

**Improving Support Systems for Individuals with Intellectual and Developmental Disabilities:  
Discussions with Caregivers in Hmong Communities in Wisconsin Project**

**CAREGIVERS OF HMONG INDIVIDUALS WITH IDD INTERVIEW REPORT**

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**September 30, 2021**



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*We don't have a word for autism. We don't have a word for speech delays. There are certain types of speech delays and certain levels of delays, and so in the Hmong community, what do you say when you have a child who is delayed? "Kuv tus me nyuam ruam." (Translation: My kid is stupid.) That's how you explain it even though they are not stupid.*

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*The only way to combat shame that sometimes comes with this topic is to talk about it and be real in our conversations.*

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*I think it's important for the Hmong community to define things in a way that makes sense, so that we can continue talking about it. If we're going to talk about intellectual disabilities within our culture, we need to find a way to describe it without making it a taboo or minimizing their experiences.*

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*We feel like there are definitely a lot of pockets of services in the community that not a lot of people are aware of yet. A lot of the time, that leaves families on their own trying to navigate that.*

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*The downfall is that there isn't always an in-person interpreter available, so you have to rely on over-the-phone. It's not as effective because it's not as personable, and sometimes they might not hear, or verbally translate, or interpret the full message.*

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# OVERVIEW

## Project Background

Northern Valley Industries (NVI) is a non-profit organization which aims to provide a wide range of opportunities to maximize human potential for persons with intellectual and developmental disabilities (IDD) striving for independence and self-sufficiency. They offer a wide range of services with a focus on job readiness skills, career exploration, resume development, interviewing, guided job searches, as well as developing interpersonal and coping skills to enhance job retention. Over the years, NVI noticed a lack of service usage by underserved populations such as the Hmong community. To accurately assess this issue, NVI partnered with the Wisconsin Institute for Public Policy and Service (WIPPS) Research Partners to gather more information from caregivers of Hmong individuals with IDD about the challenges they experience when accessing support services. More specifically, NVI wanted to obtain a greater understanding of the caregiver's perspective about IDD in the Hmong community and their experiences with public services such as education, health, and employment. WIPPS Research Partners conducted 7 private and confidential, one-on-one discussions via Zoom and through Qualtrics Survey with caregivers from the state of Wisconsin. An interview guide was used to facilitate discussions with topics including:

- What is the cultural knowledge and understanding of IDD in the Hmong community?
- What challenges do Hmong caregivers and individuals with IDD experience on a daily basis?
- What barriers do Hmong caregivers and individuals with IDD encounter when accessing support systems and programs?
- What information and support do Hmong caregivers and individuals with IDD need that would be beneficial in the short-term and long-term?

Through the one-on-one discussions with caregivers, information was collected to better understand cultural, educational, and healthcare challenges Hmong individuals with IDD face. It's important to note that the findings from the discussions do not reflect how an entire population views certain topics, rather, it shows *how* people feel about a certain topic and *why* they feel that way.

WIPPS Research Partners conducted virtual discussions via Zoom and through Qualtrics Survey in July to August of 2021. For privacy and confidentiality reasons, discussions were not held in a group setting. Conducting discussions privately and one-on-one contributed to ensuring that caregivers were able to fully share their personal experiences and the experiences of the person they care for. Understanding specific challenges and needs of caregivers can allow educators, healthcare providers, and community organizations to gain more insight on how to better support caregivers of Hmong individuals with IDD. There was a total of 7 caregivers and each virtual discussion lasted approximately one hour. Caregivers were either parents or siblings of the individual with IDD, and the caregivers' ages ranged from 20-40 years old. Those who are being cared for fall in the age range of 4-16. In Appendix A, a detailed overview of focus group methods and data procedures can be found.

## A NOTE TO THE READER ABOUT INTERPRETING AND USING FOCUS GROUP DATA

This report summarizes the information and feedback gathered from seven caregivers of Hmong individuals with IDD during the individual discussions via Zoom and Qualtrics Survey. There was one participant who suspected the individual they cared for has some form of autism, however, due to no formal diagnoses, is unsure of the nature of the disability. All other caregivers provided information about diagnosed individuals with IDD such as autism, ADHD, and down syndrome. We proceeded to include feedback from the first participant because it paints an insightful portrayal of Hmong caregivers for individuals with IDD who may not be aware of what IDD is.

It is also important to acknowledge the age, generation, and the level of adjustment to American customs of the caregivers who participated in the discussions. The caregivers' age range is from 20-40 and are characterized as 1.5 to 2nd generation immigrants. In other words, 1.5 to 2nd generation immigrants describe individuals who grew up or were born in the United States. This serves as a limitation due to their understanding and assimilation to western society and knowledge of what IDD is compared to 1st generation immigrants/refugees who may be struggling with heightened language, cultural and literacy barriers in which we were not able to engage with.

## KEY FINDINGS FROM CAREGIVER INTERVIEWS

**When asked about Hmong perceptions and understanding of IDD, most caregivers feel that there is little to no cultural understanding of IDD.**

Many commented on the lack of Hmong vocabulary for terms used to describe IDD. Because of this, they would have to explain the disabilities in complicated and confusing ways making it difficult for older Hmong parents or grandparents to understand. This has led to many misconceptions about IDD resulting in the community labeling the individual as 'ruam' (Translation: stupid) or 'tsis puv 100%' (Translation: not 100% intellectually and developmentally capable). Furthermore, Hmong elders have used the concept of having poor/impure genetics, religion (shamanism) and other spiritual ideations such as karma as alternative explanations for IDD or have stated the individual with IDD will grow out of it. Additionally, some caregivers believe the Hmong community does not understand western practices such as therapy and its impact on the child's social and intellectual progress. In the end, they believe through storytelling and education will the Hmong community become more accepting and receptive of individuals with IDD.

**When asked if caregivers felt that support systems are adequately addressing cultural differences to help Hmong individuals with IDD, most caregivers feel that support systems possess little to not cultural awareness.**

Many caregivers responded that in the school system, the school does what it can to accommodate for the individual with IDD. However, there is room for improvement when it comes to being culturally aware. Caregivers have made comments stating that there is always going to be a language barrier which leads to inadequate support and having little to no knowledge of services available. A caregiver mentioned that services may not even be applicable at home if it is not translated. For example, an evaluation survey is sent home and it isn't translated, therefore, no feedback can be provided. In addition, many of the caregivers feel that within the healthcare system, they do not address cultural barriers. Because of this, most of the caregivers experienced a lack of support and feel that the healthcare system does not understand the challenges some of the caregivers face.

**The caregivers are appreciative and grateful for the services made available to them and the individual with IDD. However, they found the pathway to these services very confusing and unclear.**

In other words, they had to navigate through different systems and organizations to receive one specific service. More importantly, they expressed that they were able to connect with and receive services they would otherwise be unaware of due to increased advocacy and prior knowledge whether through career or educational experiences. Thus, because of language and cultural barriers they worry for Hmong parents and siblings who do not know how to advocate for the child's needs. One caregiver whose sibling they suspect has a form of IDD discussed the struggle of receiving inadequate support and information from public systems and services. In terms of the education and healthcare system, the caregiver receives little to no information on how to support their sibling and noted the lack of transparency.

**Most of the caregivers believe that for support systems to gain a better cultural understanding of a specific community, support systems need to actively engage with that community and learn directly from them.**

A caregiver shared that there needs to be more representation in support systems whether it's in school or in the healthcare. Having professionals who understand a community's background will help to mitigate cultural, language and literacy barriers regarding IDD. Another caregiver shared that because they have a provider who comes from an Asian community, they have reassurance that the provider understands their needs and cultural differences. Caregivers have shared that religious practices have influenced many family members' perspective on IDD, which has led these individuals to turn a blind eye from the severity of the child's condition. By understanding cultural differences, support systems can better serve and inform these communities on IDD.

**Many caregivers expressed that they were concerned and uncertain about the next steps when they are no longer able to provide support.**

Many also shared that they fear the individual with IDD will not be independent when they grow up and will struggle with finding a job. A few caregivers questioned how the school system is preparing individuals with IDD for the next steps in life after completing school, as well as how these individuals can be helped so they can become employable or navigate jobs. A caregiver also mentioned financial and health insurance coverage concerns in the future for the individual with IDD. In response to these concerns, caregivers shared that a long-term need would be to learn of programs that are available for individuals with IDD which help with basic life skills and independence outside of school. Additionally, a long-term need they would like to see are programs that help caregivers become better informed on how to help individuals with IDD.

**Caregivers addressed the need to create a space and an opportunity for everyone to openly talk about IDD and their experiences as a caregiver.**

By doing this, it allows for stigma to be eradicated. In other words, the more IDD is talked about, the more normalized it will become. It also serves as an educational moment for those who don't know or understand what IDD is. Many of the caregivers welcome questions and note that no questions are bad questions. Lastly, caregivers, individuals with IDD and others are able to build a sense of community and belonging when they are able to share their stories and experiences with IDD. One caregiver said by telling her story, it provided other parents a safe space to talk about their experiences as well.

# FOCUS GROUP FINDINGS BY QUESTION

## Introduction

### 1. Question

How long have you been a caregiver and what is your relationship to the person you care for?

#### Response themes

- Since birth and parent or sibling was most frequently answered. The caregivers who were interviewed were either parents of the individual with IDD or a sibling. One sibling gets paid to provide care.

#### Relevant quotes

- *"My son has autism, and he was diagnosed right when he was about 1.5/2 years old. He's now 6, so it's been a good 5-6 years."*
- *"He is my brother and I have been taking care of him since he was born."*
- *"It's been 13 years and it is my child."*
- *"I've been a caregiver since 2016 or 2017. The person that I care for is my younger brother."*
- *"It's for my son. I've been his caregiver ever since he was born."*
- *"8 years, mother."*
- *"16 years."*

### 2. Question

How old is the person you care for?

#### Response themes

- There was a wide range of ages mentioned. All the individuals with IDD are under the age of 18. Ages shared range from 4-16 years old.

#### Relevant quotes

- *"He's now 6."*
- *"16 years old."*
- *"He is 13."*
- *"He's 10 now."*
- *"He just turned 4 in July."*
- *"8"*
- *"16 years old."*

### 3. Question

Can you tell me a little more about the nature of the disability of the person you care for (intellectual, developmental)?

#### Response themes

- There was a wide range of responses from the caregivers.



