

Communication and Down Syndrome



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Introduction

Young children with Down syndrome struggle with learning to talk for reasons we don't completely understand. Later, as they begin to put words together and talk in longer sentences, children and adults with Down syndrome often have a difficult time being understood by others. These communication challenges may affect a person with Down syndrome's ability to learn, to express his or her wants and needs, to form and maintain relationships, to share his or her experiences, and to meaningfully participate in the community.

This booklet includes family stories that illustrate common communication challenges of individuals with Down syndrome. The stories are from parents who have sons and daughters with Down syndrome who range in age from two to forty-one years.

Parents were interviewed by Vanderbilt University students through the Kindred Stories of Disability project. They were asked to reflect upon their experiences with early and school-based speech intervention services. The families speak frankly about how communication challenges have affected their son or daughter's education, employment, social experiences, and the broader family unit. They share their struggles with accessing and covering the cost of the speech and language services that their children need. They share what they think helped their son or daughter to begin to communicate more effectively.

Additionally, this booklet briefly outlines the results from two research studies at Vanderbilt University and shares key recommendations for supporting the development of language in young children, as well as speech in school-aged children and adolescents, with Down syndrome.

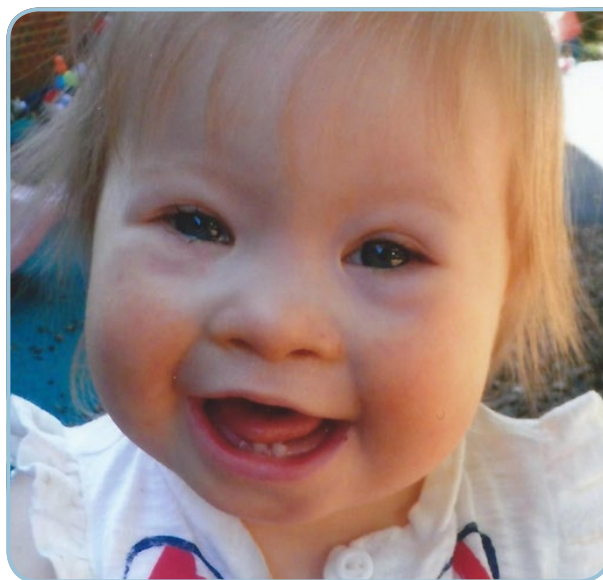
The families, students, and researchers who contributed to this booklet hope to demonstrate that early and ongoing involvement in speech and language interventions help to address the inevitable communication challenges that individuals with Down syndrome will face.

It is the goal of this edition of Tennessee Kindred Stories of Disability to educate lawmakers, educators, therapists, insurance agencies, and families about best practices and about the urgent need to give people with Down syndrome access to communication supports.

Sylvie (age 2)

Christy and her husband, Alex, are parents to Sylvie, a two-year-old with Down syndrome. Sylvie has a gregarious and magnetic personality. She attends an inclusive preschool, and she communicates primarily through sign-language. Currently, Sylvie signs approximately 10 words, which are mostly commands like “more,” “eat,” and “all done.” Sylvie plays well with peers in her class and regularly makes eye contact. When people do not understand what Sylvie tries to communicate, Sylvie feels frustrated. For example, if Sylvie is given the wrong item in response to a signed request, she will push the item away.

Christy and Alex first met with Tennessee’s Early Intervention System (TEIS) when Sylvie was a little over one month old. Still adjusting to the news that their child had Down syndrome and having had no prior connection with someone living with Down syndrome, they were informed by TEIS that it was their responsibility to formulate goals for Sylvie’s Individualized Family Service Plan (IFSP). Christy and Alex did their own research and enlisted the help of others to identify their specific needs and translate those needs into applicable goals. Sylvie’s therapists and teachers augment her communication skills through once weekly speech therapy at her preschool. Sylvie began to receive these services on a weekly basis when she was about fourteen months old. Prior to that, Sylvie received free speech therapy consultation services at home once a month from a Speech Language Pathologist (SLP)—a service suggested to her parents after she initiated contact with Vanderbilt shortly after Sylvie’s birth.



The family forged relationships with educators and therapists who acknowledged that early speech intervention would be a key component of Sylvie’s long-term communication success. Christy and Alex continued to advocate for speech services. Christy believes that by supporting people with Down syndrome in their speech and language development, we are showing respect.

