

**Supplemental Table S1. Speech Questionnaire**

Please answer the following questions with your parent/caregiver. Where there are multiple choices, circle your answer.

**Study title** The epidemiology of speech problems in young adults with 22q11.2 deletion syndrome

**Name** \_\_\_\_\_ **Gender** male / female

**Date of birth** \_\_\_\_\_ **Current date** \_\_\_\_\_

**Race** African / Asian / Caucasian / Latin American / Middle Eastern / Other \_\_\_\_\_

**History**

A. Were there feeding problems during infancy, where food and liquids came through the nose with feeding and spitting up? Yes / No

B. Was the young adult born with a cleft palate? Yes / No / Not sure

If yes, how severe was the cleft? (circle the number)

1. Both the hard and soft palate.
2. Only the hard palate.
3. Not sure.

**Surgery**

C. Did the young adult have surgery on his/her palate? Yes / No

If yes, When? \_\_\_\_\_ (month, year)

D. Did the young adult have a pharyngoplasty (speech-improving surgery)? Yes / No

If yes, When? \_\_\_\_\_ (month, year)

How would you rate the speech before surgery? (circle the number)

1. The speech was understandable and normal.
2. The speech differs from others. This did not lead to comments (from acquaintances or strangers) and the speech was understandable.
3. The speech differed from others. This did lead to comments and the speech was understandable.
4. The speech was understandable with some difficulty.
5. The speech was not understandable.

Did you expect the speech to normalize? Yes / No

Did your expectations change? Yes / No

Are you satisfied with the result? Yes / No

**Speech and language therapy**

E. Did the young adult have speech and language therapy? Yes / No

If yes, How long? \_\_\_\_\_ years

How often? \_\_\_\_\_ sessions per week

How much? \_\_\_\_\_ minutes per session

F. Is the young adult currently having speech and language therapy? Yes / No

If not, why was therapy ended? (circle the number)

1. The speech was adequately understandable.
2. The speech was not adequately understandable, but progress was no longer being made.
3. Another reason, namely \_\_\_\_\_

**Hearing**

G. Did the young adult have frequent ear infections? Yes / No

If yes, Did he/she have grommets? Yes / No

Did he/she have fewer ear infections after the pharyngoplasty? Yes / No / Not applicable

H. Do you use a hearing aid? Yes / No

If yes, in left / right / both ears?

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**Supplemental Table S1. Continued****Speech understandability**

I. Do you understand the young adult's speech?

Always / Often / Sometimes / Never

J. Does the young adult's teacher/employer understand his/her speech?

Always / Often / Sometimes / Never

K. Do adults who do not know the young adult understand his/her speech?

Always / Often / Sometimes / Never

L. Do the young adult's peers understand his/her speech?

Always / Often / Sometimes / Never

M. Do you or does the young adult receive comments about his/her speech?

Always / Often / Sometimes / Never

O. Do you have any other remarks on this topic? (for example, that the young adult often uses sign language when others do not understand his/her speech, or that you often do not understand his/her speech)

P. How would you rate the current speech? (circle the number)

1. The speech is understandable and normal.
2. The speech differs from others. This does not lead to comments (from acquaintances or strangers) and the speech is understandable.
3. The speech differs from others. This does lead to comments and the speech is understandable.
4. The speech is understandable with some difficulty.
5. The speech is not understandable.