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Jacob is 29 years old and lives with CHARGE syndrome. He is deafblind multi-handicapped ("DB+") with a history of over 50 surgical procedures (predominantly early in life). We still must manage a variety of medical conditions quite carefully, otherwise he is generally stable. Jacob's vision loss is extreme as he was born with severe bi-lateral coloboma's including the macula. A couple of years ago, he experienced a fully detached retina in his formerly 'good' eye which has left him with further reduced vision as he now receives input from only one eye (severe coloboma and nearsightedness). Jacob's hearing loss is severe. He has some functional hearing, so we have decided not to pursue a cochlear implant. We have attempted traditional hearing aids however Jacob refuses to wear them (we observe Jacob's behaviors and reactions as communication, we simply honor his request). Jacob is non-verbal and implements a TOTAL COMMUNICATION approach for communication with emphasis on ASL. Receptive communication happens through ASL, written words, spoken language (via limited hearing), vision (although limited), and touch. Expressive communication happens mainly via ASL assisted by gestures and written words.

Jacob's AUTONOMY is a high priority in his life. We remind everyone working with Jacob to "DO WITH NOT FOR". Independence, self-governing decision making, and self advocacy are critical which enable Jacob to be HIMSELF and not someone others would like him to be.

Jacob uses his cell phone extensively as a visual aid device to improve the level of visual inputs. Through the camera feature, he can see so much more and receive so much more visual input. While riding in the car, Jacob will use his phone to aid with distance vision. He will observe where he is going and will graciously direct

you (the driver) where to go. As well, he utilizes the camera feature to aid with close vision inputs as well.

- Using cell phone as visual aid to look for Lego blocks in the utility room and to look inside store



We are blessed that Jacob has a number of really great attributes. He is extremely physically mobile which helps with self advocacy. He is very curious and has an interest to explore and learn (whether physically (in community) or via his smart device). He is quite smart and has a VERY GOOD memory (better than most people). One very interesting attribute is that Jacob is a calendar savant. You can ask Jacob what day of the week was January 15, 1965 and he will answer (immediately) Friday. He collects 1000's of pics on his i-device which he can remember... He will often start to speak about a conference that occurred 15 years ago and go to his pics to find a specific picture in mind! This trait is quite amazing.

- Jacob on walk/run
- Jacob learning about plumbing
- Jacob looking for Lego blocks in HVAC return
- Jacob looking for Lego blocks in storm drain
- Jacob shows his flexibility



Jacob was served by NC public school until he aged out @ 22. During this time, we utilized the resources available through IDEA (Individuals with Disabilities Education Act) and remained active with NCDPI (North Carolina Department of Public Instruction) at the state level. During the early stages of public school we often struggled with 'appropriate' supports. As supports would come and go and we transitioned through the school systems, we were often confronted with new staff which required specific deafblind training. Jacob was served by a 1:1 interpreter (before NCDPI recognized the role of a deafblind intervener). During this time we simply wrote intervener based goals and strategies into the IEP which had to be fulfilled by the interpreter, teacher, TA, etc. We were fortunate that Jacob's interpreter agreed to further training to become a certified deafblind

intervener. This happened as NCDPI recognized a deafblind intervener as a valid position within the school system. For the interpreter (turned intervener), this was an inspiring transformation as she learned to see into Jacob's soul and be the conduit to assist with the outward expression to others. The direct support from a deafblind intervener was a SIGNIFICANT support role to Jacob. Through our experience, I would go so far to say that EVERY DEAFBLIND INDIVIDUAL SHOULD RECEIVE SERVICES FROM A DEAFBLIND INTERVENER.

- Symbol of intervener making the connection for their client



In March, 2017 (prior to graduation), we participated in the DBIE (DeafBlind Immersion Experience) program at Helen Keller National Center.

<https://www.helenkeller.org/hknc/deafblind-immersion-experience/> This was done as part of our transition plan in preparation for leaving the Public Education system. We invited NCDPI and NCDHHS (Div of Service for the Blind) to join (NCDHHS is the entity with the responsibility to provide deafblind services to adult individuals). Of the agencies invited, only NCDPI joined. At first NCDPI questioned 'why'. As we discussed further, they recognized the value to understand future opportunities for this demographic of students in order to further improve the education platform which prepares them for adulthood. This experience was absolutely fantastic and I would suggest you to consider it.

