

Fostering communication between parents and clinicians using behavioral visualizations of children with autism

Sayantani Basu¹, Ban Sleiman¹, Kaori Terol¹, Christy Yoon¹, Melanie R Martin Loya¹, Jialu Li¹, Alex Atcheson¹, Siraj Siddiqi², Mark Hasegawa-Johnson¹, Hedda Meadan-Kaplansky¹, and Karrie Karahalios¹

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Abstract

The Centers for Disease Control and Prevention (CDC) reports that 1 in 36 children in the United States have autism. Early diagnosis of autism can help parents and clinicians better plan interventions to support the child's development. Parents are the experts on their child, while clinicians are experts in evidence-based interventions. Collaboration between parents and clinicians is essential for developing appropriate interventions. However, parents report frustration in their interactions with clinicians and express the need for improved communication. Communication between parents and clinicians is an area of research that requires further study. Several instruments like the RapidABC (Rapid Attention Back and Forth Communication) help screen for further assessment, however, they are not designed for parents. Tools like EnGaze and Plexlines augment such instruments by visualizing child-clinician behaviors (both micro and macro behaviors). These visualizations use different colors to encode gaze, vocals, and gestures in the form of bars and circles respectively. These visualizations further serve as a shared artifact for parents and clinicians -- and as a longitudinal record and form of comparison over multiple clinician visits. We augmented earlier versions of the interfaces using an annotation bar for shared notes and conducted interviews to understand parent-clinician communication surrounding these visualizations. We are also exploring the advantages and disadvantages of encoding behaviors using artificial intelligence techniques. Our goal is to foster parent-clinician-child conversation to help parents participate and advocate in their children's care. IRB approval (IRB #21841) was obtained for this study; it was funded by the Jump ARCHES Research and Development Program.

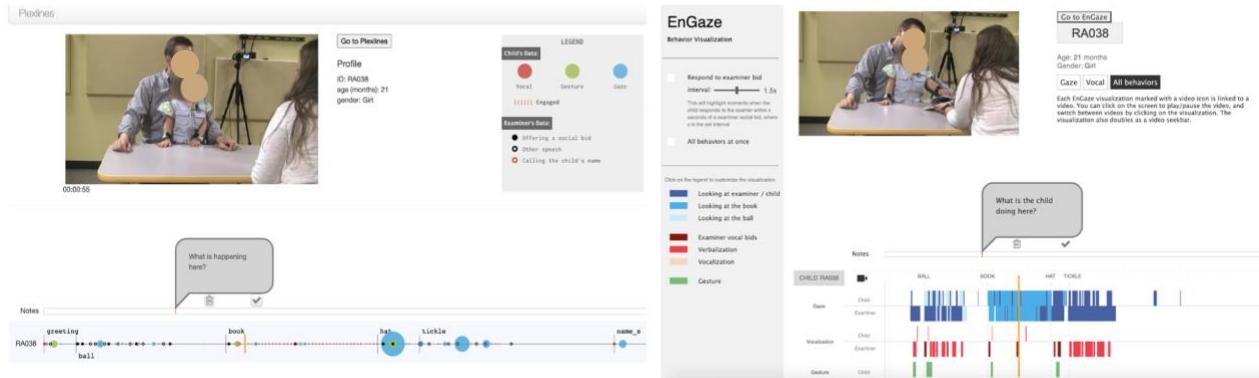


Figure 1. Augmented visualizations of Plexlines and EnGaze with annotation support for parents and clinicians

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INTRODUCTION

The Centers for Disease Control and Prevention (CDC) reports that 1 in 36 children in the United States have autism. Early diagnosis of autism can help parents and clinicians better plan interventions to support the child's development. Parents are the experts on their child, while clinicians are experts in evidence-based interventions. Collaboration between parents and clinicians is essential for developing appropriate interventions. However, parents report frustration in their interactions with clinicians and express the need for improved communication. Communication between parents and clinicians is an area of research that requires further study. Several instruments like the RapidABC (Rapid Attention Back and Forth Communication) help screen for further assessment, however, they are not designed for parents. Tools like EnGaze and Plexlines augment such instruments by visualizing child-clinician behaviors (both micro and macro behaviors). These visualizations use different colors to encode gaze, vocals, and gestures in the form of bars and circles respectively. These visualizations further serve as a shared artifact for parents and clinicians -- and as a longitudinal record and form of comparison over multiple clinician visits. We augmented earlier versions of the interfaces using an annotation bar for shared notes and conducted interviews to understand parent-clinician communication surrounding these visualizations. We are also exploring the advantages and disadvantages of encoding behaviors using artificial intelligence techniques. Our goal is to foster parent-clinician-child conversation to help parents participate and advocate in their children's care. IRB approval (IRB #21841) was obtained for this study; it was funded by the Jump ARCHES Research and Development Program.

