

DESCRIBING YOUR ADOLESCENT'S LIFE



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COMPLETED BY INTERVIEWER - ADMINISTRATION MODE (CIRCLE THE NUMBER):

- 1 In-person - Self administered
- 2 In-person - Interviewer read items
- 3 In-person - Interviewer read items and marked responses
- 4 Mail - Self administered

To all parent and guardians:

Many people are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of teenagers with craniofacial conditions.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is NOT a test, there are no right or wrong answers. Please answer as honestly as you can. Your responses will be kept strictly confidential.

Thank you for your help!

Describing How The Difference in Your Adolescent's Face Affects His/Her Life

Please circle the answer that you feel best describes how closely the statement applies to your daughter/son. There are no right or wrong answers, we are only interested in your views of your daughter/son's life. Some of the questions might be hard for you to answer, but please answer ALL of the questions to the best of your knowledge.

- | | ⁰ | ¹ | ² | ³ | ⁴ |
|---|--------------|-----------------|--------------|-----------------|---------------|
| | NEVER | ALMOST
NEVER | SOMETIMES | FAIRLY
OFTEN | VERY
OFTEN |
| 1. How often does your daughter/son meet people with a facial difference like hers/his? <i>(please circle your answer)</i> | | | | | |
| 2. How often does your daughter/son have her/his picture taken? <i>(please circle your answer)</i> | | | | | |
| 3. During the <i>past 7 days</i> , how often did your daughter/son notice others staring at her/his face? <i>(please circle your answer)</i> | | | | | |
| 4. During the <i>past 4 weeks</i> , how often did your daughter/son talk with someone about how her/his face looks? <i>(please circle your answer)</i> | | | | | |
| 5. During the <i>past 4 weeks</i> , how often did your daughter/son hear other people say something about how her/his face looks? <i>(please circle your answer)</i> | | | | | |
| 6. During the <i>past 4 weeks</i> , how often did your daughter/son tell other youth her/his age about her/his facial difference? <i>(please circle your answer)</i> | | | | | |

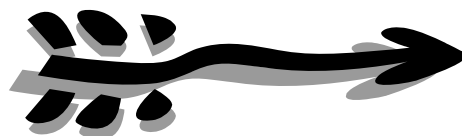
- | | 0 | 1 | 2 | 3 | 4 |
|--|-------|-----------------|-----------|-----------------|---------------|
| | NEVER | ALMOST
NEVER | SOMETIMES | FAIRLY
OFTEN | VERY
OFTEN |
| 7. During the <i>past 4 weeks</i> , how often was your daughter/son left out from doing things others her/his age were doing because of how her/his face looks? (<i>please circle your answer</i>) | | | | | |
| 8. During the <i>past 4 weeks</i> , how often did your daughter/son talk with someone s/he did not know? (<i>please circle your answer</i>) | | | | | |
| 9. During the <i>past 4 weeks</i> , how often did your daughter/son walk around in public? (<i>please circle your answer</i>) | | | | | |
| 10. During the <i>past 4 weeks</i> , how often did your daughter/son get into fights with you or your spouse because of treatments having to do with her/his face or head? (<i>please circle your answer</i>) | | | | | |
| 11. During the <i>past 4 weeks</i> , how often did your daughter/son get invited to hang out with a new group of people? (<i>please circle your answer</i>) | | | | | |
| 12. During the <i>past 4 weeks</i> , how often did other people (including you) hug your daughter/son? (<i>please circle your answer</i>) | | | | | |
| 13. During the <i>past 4 weeks</i> , how often have others talked to your daughter/son slowly or in a loud tone of voice? (<i>please circle your answer</i>) | | | | | |
| 14. During the <i>past 4 weeks</i> , how often did your daughter/son have to repeat what s/he said to other people in order to be understood? (<i>please circle your answer</i>) | | | | | |
| 15. During the <i>past 4 weeks</i> , how often did your daughter/son get into a fight with anyone because of how her/his face looks? (<i>please circle your answer</i>) | | | | | |