- Some caregivers reported that the individual they care for either has autism, is suspected to have autism, or is on the autism spectrum.
- Some caregivers reported that the individual they care for is either nonverbal or has speech complications.
- A caregiver reported that the individual they care for has down syndrome.
- A caregiver reported that the individual they care for is a concrete thinker, needs a lot of direction, and has delayed sensory processing.
- A caregiver reported that the individual they care for has slight cognitive delay.
- A caregiver reported that the individual they care for is introverted, sensitive to touch, and is a picky eater.
- A caregiver reported that the individual they care for has ADHD.

### Relevant quotes

- *“He has speech delays, expressive, and receptive. He sometimes can’t say what he means. Can’t really understand multi-step directions. He’s very much a concrete thinker. He does not understand abstract thoughts, which at his age range, he should be interacting with people and engaging in pretend play. He does not do any of that.”*
- *“\_\_\_\_\_ slightly has cognitive delay. We don’t know what he has though, since my parents never took him in, but I suspect he has some form of autism.”*
- *“He is on the autism spectrum.”*
- *“\_\_\_\_\_ is diagnosed with down syndrome. I think he also has a little bit of autism, I’m not really sure where he is on the spectrum with that. He can do stuff on his own. He is nonverbal.”*
- *“He was diagnosed with autism. My observation with \_\_\_\_\_ is that he is not socially equipped as other kids his age. There is delay in development. When I say social delay, that means that he does not have communication skills to engage in play with others... He would just play by himself, or he would hide in a corner or go somewhere away from the crowd. Very introverted in that way.”*
- *“Carries a diagnosis of ADHD.”*

### 4. Question

How would you describe your roles and responsibilities as a caregiver?

### Response themes

- Helping with the individual’s everyday routine was most frequently shared. Most caregivers shared that their responsibilities included helping with the child’s day-to-day activities which includes making sure the child is physically safe.
- Making sure the individual receives adequate support was another frequent answer. A few caregivers stated that their role included making sure therapy was involved in the child’s daily routine whether it was taking them to therapy or incorporating therapy into daily activities. A few caregivers also shared that their role is to make sure they are aware of resources available in order to meet the needs of their child.

### Relevant quotes

- *“He’s home with us during the mornings. We work on therapies and just our day-to-day activities. We have it so ingrained in our life that we don’t even know we’re doing therapy, but we’re doing therapy with him.”*
- *“Help him with his school which we struggle with at times. His work is different from other regular students that are his age.”*
- *“Because I’m his mom, that is my role to do that. He’s in middle school, so a lot of my responsibilities with him would be for a normal teenage student. He is not independent in going or doing anything himself without care. There has to always be somebody there with him.”*
- *“It is a paid position through the county. The role requires me to have trauma informed care training and first aid certified, and other various training the Family and Children Center host. We are required to do 6-month check-ins with his case worker from the county to check in with his needs and progress. Along with my job, caring for him on a daily basis, I also do the communication work with the county and program. Day-to-day stuff is more helping him with his hygiene practice and babysitting him.”*
- *“I’ve been trying to find programs and services to meet his needs...I always have to brace myself for the worst at times when I’m trying to transition \_\_\_\_\_, whether it’s waking up in the morning or dropping him off to the therapy session... Be extremely patient with him/transitions and to not react any time he throws a fit or is not ready to switch over... Whenever he’s upset I have to make sure to move him into a position or location where he isn’t over by any sharp corners or object that can hurt him because he will sometimes fall to the ground or throw his arms or head around... I have to oversee his MiraLAX intake, making sure he has it in the morning and evening.”*
- *“Making sure my son has access to every resource available and using those resources to the best of his ability to grow himself in order to maintain a stable lifestyle.”*

## 5. Question

Are there other people who share these responsibilities as a caregiver? For example, a spouse, family member or friend.

### Response themes

- Immediate family members and/or a spouse was most frequently answered. Almost all the caregivers responded that their spouse and/or other children share the same responsibilities. Caregivers who are not a parent to the child, stated that immediate family members share the responsibilities as well.

### Relevant quotes

- *“He had a very messed up sleep schedule. There would be some days where he slept 3 hours and so, myself or his father would be up with him... I have three other boys. Our lives just revolve around \_\_\_\_\_.”*
- *“Other family members also help.”*
- *“His dad and his grandma as well. A lot of his younger siblings took charge in watching out for him. Making sure that wherever he is if he’s going outside...at the store... make sure that if he’s there in his own world, that they will yell at his name say, ‘Hey we’re going to go’ Everyone has watchful eyes for him... Family and friends all do that.”*
- *“We all care after him.”*

- *“His older siblings do share that responsibility when they’re not in school. His father also shares that responsibility.”*
- *“Father, sister, and paternal grandparents.”*
- *“Yes, my husband.”*

## Cultural Understanding

### 6. Question

Within the Hmong community, do you feel that there is cultural knowledge and understanding of IDD?

#### Response themes

- Most caregivers believe that there is little to no cultural understanding of IDD in the Hmong community. Many commented on the lack of Hmong vocabulary for terms used to describe IDD. Because of this, they have to explain the disabilities in complicated and confusing ways making it difficult for older Hmong parents or grandparents to understand. Additionally, it is common for the Hmong community to label the individual as “ruam” (Translation: stupid) due to the lack of vocabulary and understanding of IDD. Hmong elders have used religion (shamanism) and spiritual ideations such as karma to interpret why the child has IDD. Even more, some caregivers believe the Hmong community does not understand the impact of therapy and how it helps the child progress socially and in other ways. They have also admitted themselves that they knew little about IDD until their child or sibling was diagnosed with IDD.
- One caregiver shared that it depends on the generation. This caregiver included that elders and those in the first generation have limited knowledge on disabilities, hence, stigmas surrounding IDD in the Hmong community.

#### Relevant quotes

- *“No, because we don’t have a word for it. We don’t have a word for autism. We don’t have a word for speech delays. There are certain types of speech delays and certain levels of delays...and so in the Hmong community what do you say when you have a child who is delayed? ‘Kuv tus me nyuam ruam.’ (Translation: My kid is stupid.) That’s how you explain it even though they are not stupid.”*
- *“No, I don’t think so... As much as we would hope that there would be because it’s 2021, there really is still a lot of misinformation or just misunderstanding and unawareness of what it is.”*
- *“I say no because oftentimes from what I’ve seen even with my own parents. Before my brother was born, I feel like we didn’t have enough exposure or understanding, like words to describe what is happening to people that we see with intellectual disabilities, even physical disabilities... I think people are afraid to ask or afraid to understand more about that person’s situation.”*
- *“There is not. At times, I think parents lump intellectual disabilities with all disabilities...I don’t think they understand that with therapy comes progress and I witness that with \_\_\_\_\_... He has progressed with speech, with his social skills, and so I don’t think parents, or Hmong parents see the benefits of these therapy sessions... Maybe some don’t understand it and don’t know that piece.”*

- *“Yes, however not a subject you really engage others about.”*
- *“It depends on the generation. Many elders and first generation have a very limited and stigmatizing view of people with cognitive disabilities. I consider myself 1.5 generation (first in my family to be born in America) and I had a very limited understanding any disabilities. It was until I recognized the different needs of my child that I started educating myself and became more aware of the nuances that comes with cognitive disabilities.”*

## 7. Question

What are some common cultural misconceptions you have dealt with as a caregiver?

### Response themes

- Those who have IDD are considered ‘ruam’ (Translation: stupid) was a frequent response for common cultural misconceptions caregivers have dealt with. There is not a Hmong phrase or term for IDD, so a lot of the time, individuals with an IDD are called ‘ruam’ when in fact they are not ‘ruam’.
- Being told that as time goes on the child will change was another frequent response to common cultural misconceptions. Some caregivers shared that they were told that as the child grows up, they will get better and grow out of it.
- Superstitions causing IDD were also mentioned a few times by some caregivers. Some caregivers experienced being told that it’s due to bad spirits, karma, or bad seeds in the family that has caused an individual to have an IDD.

### Relevant quotes

- *“What I heard a lot when we were starting our journey is that ‘don’t worry about your child...he’ll learn when it’s his time to learn.’ ‘txog nws caij ces nws mam li paub ua nas...’ but it’s like no, that’s not how this works... We don’t practice shamanism, but there’s a belief that maybe he’s got a bad spirit following him around... My in-laws are like, ‘well we will just pray for him he will be better.’ It’s like no, people don’t understand, especially the older generation... It takes a lot in order to get your child to where he’s supposed to be...There’s just that kind of attitude of “oh, they’ll learn when they learn... you need to stop worrying about it.”*
- *“When he was diagnosed, a lot of my relatives, older relatives, had made comments in regards to “well did you some time in your life do something or say something or disrespect somebody who was intellectually disabled, and that’s why you have a child who is intellectually disabled?”... Kids or people who are IDD, honestly the only term that Hmong people have for that is ‘ruam’ or stupid...The other misconception is public benefits. A lot of Hmong people, especially when my child was diagnosed, they readily assume that anyone can just apply for it and receive the benefit like here it is... without any consideration of your income and resources.”*
- *“I think the community doesn’t have a word for or at least an acceptable universal word for those with... IDD. A lot of the times the community refer it to ‘ruam’ which is someone who is like stupid... I often have to find myself like explaining what autism is, it’s not because you’re stupid, it’s more like they have a delay... The individual really just needs therapy to help them develop these skills.”*
- *“Having a diagnosis is not real and they’ll grow out of it.”*

- *“Stigmatizing labels as ‘dumb,’ ‘stupid’ or that the family tree has ‘bad seeds.’”*

## 8. Question

How have you dealt with these misconceptions?

### Response themes

- Education, advocating, and being vocal about their child or sibling’s condition was the most frequent answer. Most of the caregivers shared that they have educated those around them about their child or sibling’s IDD. A few caregivers talked about stigmas surrounding those who have IDD, the importance of combating stigmas that surround IDD, and how there’s so much more to an individual than their IDD.