AIM

We aim to visualize communicative behaviors of children with autism using visualization tools like EnGaze and Plexlines that can help facilitate parent-clinician communication. The goal is to empower families and parents to communicate with the child's clinicians and facilitate the aid needed moving forward.

METHODS

Inclusion Criteria

The children considered in our studies are between the ages of 0 and 5, show developmental delays, some with some without an official diagnosis.

RapidABC (Ousley et al., 2013)

The RapidABC (Rapid Attention Back and Forth Communication Test) is a 3-5 minute semi-structured protocol that consists of five stages: greet, ball, book, hat, and tickle. It is used as a screening tool for autism in infants.



Interviews

We conducted 8 interviews with parents and 2 interviews with clinicians for our current study. Our goal was observing and asking questions concerning how the users navigated our visualization tools and the role played in parent-clinician communication.

RELATED WORK

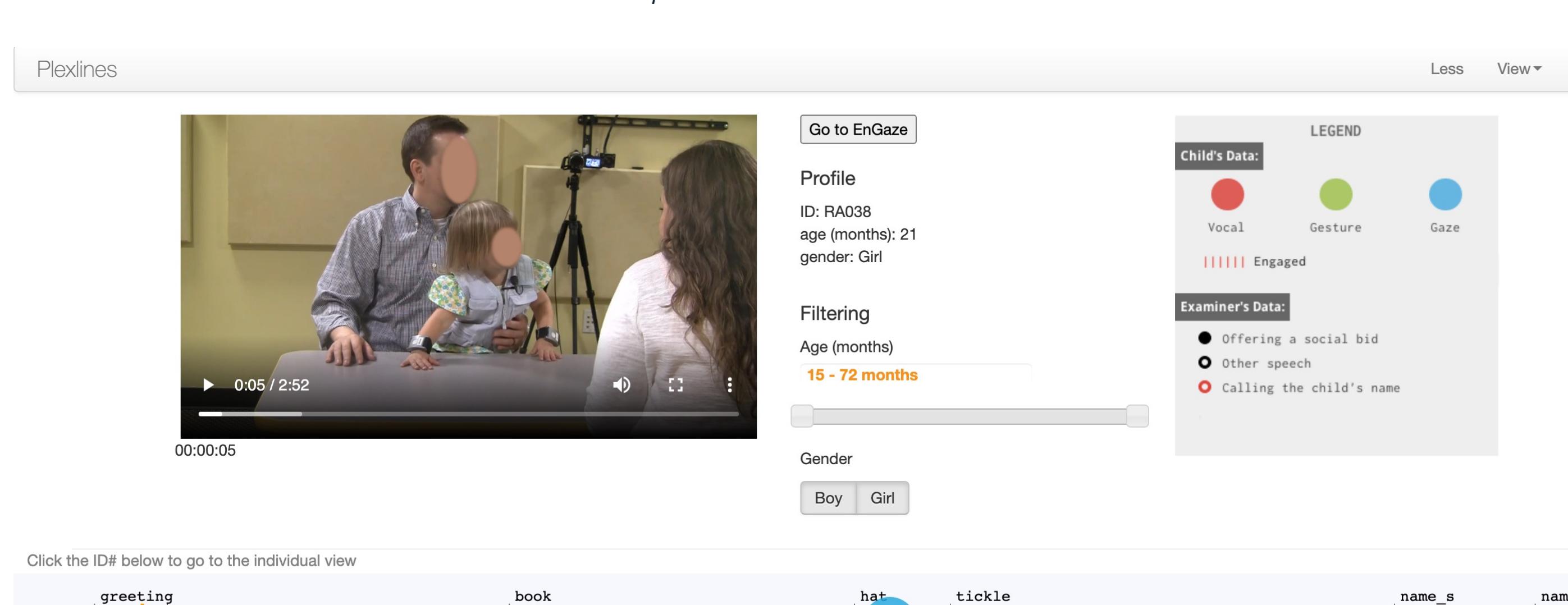
In both visualizations, blue is indicative of gaze, red is indicative of vocals, and green is indicative of gestures. The interface allows the user to sort and filter the results, with options for non-normalized views.

