KEAN

INFORMED CONSENT FORM

Title of Project: *Service delivery for selective mutism in children, adolescents and young adults with Cornelia de Lange Syndrome*

Researcher (PI):
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i) **Invitation to Participate:**

You are invited to participate in a research study via completion of an online survey. The PI is interested in investigating the service delivery with regard to assessment and treatment of selective mutism for those who are diagnosed with Cornelia de Lange syndrome (CdLS). You will be asked to share your experience and viewpoints regarding assessment and intervention for selective mutism for your patient/client/student with CdLS, and 2) provide input regarding the level of interprofessional collaboration in relation to assessment and intervention for selective mutism in CdLS. Your responses will be analyzed and data will be included in the study. Your participation is voluntary and any personal identifying information about you will not be used in the study.

ii) **Purpose of Study:**

The purpose of the study is to investigate the service delivery with regard to assessment and treatment of selective mutism for those who are diagnosed with Cornelia de Lange syndrome (CdLS). Selective mutism is an anxiety-based social communication disorder which causes inability to speak in some settings, such as school, while being able to speak in others, such as at home. It has been noted to occur especially when the demand to speak is high

iii) **Participant Selection:**

You must be a professional who works with individuals with CdLS who are: 1) aged 4 to 25 years, and 2) are diagnosed with selective mutism.

iv) **Procedures:**

You will complete a confidential online survey using your smartphone or personal laptop. The survey will discuss your experiences with and perceptions regarding the assessment and treatment services for your patient/client/student. After completing the survey, you will have an option to agree or reject an opportunity to participate in a virtual interview.

v) **Potential Risks:**

This survey carries a minimal to a moderate risk. The risks are listed below:

1a) You will complete an online survey which may take from 10 to 20 minutes, and may lead to physical fatigue.

1b) This will carry a minimal to a moderate risk.

1c) To minimize this risk, the option to stop, save and complete the survey at a later date and time will be offered.

2a) You may experience psychological stress from completing the survey. You might feel you require additional knowledge about assessment and intervention for selective mutism and CdLS.

2b) This may cause a moderate risk.

2c) To minimize this risk, contact information will be shared with you about free counseling services that are available. If needed and desired, you can reach out to Head Space (https://www.headspace.com/subscriptions?voucherCode=B2C14DANNUAL&origin=navigation-cta) and/or National Institute of Mental Health's (https://www.nimh.nih.gov/health/find-help/) websites which will be provided.

3a) You may experience sociological risk while expressing your feelings and opinions.

3b) This may carry a minimal risk.

3c) This risk will be minimized by providing links to American Speech-Language-Hearing Association's website (https://www.asha.org/), as well as the researcher's contact information at the completion of the survey.

vi) **Potential Benefits:**

You will not receive any direct benefits from participating in this research study. However, your responses may benefit the larger community of people who are diagnosed with CdLS and selective mutism. The results may add to the available literature on the topics of CdLS and selective mutism. If the study is published, your responses may add to the public knowledge, and may provide education and support for individuals with CdLS and selective mutism.

vii) **Financial Obligation:**

There is not any financial obligation associated with this research study.

viii) **Compensation/Treatment:**

There is no incentive or treatment for completing this study.

ix) Confidentiality:

- In order to ensure privacy, you will complete the survey from a secure location that will afford you confidentiality and privacy.
- You will be provided with a consent form to participate in the study which you may consent to or decline before completing the survey.
- Your name or any other identifying information will be redacted in the data collections. The data in the audio and digital files will be electronically shredded using appropriate software after 5 years as per IRB regulations.Your confidentiality will also be protected because your name or any other identifying information will not be used in presentations or written products resulting from the study.

x) Participation:
Your participation in this survey is voluntary. You may refuse to take part in the survey at any time without penalty. You will be asked about your experience and perceptions regarding assessment and treatment for selective mutism including demographic information, yes/no questions and open ended questions. Your participation is completely voluntary.

Questions/Comments:
For any additional questions or concerns about the study, you may contact the primary investigator or faculty advisor. You may also contact the IRB if there are any questions regarding your rights as a research participant.

Contact Information (Only use Kean telephone numbers and Kean email addresses)

Primary investigator/Researcher:
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Faculty Advisor:
Dr. Sarah Patten, PhD, CCC-SLP (908-737-5803) Email: spatten@kean.edu
Dr. Darya Hinman, SLPD, CCC-SLP (908-737-5803) Email: dhinman@kean.edu

IRB: (908) 737-3461 or IRB@kean.edu

Agreement to Participate:
Please sign and print your name as designated below if you agree to take part in this study. Your signature indicates that you have read and that you understand the information provided in this document, and that you agree to participate in this study. If at any time you have questions or concerns regarding the study, please feel free to contact the primary investigator or the faculty advisors at the telephone numbers or email addresses provided in this document. Your participation in this study is entirely voluntary. You may exit the study at any time. No identifying information will be included in the study. Any personal identifying information about you will not be used in the study.

Please download and print a copy of this Consent form to keep for your records. Please select your choice below. You may print a copy of this consent form for your records. Marking the "I consent" box indicates that:

- You have read the above information
- You are a parent of an adolescent with CdLS

I consent to participate in this study.
I do not consent, and I do not wish to participate in this study.

_____ _____
Signature of Participant Date

_____ _____
Printed Name of Participant Date

_____ _____

Signature of Primary Investigator Date

_____ _____

Signature of Faculty Advisor Date

_____ _____

Signature of Faculty Advisor Date