

Additional Clarifications on Why Kaleb Xiong Should Be Approved For Protective Supervision

November 13, 2023

KALEB IS BOTH MENTALLY IMPAIRED AND NONSELF-DIRECTING

Kaleb Xiong is a three years and eight-months-old boy born totally blind (diagnosed with bilateral Persistent Hyperplastic Primary Vitreous - PHPV) and developmentally delayed. As we learned more about the eligibility criteria for Protective Supervision (PS) from the County of Sacramento, we take it that Kaleb's blindness will not be considered since it is viewed as a medical condition. However, Kaleb's developmental delays, including the likelihood of Autism Spectrum Disorder (ASD), impair his mental ability to be self-directing, to remain safely at home without supervision, and to need much more supervision than a typically developing child of his age.

Dated October 3, 2023, Kaleb's pediatrician, Dr. Stephanie A. Yee-Guardino, indicated on the Assessment of Need for Protective Supervision for In-Home Support Services Program (SOC 821) form that Kaleb is diagnosed with blindness and developmental delays, and his impairments were **severe** in the areas of memory, orientation, and judgment.

In the area of memory, Dr. Yee-Guardino explained that Kaleb retains some information but not in a meaningful way for safety. He has no sense of danger. His safety is always at risk in every situation. **He does not recall the usual safety norms appropriate for children of his age**, and because of this, Kaleb is under evaluation for ASD.

It is a hit-and-miss for Kaleb regarding the things he has been taught. For example, when asked for his name, he would respond with his mother's or father's name, and at times, he would get it right by responding with his name. Due to his autistic traits, he usually uses echolalia for communication. He would repeat whatever he was told. It is not because he understands.

In some instances, when he is prevented from going to places or getting what he wants, he starts yelling out gibberish and communicating things that do not apply to the situation, such as "My name is Neejtsim." The

appropriate communication should have been something like, “I don’t want to go there.” However, he was not able to appropriately communicate his desires due to his mental impairments.

While we await Kaleb’s final evaluation for ASD, a consideration of a May 2023 Elk Grove Unified School District’s (EGUSD) psychoeducational Interdisciplinary Assessment Report, along with a Functional Vision Assessment and an Orientation & Mobility assessment, on Kaleb to determine whether he would be eligible for Special Education points Kaleb to be in the **delayed range when compared to other children his age**. A summary of the results is below:

- Cognitive Functioning Skills: Delayed range, when compared to peers of the same age.
- Adaptive Functioning Skills: Delayed range when compared to same age peers and presence of significant functional skill limitations due to his visual impairment and speech/language delays.
- Speech and Language Development: Delayed in receptive language and expressive communication compared to what is expected for his age.
- Foundational Skills: Demonstrates some skills related to social communication, while other expected skills are less reliable and/or reduced in frequency, range, or quality; overall intelligibility was rated to fall within the average range.
- Academic Skills: Emerging when compared to peers of the same age.
- Orientation & Mobility: While Kaleb is ambulatory with a cane, he is unaware of time, place, self, and other people in his environment.
- Motor Skills: Demonstrates appropriate fine motor skills for his age.
- Social-emotional/Behavior Functioning: Delayed range, when compared to same age peers; may be due to his delays with speech/language and visual impairment.

Furthermore, a Kaiser Permanente Developmental Screening on Kaleb in October 2023 shows that he is **below age expectations** in the areas of communication, gross motor, fine motor, problem solving, and personal-social. As a result, Kaleb has been referred to the Kaiser Permanente Autism Spectrum Disorder Center in Rancho Cordova. Kaleb

has also been referred to the Speech Therapy Department at Kaiser Permanente in South Sacramento.

In the area of orientation, Dr. Yee-Guardino explained that Kaleb has difficulty orienting to person and safety. His environment poses safety threats if there is no constant supervision. Examples are unexpected changes, such as wet floors, things getting moved, etc. He will go with strangers without realizing he should not.

Chris Peterson, Kaleb's Teacher of the Visually Impaired and an Orientation and Mobility Specialist, stated in his May 2023 reports and a letter dated October 3, 2023, that Kaleb freely walks on surfaces, including pavement and grass, and follows voices when walking with his cane. This, however, can pose a potential danger of him following potential strangers if he is not supervised. Kaleb is unaware of time, place, self, and other people in his environment.

In the area of judgment, Dr. Yee-Guardino explained that due to Kaleb's blindness and, **more so, his developmental delays**, Kaleb lacks appropriate judgment for his age. As mentioned above, his inability to retain age-appropriate information and disorientation cloud his judgment. If not watched all the time, Kaleb could elope, and his safety is at risk.

Chris Peterson talked about how a lack of environmental knowledge makes Kaleb potentially susceptible to hazards in the areas he occupies or travels in. For example, Kaleb may be familiar with his home's layout but lacks the appropriate judgment or maturity for his age to avoid hazardous situations or deal with unexpected changes in his environment. This lack of judgment means he cannot correctly determine if something puts him in danger of harm.