Plexlines (Lee et al., VAHC'13 ; Lee et al., AMIA'16 ; Kong et al., CSCW'18)

Plexlines uses circles of different colors to indicate different behaviors on a timeline, where the diameter of the circle indicates the duration of a specific behavior. Hatch marks are used to indicate points of engaging behavior in the visualization.



Sample examiner-child interaction in Plexlines

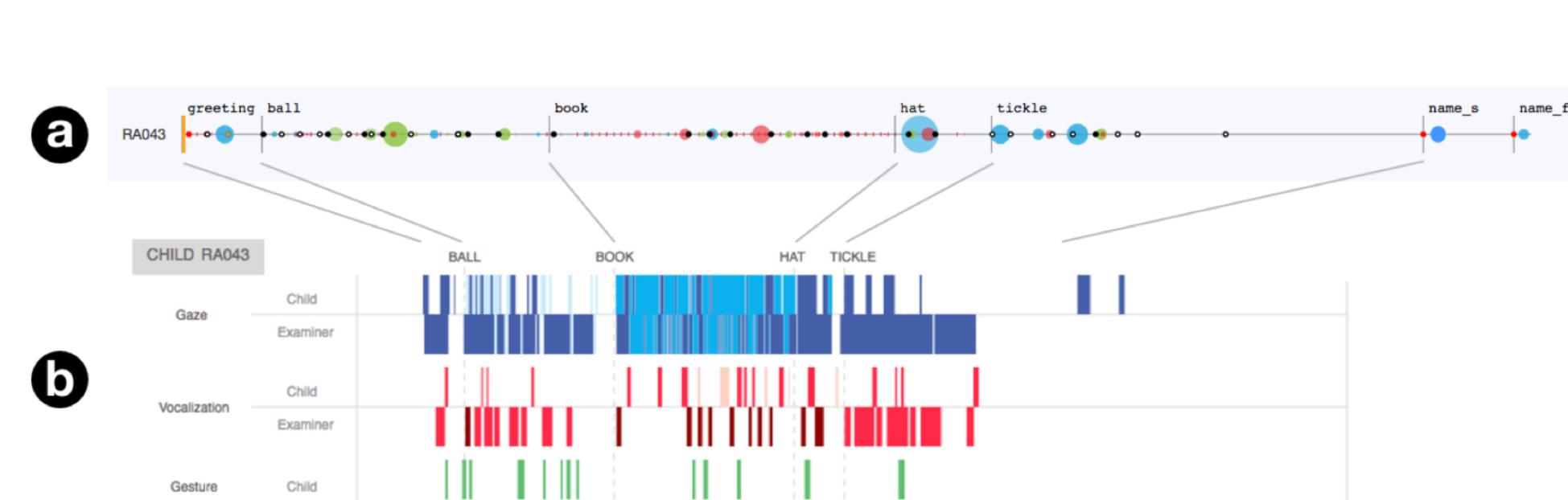


The main interface of Plexlines showing the video of the subject participating in the RABC protocol