### Relevant quotes

- *“I’m very vocal about \_\_\_\_\_’s journey on social media, so that’s kind of how I get our story out. A lot of families have come to me and said we think our child is autistic and just based off of what you’ve been sharing with your child... So really just getting that out there and educating my generation about what this...disorder looks like. There is still this misconception that...there’s a negative stigma around getting a diagnosis and so families say ‘we don’t want to get a diagnosis because we don’t want them to be labeled as you know stupid...’ It’s so much more than just a diagnosis.”*
- *“We did what we felt was best for our child at the time. Even though we got a lot of push back from my parents, my in-laws, schools about “he seems fine...you want to wait it out, just wait it out.” We educated ourselves, researched, asked the doctor a lot of questions... and the biggest one is that we had accept that our son had a disability... I think once we made that step that we were all gonna go in and be a part of his life, be a part of his journey, I think that’s when our family and friends came to accept.”*
- *“I think just reminding my parents like while we do have that spiritual side and things like that, we can only do so much to that point. Now let’s try to find other resources and other ways to make his life fulfilling and so we can’t just grieve on it... Oftentimes when I see young or old parents having children with down syndrome, I let my parents know ‘hey, it’s not just because you were older when you had this child. This young set of parents also has a child with down syndrome.’”*
- *“With the Hmong community, I have just had to educate the community the differences between autism and different types of severity of the disability.”*
- *“Engaging in honest and candid dialogue with people about my son’s challenges. This is to humanize the experience of both myself as a caretaker and the person with the disability. The only way to combat shame that sometimes comes with this topic is to talk about it and be real in our conversations. I also call out people when I hear others speak negatively or in a stigmatizing manner - engage in questioning their beliefs and educating how harmful it can be and also inviting them in conversations that can lead to empathy and compassion.”*

## 9. Question

What do you want the Hmong community to know about IDD to mitigate misconceptions?

### Response themes

- A frequent answer by the caregivers was that the Hmong community needs to find a way to describe individuals with IDD in the Hmong language. A few caregivers shared that in the Hmong community, the word ‘ruam’ (Translation: stupid) is used to describe individuals with IDD. These caregivers wish that there were better ways to describe IDD without making it a taboo or something negative.
- The significance of resources and services was another frequent response. One caregiver in particular stated that it’s important to utilize services available to receive a diagnosis. Another caregiver stated that individuals in the Hmong community who are not knowledgeable on IDD should understand that therapy isn’t meant to cure an individual with IDD, it’s supposed to make the individual’s life a bit easier to navigate.
- Another frequent response was having open conversations about IDD. A few caregivers shared that there needs to be more dialogue and questions asked to better understand the IDD community. More conversations will humanize experiences rather than minimize them.

### Relevant quotes

- *“There are so many resources out there for your child, but you have to take that first step and get that diagnosis. I think a lot of families don’t understand how the healthcare system works. They don’t understand the importance of the well child exam. They don’t understand the importance of screening for those disabilities...There are resources out there and they’re not alone...”*
- *“Just because a person has an IDD, it doesn't mean they're less of a person. They didn't choose to be that way.”*
- *“When you say IDD, I wish there was a term in the Hmong community that could be less harsh when you are talking about someone with disabilities... Not just having that one negative term to determine every disability. Whatever disability the person had, that was just the term that was used towards that individual. ‘Ruam’ or ‘that person is stupid.’”*
- *“I think it’s important for the Hmong community to... define things in a way that makes sense, so that we can continue talking about it. If we’re going to talk about intellectual disabilities within our culture, we need to find a way to describe it without making it a taboo or... minimizing their experiences or making them outsiders... We need to talk about them openly and ask questions about that community.”*
- *“I think it’s very important for the Hmong population or at least those that are not knowledgeable or don’t know anything about it to understand that just because there’s therapy and there are services, it does not mean that it’s going to fix or cure this individual. It’s just going to make their life a little bit easier for them to navigate.”*
- *“Have dialogue. Humanize the experience through storytelling. I speak openly about my experience as a caretaker. It is exhausting and emotionally draining at times. More often than not, people open up and confide about their own experiences.”*

### 10. Question

When your family talks about jobs and doing things in the community, is your child part of the conversation?

### Response themes

- Yes, but they have to consider a few factors was the most frequent response by caregivers. All the caregivers include the child in the conversation when thinking about attending

community events, however, they also consider a few factors like the type of event and whether or not the individual would like to attend. One caregiver mentioned that if the child doesn't want to try something, the caregiver may encourage the child to try it out. Ultimately, the caregiver does what's best for the child.

### Relevant quotes

- *"Yes, it really depends on what we're doing too... Every time we have something, a family gathering or just wanting to go out and do something...always included. Our family has come a long way in understanding some of his needs and some of the things he do... We ask him first...depending on his answer, that's what we'll do for him."*
- *"Depending on the size and the environment and who will be in attendance, I consider those three things. If it's just small and family then I take \_\_\_\_ and include him, and if it's going to be very casual then I will include him. If it's going to be a large water park then I would need to make sure that I'm available if we do take him. A lot of planning goes into including \_\_\_\_ when we go to large-formal events."*
- *"Even though \_\_\_\_ is a legal age of working, the family always worry if \_\_\_\_ will ever get a job. We as a family are making sure \_\_\_\_ passes High School. When it comes to the community, we do go to Hmong gatherings and go do outdoor activities. Our family involves all the kids equally and doesn't exclude one another out just because he is 'ruam' (Translation: stupid). \_\_\_\_ gets to choose."*
- *"Yes, we try to have him be an active part of the decision making but ultimately, we help guide the direction that we believe is most beneficial. For example, if my son disagrees, we may push him to experience something and then come back to reflect and decide if continuing makes sense. We check in often during the process to get a pulse check on how things are going. We also sometimes just let him make the decision and monitor from afar."*

### 11. Question

Do you feel the Hmong community has the capacity to support children with disabilities in inclusive school and community activities?

### Response themes

- No was the most frequent response by the caregivers. Almost all of the caregivers do not believe the Hmong community has the capacity to adequately support individuals with disabilities in inclusive school and community activities and see a need for improvement. One caregiver specifically shared that due to lack of education, it has resulted in the Hmong community having little to no capacity to support children with disabilities in inclusive activities. Another caregiver mentioned that depending on the severity of a person's disability, the Hmong community may or may not be able to support that individual.
- One caregiver believes that the Hmong community has the capacity to support children with disabilities in school activities but is unsure of community activities.

### Relevant quotes

- *"No, there is definitely a need for improvement... It all comes down to being more aware."*
- *"I think that the Hmong community can cater to those individuals whose disability is not as severe, where it's not going to be somewhat disruptive... Probably not, depending on the severity of the individual."*

- *“No, we do not have the capability. We don't even have the proper education to make parents understand why these children have IDD, why they are slightly different from normal children. Once the older generation understands that, they can apply it to their own kids.”*
- *“No. My son has adhd- inattention type. I feel his disability is invisible.”*
- *“School, yes. Not so sure on community activities, limited to activities due to sensory.”*

## 12. Question

Do you feel that people in the Hmong community are generally receptive to involving people with disabilities in inclusive activities?

### Response themes

- Almost all of the caregivers do not think the Hmong community is generally receptive to involving people with disabilities in inclusive activities. A caregiver shared that many activities are aimed towards individuals who are able-bodied, and in addition to that, another caregiver shared that it becomes burdensome to others when an individual with IDD is involved in activities.

### Relevant quotes

- *“I don't feel that way... I feel like as a community as a whole we still have a long ways to go.”*
- *“Once a child or a person with a disability is out of their routine that could be disruptive for them, which is an ‘inconvenience’ for folks who are trying to incorporate that person into their lives or into travel... The community is not as receptive to being inclusive to these services or to people who have disabilities.”*
- *“I haven't seen any Hmong events where it's focused around individuals with IDD. It's just more like smaller family functions that would include these individuals.”*
- *“I don't think so, the only thing that I've noticed where IDD people are included is when there is a discussion about negative stigma. The family has someone who is 'ruam' (Translation: stupid). I've never heard of anything positive in terms of people who are out of the norm. I've heard disgusting things from other family like ‘this family has a dumb person because of karma.’”*
- *“Many activities are geared towards able-bodied people. I also think people who have not had lived experience or have not been educated do not actively think about ways in which they can be more inclusive. It's similar to how people of color have to take lead in advocating for practices that are anti-racist within institutes that they work for or are a part of.”*

## Education

### 13. Question

Is the person you care for still in school?

### Response themes

- Most individuals with IDD are still in school.
- One child has not started school yet and will be entering pre-k in fall 2021.

### Relevant quotes



- *“ \_\_\_\_\_ started early intervention therapies when \_\_\_\_\_ was three years old through the school district. Again, I only know this because I know people who work in the school district and basically, we knew the head person who took care of the special needs children...”*
- *“He doesn’t start school until September, but he is in like somewhat of a daycare program.”*

#### 14. Question

What is the level of education attained thus far?

##### Response themes

- Many of the children are in elementary school, one just entered middle school and two are in high school.
- One caregiver whose child with IDD has started preparing the child for school through home education.

##### Relevant quotes

- *“ \_\_\_\_\_ will be going into first grade”*
- *“He started sixth grade. So, a fairly new school prior to the pandemic...”*
- *“ \_\_\_\_\_ will be entering his junior year in high school...”*
- *“ \_\_\_\_\_ is entering 5th grade and he has an IEP... right now he is actually in summer school so it’s an extended school year. It’s not the full week but a few hours a day for three times a week. He has activities to keep him consistent with his development. So yeah, he’s in school and gets picked up by a van and has a routine.”*
- *“I’ve purchased puzzles to help him so he can visualize where things are, help him do matching things so he can use his hands and fingers and including him in small gatherings, so he’s used to other people and not just relying on family.”*
- *“Elementary - second grade”*
- *“10th grade”*

#### 15. Question

If you can think back to before the pandemic, do you feel that the individual with IDD was provided with support and services that helped them throughout the school day?

##### Response themes

- Many caregivers think the schools provided adequate support for their child/sibling with IDD.
- Caregivers served as strong and consistent advocates for their child/sibling with IDD within the school system.
- Many caregivers expressed that their knowledge of school services is only because of increased advocacy and/or connections with school staff. One caregiver suggested that if not for their advocacy, the level of help from schools would be very superficial.
- One caregiver expressed a lack of transparency from the school.