“I want Sylvie to live as independent a life as she can,” said Christy. “Her ability to communicate increases the chances of her gaining more independence. I want Sylvie to be respected. Paying attention to the needs of individuals with Down syndrome and allowing access to enriching services throughout their lives sends a powerful message of equal respect and inclusion.” ■

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Piper (age 2)



Piper, daughter of Ginny and Chris, is a two-year-old little girl who was diagnosed with Down syndrome upon birth. She is moving into an exciting stage in her verbal learning. She makes noises and eye contact with people with whom she communicates. She also attends an inclusive preschool. Piper is a friendly child who makes her parents very happy. They have been working hard to give her the speech-language services that she needs.

Piper's mom and dad knew from the start that speech and language were a priority, and they were surprised when they were told that Piper would not benefit from receiving speech language services when she was an infant/toddler.

Piper's family has had challenges with acquiring support for services and has faced numerous difficulties with SSI. Upon Piper's birth, Ginny and Chris were not informed that they were eligible for funding from SSI and TennCare to support Piper's therapies. Eventually, they were accepted into the program, but the family continues to struggle with financial coverage and reimbursements from SSI.

Piper's family expresses deep frustration that TEIS did not recommend that speech therapy start until age two. Piper began to receive services when she was 18 months, but her parents would have preferred that she had begun even earlier.

Piper currently participates in speech therapy and occupational therapy and her parents like both therapists. Her success is due to the support of many great people who ensure she receives frequent therapies that are comprised of research-supported practices. Her parents long for more supports from TEIS, SSI, and her family's insurance company to help promote Piper's well-being. Piper has enriched her parents' lives and they will "push as hard as needed" to enrich hers. ■

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Ron (age 6)

Ron's mother, Alecia, describes her family's experience helping Ron learn to talk.

My husband and I have three children. Our six year old has Down syndrome, which has caused him difficulties in communicating. It's his biggest challenge. The first big hurdle for us was getting him to express his needs and wants. Typically, children just seem to learn to communicate easily and naturally, he was not able to communicate what he needed and we had to help him learn how.

Initially, his communication was done by crying, groaning, and yelling which later developed into pointing, moving, gesturing, and showing. He started to sign. Now he has a communication device that, while giving him some freedom, also limits him. If he wants to communicate something that is not an option on his device and he cannot vocalize what it is, we play the guessing game.

Ron started with speech therapy twice a week until age 3. He then received speech through his IEP and now receives two push-in sessions and one pull-out session. We have seen a lot of progress in his ability to be understood. His progress was only as good as it was because we advocated for as much therapy as possible, emphasized the qualitative impact of peer modeling, and supported therapies with any speech-related research that he qualified for. His therapist at school is very good, but with the school schedule consistency is very difficult, and we really wish he had access to speech year-round.

Ron's communication affects the family's daily life. We all get frustrated, Ron especially, when we don't understand what he is trying to communicate. That was extremely difficult in that 4-6 year range when he really had much to communicate but simply could not. There are times when he asks over and over for "bah" and we have no idea what that is. Sometimes he can show me "bah,"



but often times by then he is frustrated. He is so independent that he will often just do for himself rather than asking, especially if it is something he has trouble communicating. This can make it a challenge to leave him alone.

As a parent it wears you down sometimes. It makes me sad to see the determination, the will, and the knowledge he has that he cannot communicate to us. You know he has something to say and he can't use the words to say it. I think generally others' perceptions about anyone who has trouble communicating, especially with Down syndrome, is that they are not as smart as they are. People need to know that there are gaps between what they understand and what they can communicate.

His communication Issues will limit him in the future if it doesn't improve. I am fully confident in his ability to learn and understand, and we will continue to advocate to make sure he has the support he needs to do so. ■

Elisha (age 11)



Elisha is in the fifth grade and has Down syndrome. He lives with his mother, Demytris, his stepfather, his older brother, and his younger sister. Elisha “is special because he loves unconditionally,” his mother, Demytris, states. She says he makes people around him feel grateful and happy. Elisha brings joy to those around him in spite of the fact that he often feels ill. He has undergone multiple surgeries since birth, including heart surgery, a tongue reduction, the placement of tubes in his ears, and sinus surgery.