- Jacob doing laundry at local hospital.
- Jacob washing dishes in cafeteria.
- Jacob filling vending machines



Transition... As Jacob has navigated through the various transitions of life, we make the analogy to a relay race. In such event, multiple athletes are tasked with completing a section of a course. Each has their own responsibility. Once each section is completed, the baton gets passed. For there to be success, there must be an active entity to receive the baton. While in the public school system, we faced many transitions. Each had their own challenges however one governing precedence remained – IDEA. Through IDEA and deafblind specific mandates, the baton was passed from one entity to another (preschool → elementary → middle → high... Jacob graduated from NCDPI in 2017. He again faced another transition, this time to ‘adulthood’. However this time, the ‘baton’ gets dropped as there is no longer IDEA mandates to govern outcomes. Adult services in theory are ready to receive the Jacob’s of the world however in reality, were not. Most refer to this event as ‘falling off the cliff’. We immediately lost intervener services, gone were all previous supports, gone were social interactions (i.e. teachers, classmates, service providers...). So what next... For Jacob it meant continued advocacy for deafblind adult services, day programs, intervener services, and so on. It was as if we started all over again.

- Graduation day



Intervener services for Jacob in the adult world do not exist unless we (individually) make it happen. While Jacob was served by NCDPI, support staff interested to be trained as a deafblind intervener were supported through the deafblind project. Once Jacob transitioned to adulthood, those training facilities were no longer available. At present, the only option is self-paid certificate program offered by two facilities in the US (MI and UT). In recent years, we have had extended periods without appropriate caregivers (skill sets). For Jacob, not having support from an intervener results in further isolation of an already isolated life. We know the negative effects which isolation has on us. For Jacob, it is reasonable to expect with more isolation comes more destructive behaviors. We have directly seen the impact of inappropriate supports resulting in extreme and bad physical behaviors. On the contrary, when appropriate staff are in place, the bad behavior all but disappear. Inclusion of deafblind interveners in Jacob's support plan is essential for Jacob's wellbeing and is a basis for further encouragement of autonomy for him. This leads us to our latest effort, to advocate for training of staff serving the adult deafblind population as deafblind interveners.

Jacob currently lives with his parents and is served by the innovations waiver program through which Jacob receives various supports. Jacob was blessed to have a primary caregiver that worked with him before and after graduation. His caregiver became an intervener (self-taught) and served as a bridge as Jacob

moved into adulthood. Jacob also participates in programs offered through the local department of recreation and has recently started work at Haerfest Coffee (<https://haerfestcoffee.com/>).

During summer months, Jacob enjoys outdoor chalking of sidewalks and driveways. This activity provides Jacob with a sensory input which often lacks with CHARGE Syndrome / deafblind individuals. Years ago NCDPI sponsored an annual deafblind conference where Jacob attended annually. During these conferences, the family learned about education of deafblind individuals as well as networked with other families and professionals. For Jacob, the conference was a platform to develop social interactions and friendships which remain even today. As the conferences were stopped, it left a void in Jacob's life which finally led to hosting an annual summer deafblind gathering based solely as a social gathering. Jacob looks forward to this event which happens in June every year.

- Jacob chalking
- Jacob's annual party



We are now ~ 6 years past the "cliff". We continue to advocate for Jacob, push for improved services from the innovations waiver program and look for sustainable long-term living opportunities which are safe and serve the individual needs for

Jacob. We also advocate for improved working conditions for staff serving deafblind individuals as there is a need for a specific skill set (deafblind interveners). At present we dream about a vertically funded and implemented support focusing only on individuals who are deafblind. i.e. concentrated effort from professionals focused on deafblindness from Federal ☐ State ☐ County ☐ Individual.

Jacob's housing and care (as natural supports age) continues to be a primary concern for us. We have and continue to investigate a variety of housing / care facilities however each fall short to fill the individual needs for Jacob. Throughout Jacob's life an emphasis is made on individual needs and related supports (Individualized Education Plan, Individualized Service Plan, Person Centered Plan, and so on). Housing facilities, though they try to provide individualized solutions, simply cannot because of challenges related to funding and # of staff. To date, we know of no deafblind multi-handicapped (DB+) housing facility which provides appropriate individualized services for individuals like Jacob. There is a significant need, we hope to find a way to fill it.

Back to the days following Jacob's birth and in the midst of medical chaos. My father extended congratulations to us for the situation we were in. Dumfounded, we asked what he meant... He simply responded that we were about to embark on a life experience which very few people in this world will take. Embrace the experience, use the opportunity to make improvements along your journey, leave the world a better place than when you entered. He was so right... Each of us have a chance to make incremental improvements for those who follow. Embrace the opportunity.

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