##### Relevant quotes

- *“No, not in school. Very superficial support but only as a result of my pushing and advocating and holding them accountable.”*

- *“I’m not sure what his school life is because I am not properly informed. My mom would tell me that he goes to school like any regular student. In terms of services, I’m not sure if the school is accommodating to him.”*
- *“Most definitely just because I knew how to advocate for him, and most families don't. Most families just think ‘This is what they are recommending so this is what we are going to do.’”*
- *“I have seen some instances where families are like ‘just wait until your child goes to school and let the school deal with it’. It’s just not the school’s duty to do that. I have a say in it too.”*
- *“I realize that most families don’t have the networking and education and the background that I am very lucky to have. We tapped into the head person who directed the special needs students and asked, ‘where do we start?’ and so she kinda gave of the names of the school psychologist, this is who you call, and this is how you get started.”*
- *“At 3 years old, we had a speech therapist, occupational therapist, and special ed teach come work with him. Did that for a year. We had an IEP set up for him right when he was three so when he was four, all of that transferred over to pre-k. Pre-k was half a day and he went to the YMCA but we already had the resources...”*
- *“We check in often. I made the attempt to reach out to the new teachers, I made an attempt to reach out to what are some things that we can do to make the transition to a new school smooth given that we had moved from one side of town to a new side of town and then of course starting middle school too - kids he grew up with in elementary school are going to a different school and that obviously all of the fears that I have as a mother with a child with disabilities - what was going to happen seeing that he cannot verbalize if something were to happen to him. We had made very straightforward communication with the teacher and schools.”*
- *“Yeah, for sure. He was always with an aid, so he has his main special aid teacher and main classroom that he is in. But when he is walking from class to class or walking to his homeroom or lunch, he always has someone there to support him. The school district that we grew up in has a very good special ed program. They are very staffed honestly...and very privileged in that sense. In addition to that, he was also in a swimming program at the YMCA...and that’s another recreational thing he could do and that’s not very common.”*

## 16. Question

If you can think back to before the pandemic, is there anything you felt attributed to negative experiences?

### Response themes

- The public school system can be more involved and transparent with the services available for individuals with IDD. If the caregiver does not know how to advocate and ask for supportive services, they will be oblivious to what support systems exist.
- The special education is understaffed resulting in different consequences. For example, there’s poor communication from the school system to caregivers, staff experience burnout, there’s a limited range of skills, and the school is unable to adequately accommodate the student’s needs due to the lack of staff.
- School systems lack cultural sensitivity. The services provided do not adequately support Hmong students with IDD with Hmong preferences such as food.

## Relevant quotes

- *“He never tells me when I ask him [about school], so I’m not sure if he’s being made fun of. From what I’ve heard, he seems to be doing fine.”*
- *“I work in the schools and so I understand how overwhelming it is to serve the various needs of students and families. Staff are being stretched thin and it leads to poor communication and burn out. Systems aren’t set up to personalize plans for students and straight up, some staff just shouldn’t be working with students - no awareness, empathy, compassion, passion, and lack of cultural sensitivity.”*
- *“Getting the services started was stressful because I contacted the school early spring, and it wasn’t until fall until we got the ball rolling. Again, that was only because I kept pushing for it.”*
- *“He was working with a special ed teacher that actually doesn’t specialize with students that are non-verbal. I wonder what would have happened if he had been placed in a classroom with a teacher who worked with non-verbal kids.”*
- *“We feel like there are definitely a lot of pockets of services in the community that not a lot of people are aware of yet. A lot of the time, that leaves families on their own trying to navigate that. With our family in particular, we didn’t know anybody that had a child with disabilities, so we really had nobody to turn to at the time. It was just so stressful trying to navigate all of that.”*
- *“A big thing also is because our child is Hmong. A lot of the services may not cater well to some of the things he’s used to. For example, food. He’s a Hmong child and he loves Hmong food. For example, if he was to go to day services that they have been recommending, it just is not going to work for him. Even though we are more Americanized than our own parents, we still as caregivers find those barriers when we are trying to go looking for services for our child because a lot of it doesn’t cater to Hmong families and Hmong children who are used to Hmong food.”*

## 17. Question

What were some things that helped the individual with IDD throughout the school day during the pandemic?

### Response themes

- Many caregivers mentioned the convenience of having virtual school. For example, they were able to monitor their child, make sure their child understood the materials and be more organized with assignments.
- Virtual education was difficult for the caregivers in different ways. One caregiver talked about how they had to become their child’s teacher and because they are not trained to be educators, it was a struggle for both the child and caregiver. Another caregiver mentioned how their parent had to learn how to use technology to help their sibling with class.
- Many caregivers expressed relief knowing they had resources and services available to help them. To explain, the caregivers turned to educational assistants, case managers, speech therapists and more for guidance and help. It was also helpful to have staff provide schoolwork and/or help prepare and set up educational materials/technology for the student and family.
- What helped one caregiver the most was the option to enroll the child with IDD back into in-person classes. When this happened, their schedule was more organized and the student

with IDD was able to receive the support he needed to do well academically and personally, such as having peers to grow with and teachers to adequately support him.

### Relevant quotes

- *“She was really good at getting things set up and bringing things to the house.”*
- *“Because everyone is at home...we were at home to monitor \_\_\_\_\_, to make sure he’s on his laptop. My mother also had to work really hard to understand technology to make sure \_\_\_\_\_ makes it to class on time.”*
- *“I was also working remotely so I was able to monitor my child’s needs at home. The virtual setting lessened the number of classes a day from 7 to 3-4 classes. My son struggled with organization - he would lose his assignments at school or forget the instructions to assignments. He no longer had this issue because everything was accessible online.”*
- *“Videos of class for the day, interactive homework on iPads, schoolwork was done in the evenings.”*
- *“He always had an EA (educational assistant) with him. I think because everyone around him was wearing a mask he was able to keep his mask on.”*
- *“Knowing that we would be using computers more, they introduced him to using a mouse.”*
- *“He was able to go to school for half days five days a week and that helped him a lot.”*
- *“We were doing it all from home. I don’t know what helped him throughout the school day. It was really just taking the time to explain things to him and we’re not teachers.”*
- *“I guess talking with his case manager about ‘what are some different strategies we can use.’ and talking to his speech therapist about ‘what are different ways we can word this so that he will understand’. We were still in touch with his speech therapist from outside of school paid services. I found her a lot more helpful than the actual school services just because she’s been doing this for so long. It was like, ‘okay, \_\_\_\_\_, how do we do this? How do we put this so he will understand? What does it mean when he does this behavior - what does that translate to? And his body language - how do we read that?’. Speech therapy is more than just talking so I found that very very very helpful.”*

### 18. Question

What were some things that you feel attributed to a negative school experience during the pandemic?

### Response themes

- Caregivers feel that the school district did little to accommodate and make sure students with disabilities do well academically. Students with IDD require more support and help educationally and socially. Once the pandemic started, the school district did not provide alternative methods to help students with IDD.
- Some caregivers were disappointed in the lack of consistency and routine from the schools. As virtual school continued, there seemed to be a trend of an increasingly decreasing amount of time teachers spent with students. Additionally, if there were in-person classes, there were times where the students had to be quarantined or sent home due to COVID exposure.
- The responsibility of having to become the teacher, peer, and therapist fell on the caregivers. Many caregivers mentioned how stressful taking on different roles for the child with IDD was.

## Relevant quotes

- *“We didn’t have the support systems in place because he was doing school from home. We just had an IEP that said ‘hey, my child cannot do half this work that you’re expecting him to do. There was a point last year where he could not catch up and so his teacher said, ‘you know, if this was a regular kid, he would be labeled truant because he’s missing so much work.’”*
- *“The minute that they transitioned to being online, he was not able to do that online work. There was no possible way for him to stay focused and do things because a lot of his activities were hands on or he needed like guided activities.”*
- *“Within the district, if there are kids who are fully virtual, there is a dedicated teacher who would be working with those students virtually. There is not a special education teacher for just the special education students who want or need to be virtual. That was really hard because his teacher was in person with all of the students who are in the class, and he was just kinda zoomed in. I started with one hour in the morning, one hour in the afternoon...they had some ‘homework’ that he could work on, on the side. Then it just kinda slowly gradually decreased to 30 minutes in the morning [to], ‘we probably won’t be meeting in the afternoon anymore for math.’”*
- *“A lot of the responsibilities and a lot of the things that he would normally be doing at school with a teacher, or his peers falls on us.”*
- *“A lot of the things he retained and learned, we had to go back and reteach him.”*
- *“He thrived around his classmates when he was in elementary school. He mimicked a lot of the things that they had said like ‘Hello, how are you?’. Then during the pandemic, his language itself just went downhill. He was mimicking what his baby sister was saying. They weren’t full words anymore.*
- *“Lots of tears. Lots of crying from our end and his end because he didn’t understand the work. He didn’t understand the terminology. He didn’t understand the multi-step directions to get to where you are at.”*
- *“Virtual learning basically didn’t exist. I would say that he went once without being in touch with a teacher. From March until September, he didn’t have education or new material introduced to him or practiced. They did try to send home materials with him, and his teacher did try to check up on him. I think we did like two video calls. He’s been familiar with video calls so he knew that ‘okay that was my teacher’ and he was excited but it was the distance and inconsistency of not having that everyday routine. Even when he did return to half days, there were days when they were like, ‘okay, there was a COVID case we have to send your child home’ or ‘\_\_\_\_\_ was exposed to a staff member who had COVID. He has to stay home for 14 days.’”*

## 19. Question

Do you feel that you were made aware of different support systems available within the school like in the special education department or school counseling?

## Response themes

- Many of the caregivers say they feel they were made aware of the different services however only due to their background working in the schools.

- Many caregivers feel that families will only know services exist if they advocate and ask for it. If caregivers don't know how to advocate or know such services exist, they won't know how the schools can help them.
- One caregiver does not feel like they fully understand or were made aware of the school services available. This has led to confusion on their end about what the educational plan is for the student with IDD.

### Relevant quotes

- *"I think so...we had the school psychologist evaluate him and we sat down with the whole team of providers."*
- *"Yes I was. I was made aware of the different departments and services. But as far as like specifics in what each department entails, I don't know but I do know services exists in schools"*
- *"When I worked at the schools, I was a bilingual teacher assistant. One year, I had to help a student, I want to say he had MS where it had something to do with his spinal cord. I assisted him and I was exposed to the department or department for students with IDD. I was exposed to the learning environment they were in and services they received so through my work I was exposed to it. I think that if I had my role, I would know all of these different services."*
- *"Yes, we were definitely aware of the services and programs like summer school and swimming."*
- *"I think we were given the general introduction, 'this is your school, this is your counselor' but in regard to being made aware of the services, I guess I would say for me: because I am familiar with the school system it wasn't hard for me to navigate and ask and find out."*
- *"...if I was someone who wasn't familiar with the school system, I could see how there could be barriers. Typically, if you don't know what you need, you're not going to know where to look for it."*
- *"I am aware but it's because of my background of being in the schools"*
- *"Services are there but you won't know unless you ask."*
- *"I was familiar because I worked for the schools and yet I still faced some challenges. I just learned yesterday that every high school has a DVR counselor...I didn't know that. How do we know to ask for things when we don't know they exist?"*
- *"So, from my understanding, it wasn't very clear but they gave my family two options: either \_\_\_\_\_ takes regular classes [and] graduate with a high school diploma or take lower than regular classes [and] not graduate with a high school diploma. We decided to let \_\_\_\_\_ take the regular student one. Right now, he is taking regular classes like algebra and Spanish which is difficult for him."*

### 20. Question

In the school system, do you feel that support systems adequately address cultural differences to help Hmong individuals with IDD?