When Elisha was very young he received services from TEIS, which his mother describes

as “very helpful.” He received early intervention services starting at six months of age due to his medical needs. Demytris felt supported by her TEIS providers, because they granted Demytris’ requests for the types and quantities of support Elisha receives. Elisha started communicating using sign language and now speaks in short sentences. His mother feels that his communication has been negatively affected by gradual hearing loss from long-term middle ear issues.

Since Elisha started public schools, his mother has had to work very hard to get him the educational supports he needs. Because of challenges with the implementation of supports such as speech therapy and physical therapy for Elisha, Demytris always brings an advocate to her Individualized Education Plan (IEP) meetings. She believes all parents should consider doing the same. Currently Elisha receives speech-language therapy three days a week. He is working on speaking slowly and clearly, and expressing his feelings. Elisha works hard to communicate, but his mother feels he needs more time in speech classes to reach his communication goals.

Demytris’ long-term goals for Elisha are that he participates in a college program and that he gains greater independence. She knows he will achieve those goals. She is determined to continue to advocate for what Elisha needs and to encourage his self-advocacy skills. ■

Elisha works hard to communicate, but his mother feels he needs more time in speech classes to reach his communication goals.

Will (age 15)

Will's mother, Kathy, describes her family's experience helping Will learn to talk.

My son, Will, is fifteen years old, and he has Down syndrome. He has a younger brother who is twelve. Will was a delayed talker, but since I am a speech therapist I knew to get him into therapy early. When he was a toddler, he would get very frustrated with his inability to communicate his basic needs, so we started using sign language with him. Although we knew he would be a late talker, he didn't say his first word until he was three.

Will has had a lot of language therapy over the years. He has been involved at Bill Wilkerson at Vanderbilt, and he was also involved in Tennessee Early Intervention Services from the time he was born until he was three.

As Will got older, he received school and community-based speech therapy, but now he gets his services just through his school. I wish Will could continue to get as much speech therapy as he had when he was younger. As kids get further along in school, the therapies slow down. Now he only gets thirty minutes of speech a week in the classroom.

I wish his speech therapy had been covered by insurance after Will turned three. We had some preposterous issues with our insurance company. They would not cover the costs of speech therapy unless Will had an acquired brain injury.

Even though we all understand Will, sometimes new people have trouble. He has learned to repeat and to slow down. I also sometimes find myself repeating what Will says to people. I can tell by people's facial expressions that they don't always understand him. His speech has affected his ability to participate in class verbally and to do verbal presentations.

Sometimes people don't take the time to engage Will in a conversation or to give him a chance to express himself. It's a shame, because he has a lot to say. I don't know if they're afraid they won't understand him, but if he is given the appropriate topic, he loves to talk.

In the future, I hope that Will can find a work environment that he loves and co-workers who will be patient with him. I feel like he can work and live as independently as possible, but he will need his employer to be supportive of his communication needs. He learns well from his mistakes, and he needs the opportunity to be a productive member of society. ■

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Will (age 26)

Will's mother, Elise, describes their family's experiences helping Will learn to talk.

Will is 26 years old. He lives at home with us right now and he has plans to move out of our home by the time he is 30. Will was born with Down syndrome. All we heard right from the beginning was about all of the communication difficulties our child would face. Will was born six weeks prematurely and spent some time in the hospital, but as soon as he was released he started early intervention. Early on, we requested that our insurance cover additional speech, but it was denied.

Everybody warned us that they were not going to cover it, but we felt like it was so important and that maybe if enough people requested it over time, things would change. It's frustrating to families when they (insurance companies) say it's educational and not medical. If there had been some injury that led to needing speech services, it would be covered. Because he needed services from the beginning, it was declined.

When Will was three, we began to receive speech therapy through Metro Nashville Public Schools. He received speech therapy twice a week throughout high school. I know that is pretty unusual, but we would always make that part of our IEP meetings. Will started coming to his IEP meetings in middle

school, and at that time they tried to end the services. They told us that he had reached his communication potential. We felt that they could not know what his potential was, and asked that services continue so that he could keep growing. He continued to receive speech services in middle school and high school.



I think it gets harder and harder to keep services as your child gets older, and you have to pick your battles in terms of what services you're asking for. If Will could have had speech three days a week instead of two, it would have made a difference.

I think if we had not had the early intervention and related services, his communication would have affected his education. I'm so glad for the people who shared with us

early on to concentrate on speech, because I don't think that things would have turned out as well as they have if he had not been able to participate in speech therapies early.