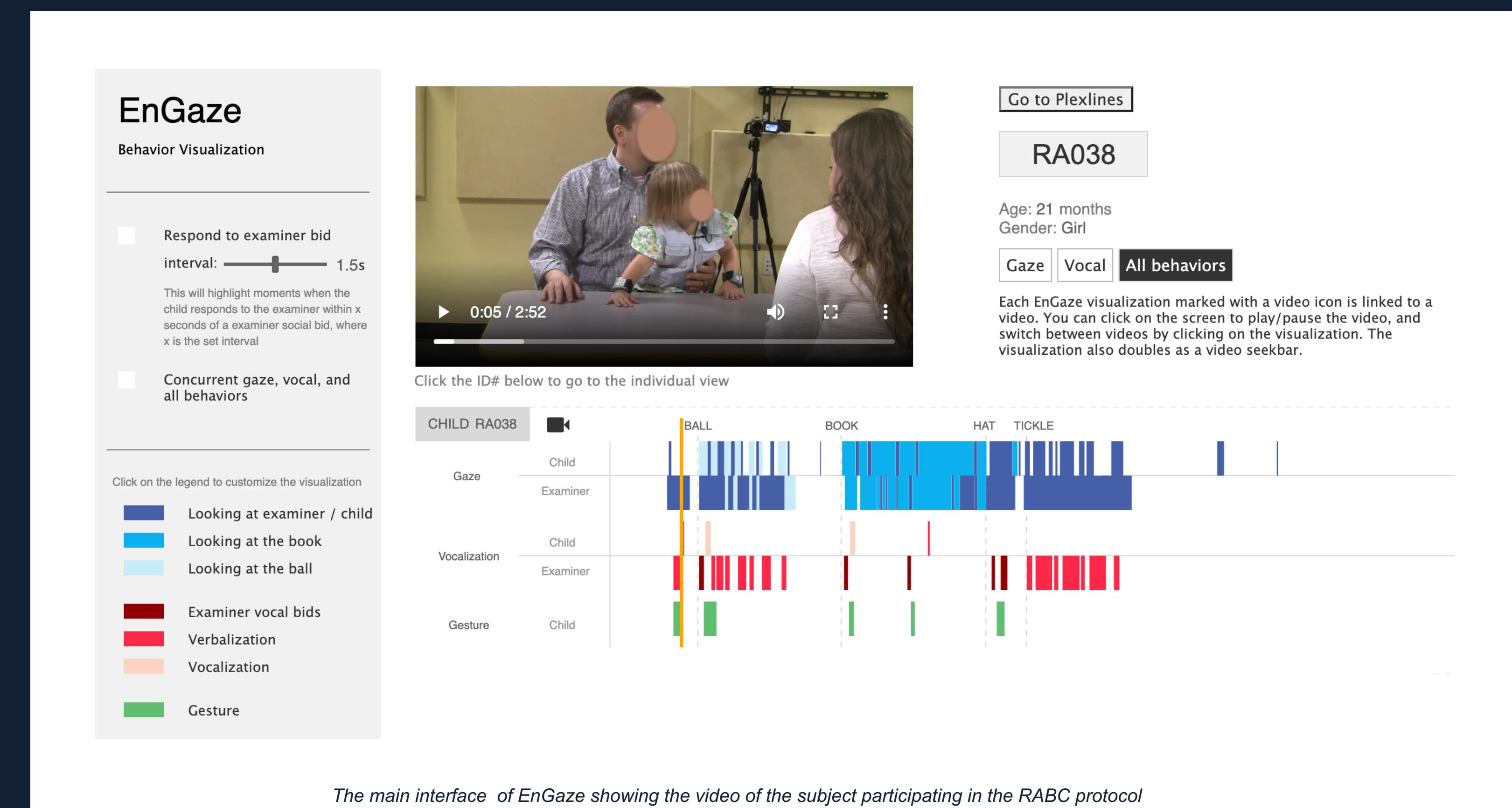
EnGaze (Kong et al., DIS'16)

The purpose of the EnGaze visualization tool is to find moments of joint attention using bars of different colors. Joint attention [5] is defined by two people simultaneously focusing on one object, person or event, and having a mutual understanding of the shared attention. The absence of joint attention is an indicator that a child may have ASD. The interface allows the user to view gaze, vocals, and all behaviors, with options to view the child's response.

A comparison of Plexlines and EnGaze shows that Plexlines is better at highlighting behaviors of longer duration while EnGaze is better at highlighting micro-behaviors [6].



