – Female, age 22 |
| **How has NF1 affected your dating and/or marital relationships?** |
| “Because I can't drive, getting around is difficult and my boyfriend is 26 and is learning to drive now. But we talk a lot. We have been together for a couple of months but have only been together twice the first time is when we met.” – Female, age 25 |
| “I am afraid that they will not want to have that risk of possibly having a child with a genetic disease.” – Female, age 24 |
| “My body looks different. Cafe-au-lait spots are no big deal, it's the neurofibromas and the plexiforms and scars from plexiform removal. I had a lateral mastectomy to remove a large plexiform. I don't know when or how to explain that. I feel like I need to prepare someone for what they see which frankly kills any mood or feeling that is happening.” – Female, age 23 |
| “I do not want to have kids and it worries me that when I start dating, my significant other will feel differently.” – Female, age 18 |
| “Kids don't like me.” – Female, age 16 |
| “Developmental delay prevents socializing with people my own age and understanding.” – Male, age 18 |
| “My ID/DD and Autism make it hard to meet friends and keep friends.” - Male, age 21 |
| **Has NF1 influenced your thoughts about having children?** |
| “I will not have children due to my impaired mental capacity.” – Male, age 15 |
| “I want to have biological children, but I'm worried that they may also have NF1.” – Female, age 21 |
| “I have to meet someone first.” – Male, age 19 |
| “I want to have biological children, but I don't think I am willing to put them through what I or others with worse cases have gone through.” – Female, age 18 |
| “I am worried what pregnancy will do to my body if and when I become pregnant.” – Female, age 23 |
| **Other Information** |
| “I would like to try clinical medications to stop or slow tumor growths as I know they can grow in my brain.” – Male, age 18 |
| “I've always been afraid people would treat me differently when they found out I have NF1, (which they normally do) so I hate bringing it up to people. Having NF1 has really lowered my self-esteem and given me a lot of personal troubles, mainly because hardly anyone knows what it is and how serious it really is. Also I feel that when receiving medical help, when asked if I'm in any pain/what pain level I'm normally at doctors and others don't realize or take into account that I'm used to being in pain and I have gotten used to it to the point I don't always notice when I'm actually having nerve pains, and that my tolerance level for pain is very high. Because of this my issues aren't taken seriously and I'm not given the correct medicines to treat my symptoms.” – Female, no age given |
| “Possibly a topic related to if you feel you have ever been 'looked over' by a job opportunity because of your disability, and relate that to how it has impacted you. Such as, I am impacted physically because of my body pain.” – Female, age 23 |
| “It is scary going from pediatrics to switching to a whole new team. I have had these doctors for a very long time and it is scary to have to try to find and get to know new doctors.” – Female, age 18 |
| “Well I would like to have biological children but I don't want them to have NF1. So this is the reason I want to adopt or foster a child. But also I'm 18 and I'm not all that sure. But I know that if I were to have biological children it would break my heart that they could end up having NF1.” – Male, age 18 |
| “Mine covers my entire left ankle. I have no issues with it whatsoever, except for the fact that I can't wear certain types of shoes (heels, sandals). The only time I really notice it is when someone points it out and asks about it.” – Female, age 20 |
| “My mother coordinates most of my healthcare but I am starting to work on it more.” – Female, age 19 |
| “In addition to NF1 I have had a stroke that impairs my speech and learning.”- Female, age 17 |
| “I do not personally have a NF doctor I see on a regular basis. I haven't seen one on a regular basis since I was 6 (at that point I saw one at least once a year). I saw one when I was 19 but that was 4 years ago.” – Female, age 23 |
| “I am still at school and able to join clubs like scouts. but when I am over 16 my choices are limited and because of my problems with NF it is hard to join clubs. This makes it hard to make friends. It would be helpful to have a support group or class teaching some of self care (added by parent).” – Male, age 15 |