### Response themes

- Some caregivers think support systems in schools do not adequately address cultural differences to help Hmong individuals with IDD. The staff who work with them are accommodating and kind however, as a school, cultural differences are not addressed.
- Two caregivers addressed the need to advocate and correct cultural misinterpretations.
- Some caregivers address their concern with services not being provided in the Hmong language. Many non-English speaking parents/caregivers may not know how to use the technology (which is provided in English) or understand how to apply the skills and services at home.
- Two caregivers acknowledged the staff shortage and the resulting consequences. The workload for staff is immense and therefore, they may struggle to put effort into learning and addressing cultural differences.
- One caregiver mentioned how she and her husband are able to set aside cultural differences because they are college educated and more ‘Americanized’.

### Relevant quotes

- *“It’s nice but I feel like it is not as effective applying it at home especially since my family speaks Hmong at home.”*
- *“No, no, no, no. Walking into a Hmong house is really different and so sometimes there’s that reluctance to go into somebody’s home to provide care.”*
- *“No. I think within the school system, they do what they can. A lot of the teachers and staff that we have worked with have been very kind and accommodating but yeah, to answer your question and with anything else, there could be improvements.”*
- *“Because I am college educated and ‘Americanized’ I can set aside cultural barriers.”*
- *“One thing that comes to my mind first is that there are family surveys that are sent out. If a Hmong family or a Hispanic family does not check their email or know how to speak English, they will not be able to provide feedback. I wonder how many Hmong families did not fill out that survey and provide feedback.”*
- *“I think there needs to be an emphasis [from the schools] especially to Hmong parents, that these services do not cure their child. It just enables them to navigate the world better.”*
- *“Yes and no. I make sure to tell them if something may be misinterpreted.”*
- *“It depends on whether there are staff with awareness or lived experiences working on those teams. It also depends on if the caregivers know how and/or have energy to advocate for what systems they need. Burnout for caregivers is real too.”*

### 21. Question

What can the school system do to have better cultural understanding of the Hmong community?

#### Response themes

- Many caregivers suggest the school system should learn about the surrounding communities and culture. One caregiver suggested that school staff who work with Hmong children with IDD should follow a Hmong family for a day to see what it is like and all who are there to support and care for the child with IDD.
- Caregivers think the school staff should work on mitigating cultural, language and literacy barriers regarding IDD. Some methods mentioned included providing a Hmong

professional/staff specialized in IDD or special needs, just becoming aware of the barriers, providing services/information in different languages and more.

- One caregiver recommended the schools to host family game nights especially for families with children who have IDD to create and build a sense of community.

### Relevant quotes

- *“Allow the parents to explore cultural healing. For example, when we realized there was something going on and because I follow the traditional Hmong belief. We did a couple rituals for \_\_\_\_\_. I understand that it doesn’t really make much difference, but it does make me feel a little bit better that we tried everything we can to help him. If the support system encourages parents to seek whatever methods to help them overcome or help this individual will make them feel better.”*
- *“I think first, learning the culture that is around you. Being aware and spreading the disability programs to the community. Possibly have teachers address and inform families at family conferences that there are programs for children who have disabilities.”*
- *“Live a day in their shoes. Follow around a Hmong family for a day to see what their life is like. Just learning about our multi-generational household and how we incorporate that into the day to day care we provide for \_\_\_\_\_.”*
- *“I don't know what the districts have in regard to professional training related to cultural awareness or being out in the communities, but it shouldn't just only be teachers and staff that work directly working with Hmong families.*
- *“Being aware of some of the cultural differences such as language barriers.”*
- *“I hope the schools will be providing information to families who do not speak the language and involve the families in some way with the decisions.”*
- *“I hope the school district could provide a professional individual within the school that can communicate with the families in regard to rights and services to bridge the gaps.”*
- *“Maybe having family nights for family members with children with disabilities and make it a fun thing and not like an informational thing. They don’t have to necessarily be Hmong but to be able to bring your child to an inclusive space.”*
- *“A sense of community is super important with being able to start connecting with caregivers.”*

## Employment

### 22. Question

When reflecting on [individual with IDD] and their educational experience so far, do you feel that [individual with IDD] is adequately prepared for life outside of school such as employment preparedness, health, or finances?

### Response themes

- Almost all of the caregivers do not feel that their child is prepared for life outside of school. The school system does prepare the child for life-based skills and activities.
- Some caregivers expressed their child/sibling’s dependency on them and how it is difficult to encourage independence. One caregiver said she has accepted that she will have to support her child into adulthood.



- Due to the young age of the individual with IDD, one caregiver said they have not thought about what the child with IDD's future is going to look like.

### Relevant quotes

- *"In terms of educational services? No, because school-based services are focused on the skills the kids will need for school. So, it doesn't prepare you for life outside school."*
- *"\_\_\_\_\_ is not prepared for life outside of school unless he finds a job that he really enjoys. He likes Minecraft and he can tell you the ins and outs of Minecraft. However, when it comes to other things, it's difficult to get him to try other things. To get \_\_\_\_\_ to drive is going to be hard...to get him to do something alone is difficult at the moment."*
- *"Not prepared whatsoever. I've come to accept that a 4-year college may not be in his pathway and that I will need to support him well into his adulthood."*
- *"To be honest, I haven't really thought about that. If I were to think about \_\_\_\_\_ as an adult, I think he would need someone to model things for him. I think he would also need preparation. Also be readily available if he does encounter any issues that needs troubleshooting."*

### 23. Question

Do you envision [individual with IDD] being employed after high school? Why or why not?

#### Response themes

- Being employed is something that the caregivers have not thought about as much due to the young ages of the children with IDD.
- Caregivers are trying to remain hopeful and optimistic about their child/sibling potentially obtaining a job. One caregiver hopes she will find programs to help with this process.

#### Relevant quotes:

- *"No, unless he finds a job he really enjoys, getting him to try new things will be difficult."*
- *"Not sure yet, high school is a long way. Being optimistic I would hope he does."*
- *"Yes, I will make sure of it - by looking at programs that can facilitate and support this."*

### 24. Question

What supports do you believe [individual with IDD] will need to work?

#### Response themes

- There are many different support systems that the caregivers believe the individual with IDD needs to be able to work and be independent - many of them being basic society and life skills.

#### Relevant quotes

- *"\_\_\_\_\_ is independent on basic life skills such as showering, eating, and cooking. Something to help him function more independently as he grows older is maybe services that gives him more hands-on activities and explore different career fields. I also wish there were*

*other programs to keep him active. He doesn't like to be active and usually stays home and eats."*

- *"I haven't given much thought long-term. He would need someone to model and show how something is done. He's very good with visual memory."*
- *"Understanding leadership at the place of employment."*
- *"Learning his schedule, preplanning his workday, making sure he has appropriate work attire (aka clean clothes), preplanning about transportation, how to navigate conflict at work, how to problem solve when things come up unexpectedly, how to manage his finances, how to advocate for himself, how to hold himself accountable...so many things."*

## Healthcare

### 25. Question

As a caregiver, do you feel that healthcare providers understand and accurately address your concerns regarding the health and wellbeing of [name of person with IDD]?

### Response themes

- Most caregivers shared that healthcare providers understand and accurately addressed their concerns regarding the health and wellbeing of the child. These caregivers shared that the healthcare providers they work with have done a good job at advocating for the child, coordinating appointments, and making referrals.
- A few caregivers responded that to an extent they felt that healthcare providers address their concerns. A caregiver mentioned that although it's helpful that there is a healthcare provider coordinating her sibling's appointments, there are downfalls to some of the family's interaction with healthcare providers. Another caregiver shared that there are times when they have to remind the provider of the child's wellbeing.
- One caregiver shared that physicians do not understand and accurately address concerns of their sibling. The caregiver expressed a concern that the child's physician was not doing their role in accurately addressing the child's wellbeing.

### Relevant quotes

- *"I felt our providers did. We had a wonderful pediatrician. I actually worked with this pediatrician, so it was nice when I said, 'somethings wrong with my child.' He was like 'yeah, let's take a look.' So really, him advocating for us too and getting us connected to the resources that we need. So yes, I think we had a positive experience."*
- *"Our pediatrician was very great...If you're not saying anything then it's not going to be provided or it's not going to be brought up... You can lose that time or opportunity to gain whatever valuable information you may need for your child at the time."*
- *"Yes, to a certain extent... Our family is very lucky to have a... she's like a nurse but she also coordinates all his medical appointments... The positive is that we have someone who coordinates that and communicates those things and tries their best to add an interpreter for my mom during those appointments... They have a good understanding that this child has a lot of different needs and 'hey, let's address them, get him the right prescription, get him the right fitting for his foot brace.'"*
- *"We already have a family doctor and so, once we reached out to our family doctor, she was able to make the referrals. So, we did try the different services available before we sought*

*the assistance of an actual behavioral specialist. Meaning we reached out to the county birth to three program."*

- *"Physicians do not. Our physician seems like he is a 'lazy' worker and never looked into the condition that \_\_\_\_\_ has. there is a sudden weight gain in \_\_\_\_\_ and it's sad that it had to get to that point to get \_\_\_\_\_ to a physician."*
- *"I think they understand but they carry a huge caseload and so I've found myself reminding the doctor about what we've been doing."*

## 26. Question

Can you think of an instance in the last year where you had a positive experience in the healthcare system?

### Response themes

- Most caregivers shared a positive experience which all varied.
  - Having someone to coordinate care is helpful.
  - Lab technician was understanding of the child's condition.
  - Doctor was playful when taking the child's blood pressure.
  - Doctor provided clear information.
  - During flu shots.