Comparison of (a) Plexlines and (b) EnGaze for the different stages of RapidABC

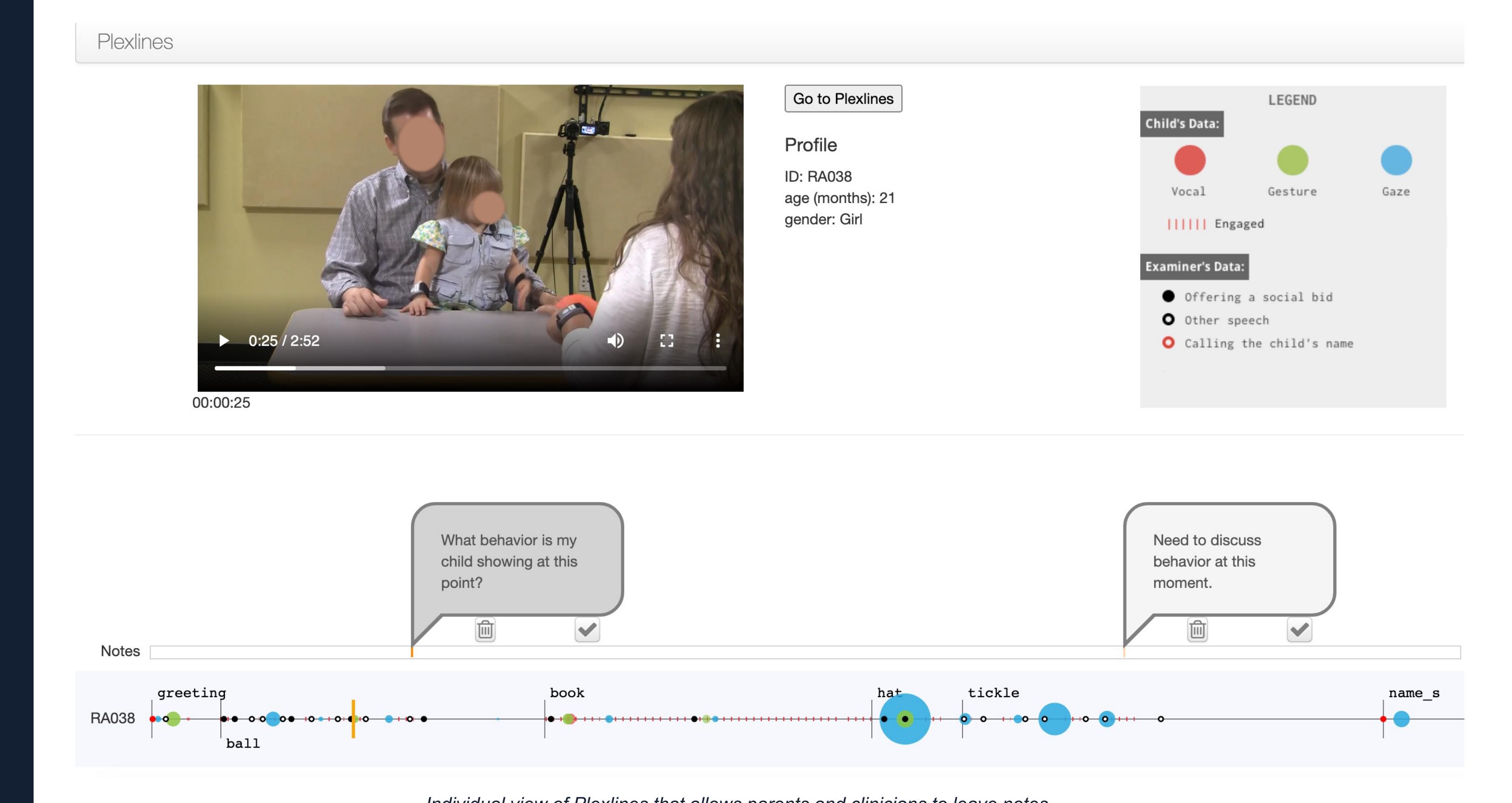


The main interface of EnGaze showing the video of the subject participating in the RABC protocol