16. During the ***past 4 weeks***, how often was your daughter/son teased about how her/his face looks? (*please circle your answer*)
- | | | | | |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
| ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
17. During the ***past 6 months***, how often did your daughter/son go out with a girlfriend or boyfriend? (*please circle your answer*)
- | | | | | |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
| ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
18. During the ***past 6 months***, how often did your daughter/son get invited to parties? (*please circle your answer*)
- | | | | | |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
| ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
19. Does your daughter/son expect to have any surgery in the next ***12 months***? (*please circle your answer*)
- | | | | | |
|-----------------------------------|---------------------------------|---------------------------------|---------------------------------|-----------------------------------|
| ⁰
DEFINITELY
NOT | ¹
PROBABLY
NOT | ²
I'M NOT
SURE | ³
PROBABLY
YES | ⁴
DEFINITELY
YES |
|-----------------------------------|---------------------------------|---------------------------------|---------------------------------|-----------------------------------|
20. Has your daughter/son ever decided to put off for ***6 months or more*** any surgery that the doctor(s) wanted her/him to have? (*please circle your answer*)
- | | |
|---------------------|--------------------|
| ¹
YES | ⁰
NO |
|---------------------|--------------------|

If yes, why did s/he put this surgery off? (*please write your answer below*):

Did s/he ever have this surgery? (*please circle your answer*)

¹ YES	⁰ NO
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ASSESSMENT OF NEED FOR ADDITIONAL CRANIOFACIAL SURGERY

The following statements relate to how you feel about your daughter/son's need for additional craniofacial surgery in the future. Please circle the answer that you feel best describes how closely the statement applies to your daughter/son. There are no right or wrong answers, we are only interested in your views of your daughter/son's life.

21. I feel my daughter/son would benefit from additional craniofacial surgery in the future (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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22. I feel my daughter/son has had enough surgery for her/his facial difference (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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YOUR DAUGHTER/SON'S FACE

Please circle the number below that most closely describes the severity (seriousness) of the medical problems currently affecting your daughter/son's face.

23. The medical problems <i>currently</i> affecting your daughter/son's face are (<i>please circle the number</i>):	Not at all Severe 1	Minimally Severe 2	Mildly Severe 3	Moderately Severe 4	Markedly Severe 5	Very Severe 6	Extremely Severe 7
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About Yourself (Parent/Guardian)

The following questions ask for general information about you. Please circle the number next to the option which best describes you or fill in the blank.

24. What is your age? *(please write number in blank)* _____ YEARS
25. What sex are you? *(please circle the number)*
- 1 FEMALE
- 2 MALE
26. What is your marital status? *(please circle the number)*
- 1 SINGLE
- 2 MARRIED
- 3 SEPARATED/DIVORCED
- 4 WIDOWED
27. What is your highest level of education attained? *(please circle the number)*
- 0 NO SCHOOL
- 1 PRIMARY SCHOOL (GRADES 1-8)
- 2 SOME HIGH SCHOOL
- 3 HIGH SCHOOL GRADUATE/GED
- 4 SOME COLLEGE
- 5 COLLEGE GRADUATE
28. What is your occupation? *(please write your answer in the blank)* _____
29. What is your approximate household income? *(please write your answer in the blank)* _____

30. What do you consider to be your ethnic or racial background?
(please circle all that apply)

- 1 WHITE (NON-HISPANIC)
 - 2 HISPANIC/LATINO
 - 3 AFRICAN AMERICAN/BLACK
 - 4 AMERICAN INDIAN/ALASKAN
NATIVE
 - 5 ASIAN/PACIFIC ISLANDER
 - 6 OTHER, PLEASE SPECIFY
-

31. What is today's date?

ENTER TODAY'S DATE HERE

_____, ____ 20____
MONTH DAY YEAR

We realize that answering these questions may have brought up some unpleasant issues for you. If you have been upset at all by this experience, we would encourage talking about it with someone close to you, such as a friend, minister, counselor, or doctor.

Thank You Very Much For Your Help!