In fact, Kaleb succeeded in eloping to the neighbor's garage door once when our front door was still open as we carried groceries inside. Despite his blindness, Kaleb made his way to the neighbor's garage door when we found him. Kaleb did not have the mental capacity to assess and understand that he would put himself at risk as he wandered off.

Furthermore, for self-soothing purposes, typical of people with Autism, when things are not in line with his desires, he engages in self-injurious behaviors (hitting himself with his hand, banging his head on the couch, floor, and wall, and rolling all over the floor, which leads to bumping into walls and the legs of chairs and tables, and other objects). He lacks the understanding and good judgment that the behaviors he has displayed for self-soothing purposes could get him injured.

Essentially, when compared to a typical developing child of his age, Kaleb is nonself-directing due to his mental impairment. He is unable to assess danger and the risk of harm. Consequently, he has sustained some minor self-injuries and continued to put himself at risk for self-harm.

KALEB HAS THE ABILITY AND LIKELINESS TO ENGAGE IN POTENTIALLY DANGEROUS ACTIVITIES

Despite Kaleb's blindness and developmental delays, Kaleb is ambulatory and is physically capable of harming himself. Due to his autistic tendencies, most of the time, Kaleb would be stimming (jumping or turning around while singing or engaging in echolalia), and sometimes, he would lose his balance and hit the corner wall, dresser, or the side of the bed. Additionally, due to his blindness, Kaleb's primary way of getting around is to use his hands to trail along the wall and counters. As pointed out by Chris Peterson, in the school environment, "When encountering objects along the wall such as on shelves, he would explore what the item was with his hands..." This behavior also occurs at home. It creates hazardous situations in the home if he explores or touches things that could cause harm, such as a hot stove or pushing an object that could accidentally fall on himself.

Kaleb engages in an additional dangerous activity almost 100% of the time when he gets an object in his hand. He must first put it in his mouth and bang his teeth with it regardless of the object, whether it is dirty, clean, or dangerous. There have been a few incidents where Kaleb almost succeeded in putting a phone charger cord, still plugged into the wall, into his mouth. Other items that he has succeeded in putting in his mouth were coins, batteries, a small paint bottle, eczema cream tubes, and a metal flier that has a sharp tip.

Due to his autistic tendency to stick to certain routines, Kaleb routinely attempts to play with the water in the toilet bowl. He has been caught most of the time, and we have explained that it is dirty water. However, he does not understand and continues to engage in the behavior. Also, during potty training, despite our continuous attempts that have been over a year to teach him not to engage in the behavior, he continues to attempt to reach down to try to touch his penis and dirty bottom and then put his hand in his mouth.

Although Kaleb is developmentally delayed, he is ambulatory. He can engage in potentially dangerous and harmful situations. Without someone watching him all of the time, he will succeed in engaging in self-harm.

KALEB NEEDS MORE SUPERVISION THAN A MINOR OF COMPARABLE AGE WHO IS NOT MENTALLY IMPAIRED

As seasoned parents of eight children, we take our responsibility to care for and protect our children very seriously. We know the level of needs for a typically developing child Kaleb's age. Also, Kaleb has a little brother who just turned one year old, but we can already see that his little brother has already caught up to Kaleb in many areas of development, and in some areas, he has even surpassed Kaleb. Specifically, Kaleb's little brother understands our instructions for him not to engage in a particular activity, but Kaleb does not, even after repeated attempts to teach him.

Due to Kaleb's blindness and developmental delays, he needs more care and supervision than typically developing children of his age who are not mentally impaired. This need is evident in the two sample logs we kept documenting Kaleb's incidents and dangerous behaviors. The first log covered the period of 8/29/2023 - 9/15/2023, which was shared with the IHSS social worker who came out on September 15, 2023, to conduct Kaleb's initial IHSS assessment. Following the assessment, we kept another log for the whole month of October 2023.

Below are these two sample logs:

Log Period: 8/29/2023 - 9/15/2023

- 8/29, 10:05 PM – He would not sleep, kept jumping around, and hit his head on the wood beam that is used to fill the gap between the bed and the wall.
- 8/31, 6:18 PM – He couldn't find his rubber ducky, so he started hitting his ears.
- 9/1, 9:45 PM – Bumped his forehead into the corner of the table.
- 9/2, 9:20 AM - Kaleb's head hit the cupboard trying to find his toy.
- 9/3, 4:15 PM – Bumped his forehead into the cabinet cover while opening it.
- 9/3, 6:05 PM - Walked into the corner table.
- 9/4, 3:25 PM - Walked into the wall corner in the hallway.
- 9/6, 7:18 PM - Took phone charge out of the wall and put the plug in his mouth.
- 9/7, 3:40 PM – Hit his head on the toy box from getting up.
- 9/9, 11:00 PM - Wouldn't go to sleep, was jumping up and down (stimming), ran into the dresser, and hit his head.
- 9/9, 12:22 AM - Still not asleep. Put him in bed, jumping, rolling around, and hitting his head on the wood.
- 9/10, 10:15 AM - Kaleb kept banging his head on the wood part of the rocking chair, on the carpet, or using his hand to hit his head because he was not able to find one of his toys. This happened throughout the day as he remembered to ask for the toy, but we couldn't find it for him.
- 9/10, 3:36 PM - Fell off the bed, trying to get off.
- 9/12, 5:30 PM - 2nd time for the day going into the cupboard, taking out cooking wear to play.
- 9/12, 7:06 PM - Lost his toy. Have a meltdown. Doesn't understand that we were not able to find it. He started banging his head on the chair he was sitting on.
- 9/13, 6 PM - He walked into the diner, trying to go to the bedroom, and hit his head.