### Relevant quotes

- *"Having that one person to coordinate care."*
- *"Every healthcare visit we have done for our child has really been positive and I think it's because we have established that long relationship with our pediatrician. The healthcare staff are well aware... There was an instance where we needed to get his blood drawn... When we had taken him in...we had to explain to the lab technician there that 'our child is on the spectrum and he is afraid of needles...' 'oh, no problem...find a couple of nice nurses to come in and hold him down.' We were all just huddled in and getting it taken care of."*
- *"Doctor explains the procedure in a playful way before doing so, for example taking blood pressure on herself prior to taking his."*
- *"I usually do. I advocate hard, ask a lot of questions, I'm honest about my concerns and our doctor gives clear information."*
- *"Besides getting Flu shots and basic needs, there is nothing in particular."*

## 27. Question

Are there any challenges you come across when interacting with the healthcare system such as receiving the right care or accommodations?

### Response themes

- Almost all the caregivers shared a wide range of challenges experienced.
  - The therapist told the caregiver that the child doesn't have autism, when in fact, the child's doctor has said that the child is on the spectrum.
  - Due to the child being non-verbal, a caregiver found it difficult to explain the child's signs and symptoms to healthcare providers.
  - Interpreters aren't always available which has made it challenging during communication.

- The birth to three program was not helpful for a caregiver. The caregiver did not see it being effective for the child. Additionally, they were not receiving any referrals by that program.
- A caregiver shared that finding youth services/accommodations is difficult.
- Dental visits are challenging for a caregiver because the dentist is always changing.

### Relevant quotes

- *“We were getting physical therapy and the therapist was like “your child isn’t autistic” and I’m like, ‘you haven’t trained in this, you don’t get to make that judgement call’ you know, when his doctor has clearly said ‘your child is on the spectrum.’”*
- *“If he was in pain anywhere, he can’t tell us. We just have to look for the signs and have to go in to talk to someone at urgent care or a healthcare provider... Our provider has been very good in regards to evaluating everything and anything.”*
- *“The downfall is that there isn’t always an in-person interpreter available, so you have to rely on over-the-phone... It’s not as effective because it’s not as personable and sometimes they might not hear or verbally translate or interpret the full message. I just wonder how my mom and dad are like ‘okay, yeah, that works.’ There have been times where people in the reception area have been very dismissive of my mom bringing in a child... They would have to wait a long time.”*
- *“I feel like birth to three was not appropriate for \_\_\_\_\_. Just because I felt like his needs were much higher. I mean birth to three comes into your home, teaches you how to say things or repeat things...but \_\_\_\_\_ is more severe than that. He wasn’t even giving you any eye contact... I feel like birth to three didn’t do an adequate job as far as directing me somewhere else when they made those observations... The birth to three person wouldn’t make us a referral, wouldn’t sit me down and say, ‘I feel like \_\_\_\_\_ needs something more vigorous.’”*
- *“When I go to the family clinic, I don’t see anything that promotes youth services/accommodation.”*
- *“Just dental. We go to First Impressions and it’s a different dentist every visit.”*

### 28. Question

In the healthcare system, do you feel that support systems adequately address cultural differences to help Hmong individuals with IDD?

### Response themes

- A little to no was the most frequent response caregivers gave. A few caregivers shared that support systems have little to no knowledge on the Hmong culture, which results in lack of addressing cultural differences to help Hmong individuals with IDD. A caregiver was curious as to whether or not healthcare providers consider that an individual is trilingual, and how that can affect an individual’s communication progress.
- A caregiver responded that having a pediatrician who is Chinese American is helpful. The caregiver shared that because they both come from an Asian background, the healthcare provider is more familiar with cultural differences.
- A caregiver shared that they think support systems can adequately address cultural differences if needed.

## Relevant quotes

- *“No, because you have a Caucasian person who does not understand the culture talking to a Hmong family. I think it would be more beneficial if you had a Hmong person who understands all the intricacies of our culture - talking to this family and saying these are the options, these are the resources, this is what this means for your child. Again, stressing that it’s just a diagnosis, it doesn’t divide your child.”*
- *“There could be improvements, I think health systems are a little bit more self-conscious...”*
- *“Sometimes... because my parents speak Hmong to \_\_\_\_ so I just wonder as they’re measuring certain things of his development or his progress, are they considering that he might be delayed because he’s...trilingual. I just wonder how much are they measuring his knowledge or development based on the fact that they don’t know how to measure the Hmong part. What if there was a nurse or a doctor that was speaking Hmong to \_\_\_\_ to track how well he responds to that?”*
- *“I can only speak from my experience. When I was pregnant and found myself having to choose a pediatrician, I specifically looked for a bipoc doctor. Our pediatrician is Chinese American and although I am Hmong, it is reassuring knowing that he’s Asian and would be more in tuned with cultural differences.”*
- *“Not that it was ever a topic that came up, but I believe they would if needed.”*
- *“Not that I noticed. I do notice that there is a cultural barrier which creates such walls--we don’t have access to services.”*

## 29. Question

What can support systems do to have better cultural understanding of the Hmong community?

## Response themes

- Caregivers provided a wide range of responses to what support systems can do to have a better cultural understanding of the Hmong community.
  - A caregiver stated that becoming educated on the community’s culture is crucial. There are many cultural influences that play a role in many individual’s outcomes.
  - A caregiver responded that there needs to be more representation in all support systems, not just healthcare. Speaking to someone who understands you, can better one’s experience and progress.
  - A caregiver shared that healthcare providers should have required training to learn more about the different cultures in their community. For example, these trainings could be led by a knowledgeable Hmong representative who can teach the history of the Hmong people.

## Relevant quotes:

- *“Really learning. Taking initiative to learn about the cultural influences. For those who still practice shamanism, it’s something wrong with...your child’s spirit, or it’s evil spirits coming to attack your child that’s causing this. This is what their level of belief is...”*
- *“We need Hmong speech pathologists and Hmong special ed. teachers...Hmong administrators. We need more representation; I think that’s the biggest thing... We’re able to practice speech pathology things in a Hmong tone of language. Maybe that could have helped him with his speech progression... It’s obvious that we need more folks going into those fields and more access to young people to go into those practices.”*

- *“I think healthcare systems should implement training that has providers sit in and learn more about the community that surrounds them. Have a proper Hmong representative who understands the community, the Hmong past/current/present culture and just does a presentation... You need cultural brokers who understand both the healthcare system in Western medicine and the Hmong culture.”*

## Conclusion

### 30. Question

What is an immediate need for you as a caregiver in the following areas: In the school system? In the healthcare system?

#### Response themes

- Some caregivers spoke about the need to be transparent with the services available. It became confusing and stressful to have to research and find services themselves. One caregiver wishes support systems would dedicate more time to explain, educate and work with families who have an individual with IDD.
- Two caregivers expressed the need for different organizations and systems to communicate and work together. The caregivers ran into many complications because they had to become the messenger for the different organizations or had to seek out services outside of the organization they worked with due to the lack of communication.
- All caregivers provided different immediate needs for caregivers, individuals with IDD and support systems. For example, there needs to be mental health services for caregivers, after school programs for individuals with IDD, increase student assistants, supporting school staff, advocators for individuals with IDD other than the caregivers, become more culturally sensitive, and more.

#### Relevant quotes

- *“I wish there was more one-on-one time for my parents with a teacher to understand \_\_\_\_\_. To educate my parents.”*
- *“I would like to see more after school activities for those who have disabilities to help them get more extra practice in school, possibly volunteer and more hands-on activities.”*
- *“Someone to assist during lunch and making sure he eats or tries something.”*
- *“Systems that allow staff to do their job, not stretch thin and having to carry such heavy caseloads. Also providing intervention early on so it's not just putting out fires.”*
- *“With the healthcare system or different services involving healthcare organizations, someone needs to stop the services and say ‘hey, I think \_\_\_\_\_ needs something more intensive so he can gain these skills.’”*
- *“I think there needs to be some sort of mental support for the family around \_\_\_\_\_. As a parent when you have your child, you envision what their future is going to be like...but once your child or individual in your family has a disability that changes up the dynamic completely and so I wish there were mental therapy sessions for support for family members so that they can go through the different kinds of stages kind of like grieving stages. I wish there was something like that, especially with the health systems. For example, when you’re a family doctor at least do some referrals or a mental health therapist.”*

- *“The access to information or transparency of information is really important in between school, hospital, and doing the care work and reporting to the county. For instance, in order to get \_\_\_\_\_ a laptop through the county, we need to verify with his healthcare provider and his school to process that and get permission.”*
- *“With his IEP reports, making sure that it's accurate and up-to-date and doesn't have a bias on his identity as a Hmong student because sometimes they undermine his progress because he speaks Hmong at home.”*
- *“More visible services. More educational outlets. More culturally sensitive services where I'd feel comfortable bringing my child to. Feeling like being a part of some sort of community.”*
- *“Something that can be readily available to provide you with resources.”*
- *“For school system's immediate needs, it would be nice to talk to a psychologist during the summer and have them check in with us - where are we going to start in the fall?”*
- *“As a provider as a whole, it's more of [informing us] what a normal child is doing at this age level. I feel that sometimes I just don't know anymore. I don't know what's normal for him and what is not normal for him.”*
- *“Marshfield clinic is good at connecting you to the right people but again, it's just individually for the child and not looking at the family as a whole.”*
- *“[Healthcare organizations] don't like to refer you to other organizations. So like feeding therapy we had to go through Aspirus. The speech therapist [from Marshfield clinic] said she does feeding therapy 'but I'm full' and didn't give us any other places. I had to do research on my own time.”*

### **31. Question**

What is a long-term need for you as a caregiver in the following areas: In the school system? In the healthcare system?

#### **Response themes**

- Caregivers would like to be introduced to services that would help the individual with IDD once they are out of high school and are an adult. Many caregivers are focused and preoccupied on what the individual with IDD requires right now and do not have the time to look at services available for adults with IDD.
- Many caregivers express worry over what the life of the individual with IDD will be like when they are no longer able to care for the individual. They worry whether the individual will be able to take care of themselves or perform basic life skills such as folding clothes, cooking for themselves and more.
- All caregivers provided different long-term needs. Some examples are:
  - Providing information in different languages.
  - Educating caregivers and family members about IDD.
  - Educating support services about cultural differences and barriers.
  - Providing available financial support programs or services (such as building a fence for safety).
  - Planning the individual with IDD's future with caregivers.