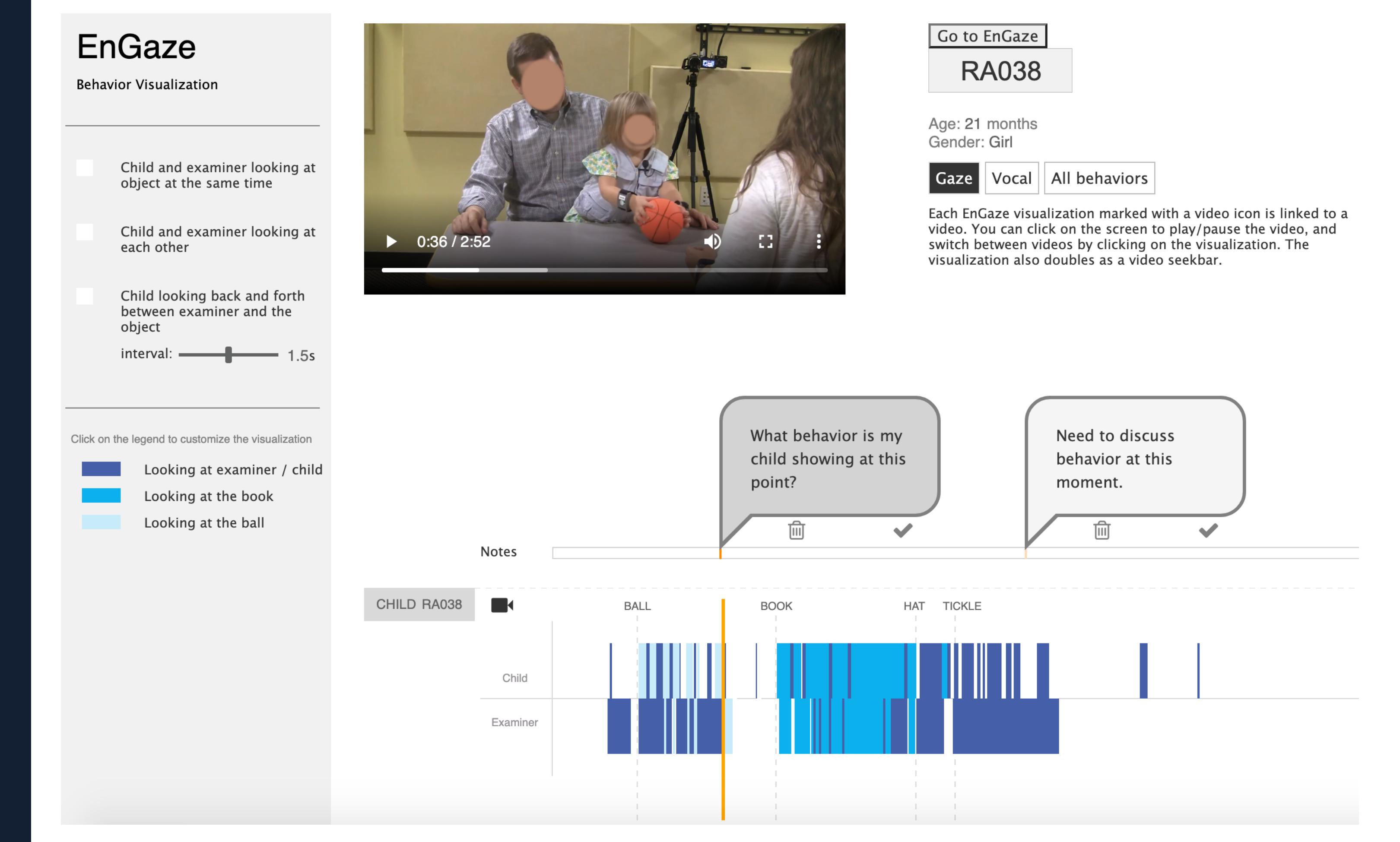
WORK IN PROGRESS

Notes bar feature that allows parents and clinicians to leave notes

We introduced an annotation bar feature in both EnGaze and Plexlines to facilitate parent-clinician interactions. We have implemented an annotations bar feature in both EnGaze and Plexlines that would enable parents and clinicians to leave notes at any point of time.



Individual view of Plexlines that allows parents and clinicians to leave notes



Individual view of EnGaze that allows parents and clinicians to leave notes

In our ongoing study, we have collected data from 14 subjects. We are currently in the process of manually hand-coding and generating the visualizations, as well as scheduling interviews with the caregivers and clinicians. In the future, we aim to automate the process of generating visualizations by using artificial intelligence methods [7] to annotate the child's gaze, speech, and gestures. We will also explore the possibilities of using these visualizations as longitudinal records.

CONCLUSION

We propose the use of two visualization tools, EnGaze and Plexlines that visualize communicative behaviors in children based on RapidABC. We focus on encouraging parent-clinician interactions through iterations of these tools and discuss our ongoing findings.

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- [1] O. Y. Ousley, R. Arriaga, G. D. Abowd, and M. Morrier. Rapid assessment of social-communicative abilities in infants at risk of autism. Technical Report CBI-100, Center for Behavior Imaging, Georgia Tech, Jan 2012.
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