Log Period: 10/1-2023 - 10/31/2023

- 10/1, 6:30 PM - While I was still chopping some vegetables, Kaleb walked over to the stove and started searching for things. His hand was so close to getting burned if I had not seen it.
- 10/2, 7 PM - He found an AA battery and was about to put it in his mouth, but I caught him before he could put it in his mouth.
- 10/4, 1:15 PM - I was changing Kaleb's baby brother's diaper, and when I saw Kaleb, he was climbing on the table, trying to search for things. He got a hold of my cup of tea and spilled it over the table and on him. Luckily, my tea was cold.
- 10/5, 12:35 PM - Found him biting a lead on the pencil.
- 10/5, 3:20 PM - Got hold of a nail clipper and was eating it. I took it away, and he started hitting his head on the rocking chair.
- 10/6, 12:15 PM - He did his rollover and hit the corner wall with his back.
- 10/6, 2:25 PM - Got a hold of a bottle of glue and was chewing the tip.
- 10/7, 4:00 PM - Found him messing with the outlet.
- 10/8, 2:05 PM - He has already pulled out my charger from the wall and was biting the cord.
- 10/10, 4:09 PM - Dropped his toy while jumping up and down, and he couldn't find it. He threw a fit and was banging his head on the rocking chair. When I asked him what was wrong, he couldn't tell me. He only got more irritated.
- 10/12, 4:40 PM - He was stimming and hit his head on the corner table.
- 10/12, 7:00 PM - Found him playing with the toilet water. He does not understand whether it's dirty or clean.
- 10/14, 10:30 PM - He walked into the kitchen, and his head hit the air purifier.
- 10/14, 11:50 PM - He was stimming in the bedroom, slipped, and hit his head on the corner bed.
- 10/15, 2 PM - Found him in the bathroom playing with the toilet water.
- 10/18, 7 PM - Fell off the dining chair while trying to get off.
- 10/23, 12:35 PM - He got into the cupboard, got a hold of a paint bottle, and banged it on his teeth.
- 10/25, 3:30 PM - He got a hold of my tea cup from the counter and spilled it all over him; lucky the tea had cooled down.
- 10/26, 6:30 PM - After I had just finished cooking, Kaleb walked over to touch the stove. I was able to run quickly enough to stop him.

- 10/28, 9:20 PM - Jumping on the rocking chair and falling off and hitting his head.
- 10/30, 8:05 PM - After Kaleb finished drinking his bottle, he decided to get out of bed. He hit his head on the wall in the process of getting out of bed.

From these sample records, we see that Kaleb had sustained some injuries and engaged quite frequently in dangerous behaviors. To keep him safe in the home, he requires additional supervision that is significantly more than routine child care.

KALEB IS IN NEED OF 24 HOUR-A-DAY SUPERVISION

We recognize that a child of Kaleb's age still needs parental supervision and protection on a 24-hour-a-day basis, regardless of whether or not the child has a mental impairment. We intend to continue to carry out our parental responsibilities to keep Kaleb safe, but as mentioned above, Kaleb is totally blind and mentally impaired. From the sample logs, we see that Kaleb sometimes even gets hurt late into the night. That is because he has an irregular sleeping pattern. He often wakes up throughout the night crying about things he thinks are happening, like a particular show still playing on TV or his iPad.

The two logs show the frequency of Kaleb getting hurt and putting himself in harm's way. While every child will still get hurt as accidents are prone to occur, Kaleb is much more prone to getting himself hurt than those of a typically developing child his age. EGUSD recognized Kaleb's propensity to be in harm's way. As part of his Special Education accommodations and services, he is given a 1:1 aide in addition to the paraprofessionals and teacher while Kaleb is at school. Kaleb must always have someone to be with him to help safeguard him from injury, hazard, or accident.

Regardless of where Kaleb is, he will always need to be closely watched and supervised, much more than a typically developing child of his age. His multiple disabilities of blindness and, more so, developmental delays impair his memory, judgment, and orientation. Altogether, it impacts his ability to be self-directed. Yet, Kaleb still can get himself hurt because he is

ambulatory. The approval of Protective Supervision for Kaleb will help reduce the propensity for Kaleb to place himself in harm's way.