#### **Relevant quotes**

- *“I'm not sure what the government offers to individuals with IDD. If things do go wrong in the future and if \_\_\_\_\_ can't find a job or place to live, I would want to have a place where he*

can stay. I believe \_\_\_\_\_ is not dumb. He just needs someone to help him pick himself back up. If prisoners are able to have resources to prepare them for jobs outside of jail, then I wish I knew that there are programs like that for \_\_\_\_\_. Even if there is, I also don't know if \_\_\_\_\_ knows how to even seek those services himself. I wish there were programs to help him navigate for jobs."

- "With the school system, maybe allowing the parent to shadow and experience what it is like for their child to go through school."
- "I know that there is a need for fencing and keeping the child with IDD safe. Maybe programs to supplement or stipend to help with providing fencing for families so they can keep their child safe when they are outside."
- "We need to renew our first aid certification every two years and we have to pay for that and it's a huge barrier for me having the requirement to do that and yet have to pay for it. They should just give us that training for free as well as the parents and everyone else around the child. Like shouldn't we all be required for that?"
- "Translating information in different languages."
- "Make sure I am updated with the standards and provide free webinars to educate caregivers."
- "How many years out can I plan when my child ages out of school? What are the steps after that? In the case that I go before my child, is he going to be taken care of? How can the school help prepare my child so that he can be and live a full and happy life and still be able to maintain his independence in some sense? How can he navigate the system in the case that he becomes an adult? What changes form there in regard to healthcare? What are some of the health services for him in the case that he needs to seek medical attention and be able to communicate. How can he be helped so that he can be employable? Dentistry, that's a big thing too. We understand that Medicaid is not something that is used by all dentists. How can he access affordable and compassionate dental care? How can all healthcare, whether it's vision or dental or anything outside of general practitioner, be aware of the disabilities in the community and cultural differences?"
- "I worry every day that my child is not going to have a job and care for himself after I'm gone. Just teaching him the basic life skills like how to fold your laundry, how to cook for yourself, how to pay your bills. I don't think they teach that anymore in the school system because it's very academic focus and test scores. How are you teaching him problem solving skills? If my child no longer qualifies for the special needs services, who is going to teach him the skills at school?"
- "Focusing on the family as a whole and who is going to make healthcare decisions for my child when I'm gone? We don't talk about advance care planning and healthcare power of attorney."

### **32. Question**

If you could speak to anyone in the community about what needs to improve in terms of support systems for caregivers, for people with IDD or both? What would your main points be?

#### **Response themes**

- Caregivers expressed the need for the Hmong community to become more open-minded, welcoming and acceptive of individuals with IDD. They feel that due to the stigma and taboo, the Hmong community is not able to have open dialogs about experiences with IDD.



- Many caregivers feel burnt out and ask that there be support services for them. They spend so much of their time and effort advocating and helping the individual with IDD in both cultures that they are unable to care for themselves mentally and physically.
- Two caregivers talked about the need for policies to change or be created to help individuals with IDD and their families. For example, one caregiver feels that policies are geared towards individuals who become disabled and not those who are born with disabilities.
- Caregivers ask for others to be more receptive of individuals with IDD and for others to ask questions instead of avoiding the topic and situation. By doing this, it relieves the stigma and also educates people about IDD.

### Relevant quotes

- *“We need to have open and honest dialogue with one another to remove the stigma. We also need to call out when we see things that are getting in the way of supporting our children’s needs.”*
- *“We need people to advocate for us... not just us advocating for ourselves.”*
- *“I would like support systems to aid someone like \_\_\_\_\_ because people with IDD may not know how to access these programs and services that are meant for them.”*
- *“Really looking at the family as a whole and providing holistic care. Caring for the caregiver is so important because we give 110% of ourselves to others and then we don’t give to ourselves.”*
- *“More transparency, having more visibility about what is available.”*
- *“I hope legislatures look at policies in regard to benefits and eligibility criteria because sometimes with some of these policies, I see that it is geared towards those who become disabled vs those born disabled.”*
- *“People with disabilities - that’s the only life they have known and it’s normal for them. We should not continue isolating people with disabilities. We should not continue taboos talking about people with disabilities or fearful to ask about it.”*
- *“There is a lot of fatigue with caring for folks with IDD so there needs to be a system to care for the caregivers. There needs to be support all around.”*
- *“At the political level, being able to pass laws, regulations and policies for them [individuals with IDD] so they can access them [support services].”*
- *“For caregivers, I think they really need the mental support from specialist.”*
- *“For the individuals with IDD, there are parks that cater to children with disabilities such as Jojo’s Jungle Gym and I was really appreciative of that. \_\_\_\_\_ is in a daycare where they can provide ABA therapy and I love that.”*

### 33. Question

Is there anything else you would like to share about your experience as a caregiver?

### Response themes

- Many caregivers encourage others to ask questions and for others to share their experiences to mitigate or even get rid of stigmas and taboos. Building a sense of support and community is important in fighting against the stigma.
- Two caregivers noted the positive aspect of seeing their child with IDD grow despite the difficult road to getting there.

- One caregiver reiterated the need for services to be shared and be made more publicized so they can know where to look for help when the time comes.

### Relevant quotes

- *“It’s been hard but very rewarding to watch the progress.”*
- *“It’s been exhausting but rewarding to see my son overcome challenges.”*
- *“I do notice that some siblings care more for the family member who has IDD. I feel like the stigma that my parents labeled \_\_\_\_\_ with influences other siblings and they start to perceive \_\_\_\_\_ the same way my parents perceive him.”*
- *“It’s very difficult explaining to the elders what my son’s disabilities are, why we have a service dog, why the dog gets to go everywhere my son does. I know we are never going to change their misconceptions so we gotta start with my generation and the generations after that about what life looks like caring for a child with disabilities.”*
- *“It’s just amazing once you open up about your child’s disabilities and then other people say, ‘oh yeah, we’re going through the same thing.’ You don’t know unless you share.”*
- *“We need to talk about it [IDD] more and not see it as a taboo, bad luck or anything like that. I think a lot of families kind of conceal that just due to them not wanting their child to act out or to cause trouble or because they’re afraid other families will not understand. I think just becoming accepting of it and talking more about it. Having a support group for Hmong families who are going through this. Some support groups we participate in are wonderful, but you know the majority of them are Caucasian families.”*
- *“It’s okay to disagree and you can ask questions.”*
- *“In relation to Northern Valley’s mission and thinking long-term for \_\_\_\_\_, I would like just to know a little more about the services available to him once he’s done with school. What resources are there? I think if I can receive that information or at least the support around the individuals with IDD ahead of time so we can plan for the future. Making them informed about the services and resources available.”*

## APPENDIX A – OVERVIEW OF FOCUS GROUP METHODS AND DATA COLLECTION

### Methods and Approach to The Caregivers of Hmong Individuals with IDD Focus Groups

Northern Valley Industries (NVI) offers a wide range of services with a focus on job readiness skills, career exploration, resume development, interviewing, guided job searches, as well as developing interpersonal and coping skills to enhance job retention. NVI is located in Wausau, WI where it has a fairly diverse population, which includes the Hmong community. Due to lack of service usage by underserved populations, specifically by the Hmong, NVI wanted to understand the challenges this community faces.

NVI partnered with the Wisconsin Institute for Public Policy and Service (WIPPS) Research Partners to gather more information from caregivers of Hmong individuals with IDD about the challenges they experience when accessing support services. More specifically, NVI wanted to obtain a greater understanding of the caregiver's perspective about IDD in the Hmong community and their experiences with public services such as education, health, and employment.

In July to August of 2021, WIPPS Research Partners conducted 7 private and confidential, one-on-one discussions via Zoom and through Qualtrics Survey with caregivers from the state of Wisconsin. To ensure a personable, private, and confidential experience for caregivers, discussions were not held in a group setting. This allowed caregivers to have enough time to fully share their experiences and the experiences of the individual they care for. During the search for caregivers, the WIPPS Research Partners reached out to businesses and shared flyers to see if there was any interest from caregivers. It was difficult to find caregivers who first showed interest in participating, so it came down to finding caregivers through word of mouth. Although there were only 7 caregivers who participated, this study was still very meaningful considering the high level of stigma IDD has within the Hmong community. For this reason, the 7 caregivers provided a detailed glimpse of the unique experiences not commonly discussed in either the Hmong or American culture.

It is important to note that the findings from the discussions do not reflect how an entire population views certain topics, rather, it is used to better understand the reasons underlying specific individuals' perspectives or the variety of perspectives on a given topic. If there were a larger number of caregivers that participated, the study could have portrayed even more perspectives on topics discussed, and/or expressed deeper understandings of experiences caregivers have had. WIPPS Research Partners felt that the 7 interviews were more than a success and all the caregivers that were a part of this conversation need to be heard no matter what.

### Designing The Interview Guide

NVI wanted to hear from caregivers of Hmong individuals with IDD about their perception of IDD and their experience with gaining access to public services. The project has a particular focus on the Hmong cultural understanding of IDD, the barriers caregivers experience when accessing school and healthcare systems, their impression of the system's understanding of Hmong cultural needs and differences and lastly, what the immediate and long-term needs are for the caregivers and individuals with IDD. WIPPS Research Partners designed a focus group discussion guide that allow for information to be gathered on topics such as:

- What is the cultural knowledge and understanding of IDD in the Hmong community?
- What challenges do Hmong caregivers and individuals with IDD experience on a daily basis?
- What barriers do Hmong caregivers and individuals with IDD encounter when accessing support systems and programs?
- What information and support do Hmong caregivers and individuals with IDD need that would be beneficial in the short-term and long-term?

The interview guide (see Appendix B) enabled WIPPS Research Partners to gather qualitative data from caregivers based on discussions with them about their perceptions, insights, feelings, and explanations. Observers of the discussions listen carefully to identify common themes or “threads” that emerge within a caregiver, as well as across all caregivers. These common themes were then summarized, with de-identified quotes or comments from the participants used to illustrate or support the overarching themes. The focus group facilitators independently review the overall summary of themes prepared by the observers in order to provide a secondary check for accuracy and completeness and to minimize the potential for any bias in how the information is presented.

### **Participant Selection Criteria**

Caregivers of Hmong individuals with IDD had the opportunity to participate in this project. There was no limitation on the age range, educational level, socioeconomic status, or gender of either caregiver or individual with IDD.

### **Methods**

The following is the basic framework that was followed with respect to organizing and conducting the discussions.

- Individual discussions were held for each participant to account for confidentiality and scheduling conflicts.
- Each discussion lasted approximately 1 hour.
- The participants were caregivers of Hmong individuals with IDD that represented a broad mix of age ranges, educational level, socioeconomic status, and genders.
- Caregivers were identified for participation through direct outreach through various means such as referrals and networking. Email, Facebook, and other internal communication channels were also used. Advertisement searching for participants was also used, however unsuccessful.
- Caregivers who were unable to participate in the Zoom discussion was provided with a Qualtrics Survey to complete with all interview questions.
- Caregivers received a \$25 gift card in appreciation for their participation.
- Caregivers were informed that they would not be personally identified in the report or summary of the findings, nor would quotes be reported with attribution to a specific individual.
- The focus groups were conducted via Zoom and were recorded in order to assist with analysis.

### **Protecting Caregiver and Individual with IDD Confidentiality**

For privacy and confidentiality reasons, discussions were not held in a group setting. Through Zoom, interviews with caregivers were one-on-one with WIPPS Research Partners. Sessions were recorded to help with analyzing common themes and identifying relevant quotes. The recordings and notes were kept

private, and only members of the WIPPS Research Partners had access to these items. This applies for the Qualtrics Surveys as well. Several steps were taken to minimize identified risks and confidentiality:

- Before, during, and after interviews and recordings on Zoom and through Qualtrics Survey, WIPPS Research Partners made sure to remind the caregivers that the entire discussion was to remain private and confidential.
- WIPPS Research Partners explained to the participants that the information collected is not geared towards anything negative, rather, it is geared towards educating local community members of the experiences caregivers of Hmong individuals with IDD have had.
- Caregivers were never pressured to answer and/or discuss anything they did not want to.
- Caregivers could opt out of discussions at any time or have their video feature off.
- Names of caregivers or the individual that they care for were never mentioned in the report. No specific personal or demographic is shared such that a quote or comment could potentially be applied to someone.

### **Benefits of Participation in This Project**

Participants in this project have the opportunity to share their experiences, challenges, and perspective to not only Northern Valley Industries, but to other community organizations, healthcare providers, and educators. It is with hope that these findings will help professionals in the community to make more informed decisions on how to better serve caregivers and individuals with IDD from underrepresented communities. Community organizations, healthcare providers, and educators will benefit by:

- recognizing common challenges and experiences caregivers of Hmong individuals with IDD have in order to implement better services.
- understanding the cultural differences that need to be addressed in order to serve the community to the best of their ability.
- gaining knowledge on how to become more educated on a communities' history.

Additionally, this project is not only beneficial to organizations, healthcare providers, and educators, but to the Hmong community as a whole. The Hmong community will benefit by becoming more aware and educated on not only IDD, but specifically the challenges caregivers and families of Hmong individuals with IDD face. This project aims to combat the stigmas that surround IDD in the Hmong community, and it aims to start more conversations. Furthermore, this project will hopefully reach other caregivers and help them understand that they aren't alone, and there are others who share similar experiences.

# APPENDIX B – INTERVIEW GUIDE



## KEY INFORMANT INTERVIEW GUIDE NORTHERN VALLEY INDUSTRIES – IDD GAP STUDY

### INTRODUCTION, PURPOSE, LOGISTICS, GROUND RULES

I would first like to thank you for talking with me today and contributing your time and expertise to this project. My name is [NAME] and this is my colleague [NAME 2]. We work with the Wisconsin Institute for Public Policy and Service based in Wausau and we are serving as a research partner with Northern Valley Industries on this project.

We are working with Northern Valley Industries to gather information and understand the gaps and barriers in marginalized communities for those with intellectual and developmental disabilities (IDD). The goal of this project is to hear about the challenges that caregivers have navigating services in the community.

Northern Valley Industries' mission is to provide a wide range of opportunities to maximize human potential for persons striving for independence and self-sufficiency. A wide range of services are offered with a focus on job readiness skills, career exploration, resume development, interviewing, guided job searches, as well as developing interpersonal and coping skills to enhance job retention.

Our interview will take one hour. My colleague will take notes while we are talking and at the conclusion of the interview, I will write up summary notes. We will then synthesize the information we learn across all the people we interview and provide Northern Valley Industries a summary report. A summary will also be provided to you. Comments will not be attributed to you directly in the report and you will not be quoted.

Any questions about the purpose of the interview and how the information will be used?

Before we begin, I would like to request your permission to record our conversation today. The recording will help us develop a more accurate reflection of your input as we write up our notes. It will only be used by our team and not shared with anyone else, including Northern Valley Industries. Would it be OK with you to record our conversation?

### INTRODUCTORY QUESTIONS FOR CAREGIVERS

1. How long have you been a caregiver and what is your relationship to the person you care for?
  - How old is the person you care for and what is their name?
2. Can you tell me a little more about the nature of the disability of the person you care for (intellectual, developmental)?

3. How would you describe your roles and responsibilities as a caregiver?
  - Are there other people who share these responsibilities as a caregiver? For example, a spouse, family member or friend.

### **CULTURAL UNDERSTANDINGS**

1. Within the [Hmong or Hispanic] community, do you feel that there is cultural knowledge and understanding of IDD?
  - What are some common cultural misconceptions you have dealt with as a caregiver?
    - How have you dealt with these misconceptions?
2. What do you want the Hmong community to know about IDD to mitigate misconceptions?
3. When your family talks about jobs and doing things in the community, is your child part of the conversation?
4. Do you feel the [Hmong or Hispanic] community has the capacity to support children with disabilities in inclusive school and community activities?
5. Do you feel that people in the [Hmong or Hispanic] community are generally receptive to involving people with disabilities in inclusive activities?

### **ACCESS IN EDUCATION**

1. Is the person you care for still in school?
  - If yes, what is the level of education attained thus far?

If person with IDD is currently in school:

2. If you can think back to before the pandemic, do you feel that [name of person with IDD] was provided with support and services that helped [name of person with IDD] throughout the school day?
  - Is there anything else that you felt attributed to a negative experience?
3. Now thinking about this past school year with the pandemic, what were some things that helped [name of person with IDD] throughout the school day?
  - Is there anything else that you felt attributed to a negative experience?

If person with IDD has previous schooling:

4. When reflecting on [name of person with IDD] educational experience, do you feel that [name of person with IDD] were adequately prepared for life outside of school, such as employment preparedness, health, or finances?
  - If yes, were there any specific support systems in the school that prepared [name of person with IDD]?
  - If not, why? What could the school have done better to prepare [name of person with IDD]?

For all participants to answer:

5. Do you feel that you were made aware of different support systems available within the school, like in the special education department or school counseling?
6. In the school system, do you feel that support systems adequately address cultural differences to help Hmong individuals with IDD?
  - What can support systems do to have better cultural understanding of the Hmong community?

## **EMPLOYMENT**

1. When reflecting on [name of person with IDD] their educational experience so far, do you feel that [name of person with IDD] is adequately prepared for life outside of school, such as employment preparedness, health, or finances?
2. Do you envision [name of person with IDD] being employed after high school? Why or why not?
3. What supports do you believe [name of person with IDD] will need to work?

## **ACCESS TO HEALTHCARE**

1. As a caregiver, do you feel that healthcare providers understand and accurately address your concerns regarding the health and wellbeing of [name of person with IDD]?
2. Can you think of an instance in the last year where you had a positive experience in the healthcare system?
  - Are there any challenges you come across when interacting with the healthcare system such as receiving the right care or accommodations?
3. In the healthcare system, do you feel that support systems adequately address cultural differences to help Hmong individuals with IDD?
  - What can support systems do to have better cultural understanding of the Hmong community?

## **MOVING FORWARD: SUPPORT NEEDS**

1. What is an immediate need for you as a caregiver in the following areas:
  - In the school system?
  - In healthcare?
2. What is a long term need for you as a caregiver in the following areas:
  - In the school system?
  - In healthcare?
3. If you could speak to anyone in the community about what needs to improve in terms of support systems for caregivers? Or for people with IDD? Or Both? What would your main points be?
4. Is there anything else you would like to share about your experience as a caregiver?



# APPENDIX C – PROJECT INFORMATION SHEET

## Improving Support Systems for Individuals with Intellectual Developmental Disabilities: Discussions with Caregivers in Hmong Communities in Wisconsin

### PROJECT GOALS

Northern Valley Industries and the Wisconsin Institute for Public Policy and Service (WIPPS) Research Partners are gathering more information from caregivers about the challenges that individuals with intellectual and developmental disabilities face when accessing support systems and services. This project has a specific focus on Hmong caregivers in communities in Wisconsin and will address gaps, barriers, and opportunities in public service areas such as healthcare and education.

To gather this feedback, WIPPS Research Partners will conduct private and confidential, one-on-one discussions via Zoom with caregivers of Hmong individuals with IDD. Topics include:

- What is the cultural knowledge and understanding of IDD in the Hmong community?
- What challenges do Hmong caregivers and individuals with IDD experience on a daily basis?
- What barriers do Hmong caregivers and individuals with IDD encounter when accessing support systems and programs?
- What information and support do Hmong caregivers and individuals with IDD need that would be beneficial in the short-term and long-term?

### WHO CAN PARTICIPATE?

Caregivers of youth and adult Hmong individuals with IDD.

### WHEN ARE THE DISCUSSIONS?

Caregivers who are interested in participating in this project can sign-up for a one-hour spot through Doodle Poll. Individual discussions will be held from July 12th - August 6th, 2021.

### HOW WILL THE DISCUSSIONS BE CONDUCTED?

- Discussions will be conducted via Zoom and will last about 1 hour.
- Only caregivers and the members of the WIPPS Research Partners project team will participate in the Zoom discussion. For privacy and confidentiality, WIPPS staff will conduct discussions one-on-one with caregivers, not in a group setting.
- Sessions will be recorded to help with the analysis. The recordings and notes will be kept private. Only members of the WIPPS project team will see the recordings or notes.
- After discussions are completed, WIPPS Research Partners will analyze the information to identify common themes and insights.
- Caregivers will NOT be personally identified in the report. Any quotes or comments included in the report will NOT be attributed to any individuals by name. The names of caregivers that participate in this project will NOT be listed on the report, nor will individually identifiable information be reported.
- Participants will receive a \$25 gift card in appreciation for their participation, and a copy of the report.

**HOW WILL THE INFORMATION BE USED?**

Findings will be compiled in a summary report and shared with Northern Valley Industries. This information will be used to help educators, healthcare providers, and community organizations to make more informed decisions about how to support caregivers and individuals with IDD.

**QUESTIONS?**

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