Our hope for the future would be that he continues to be healthy and that if he does need some kind of speech support in the future it would be there. People like Will have to keep working to show younger families what all is possible. I want to make sure that especially young families and educators know what the full potential is for people with Down syndrome. ■

I think it gets harder and harder to keep services as your child gets older, and you have to pick your battles in terms of what services you're asking for.

Eric (age 27)

Eric's mother describes their family's experiences helping Eric learn to talk.

Eric is 27 years old and has Down syndrome. He is the oldest of our three kids, and he was born in Chattanooga. He currently lives at home with us in Franklin, where he also has a part-time job at Publix.

Communication was always our number one concern developmentally for Eric. Because his receptive communication was always much much higher than his expressive, we signed with him from day one. When Eric was ten weeks old, we began enrolling him in any speech therapy that became available. We paid a lot of money for therapies.

Eric's communication was initially pretty good, but then his cognitive skills very quickly surpassed his ability to express himself. He communicated mostly by grunting and gesturing and would get frustrated with us when we didn't understand him. In elementary school, he exhibited a lot of difficult behaviors that stemmed from his challenges with communication. For example, if someone got in his way, instead of an, "Excuse me," it was easier to just push somebody. Both siblings went down flights of stairs at one point or another. I didn't work the whole time Eric was in school because, really, it was just about a full-time job to take care of him.

Currently, Eric participates in a theater program. That has been helpful in teaching



him to project his voice. He had trouble with not being heard at work. I would see him saying something, and a customer wouldn't acknowledge him, but now he talks with his head up and they can hear him.

One of our biggest concerns with Eric's communication challenges has been keeping him safe. That's a real concern as our sons and daughters age and become more involved in the community. How do people with communication challenges remain safe? It's not a minor issue. Our sons and daughters need to be able to communicate. ■

How do people with communication challenges remain safe? Our sons and daughters need to be able to communicate.

Julie (age 38)



Julie was born with Down syndrome in Jackson, Tennessee in 1976. When Julie was about seven months old, she began early intervention services. Her mother said that if Julie hadn't received the early intervention, she wasn't sure how the family would have managed on their own. Speech intervention was an especially helpful support. In preschool, it was difficult for Julie to communicate with her peers and teachers. She matriculated to public school at age five, and received speech and language therapy for thirty minutes, twice a week until

she graduated high school at the age of twenty-two.

When Julie left high school, she found a job as a dining room assistant at a retirement home. She has been working at that job for fifteen years.

"Overall, everything is going smoothly now," said Julie's mother. "Julie has a social life and a job. She makes and spends her own money. She enjoys watching television and working on her computer. She is living a fairly typical life. Having Julie really changed me. I was a very shy and quiet person, and then all of a sudden I was doing research and asking questions. I had to navigate and fight for my daughter, or else she wouldn't have received what she needed. My husband and I learned to be advocates, and now, all these years later, I advocate for other children with disabilities and their families. Services have improved, but families still need so much."

Julie's mother credits early intervention services as being essential to Julie's speech and language development. She says that speech and language therapy helped Julie not just to say words, but to communicate and connect. ■

"I had to navigate and fight for my daughter, or else she wouldn't have received what she needed."

Keith (age 41)



Keith is a 41 years old. He owns a home, has a job, and is involved in church activities and with local charities. Keith's mother, Carol, has been a constant and devoted advocate for Keith. In fact, it was because of Keith's challenges with speech that Carol made the decision to become a speech-language pathologist.

Keith's current communication challenges do not stem from a lack of understanding on his part or on a poor vocabulary. Indeed, Carol says that Keith has a very large vocabulary, which he uses often in day-to-day conversations. He struggles to articulate

well, to select appropriate pronouns, and to choose correct subject and verb agreement. Although Keith was enrolled in speech therapy from the age of two to the time he left high school, challenges remain.

Keith still needs communication support in certain situations. Carol said that "We were in a physician's office and he was asking Keith about what his condition was, and Keith was using words like 'pneumonia' and things like that. It was very difficult for the physician to follow him, and if I hadn't been there to repeat what he had just said, his doctor wouldn't have been able to understand Keith. It makes you stop and think about how important it is that your doctor understands you."

Keith's most effective speech therapy intervention came during high school. This therapy allowed Keith to interact with speech partners, and it was during this time that Carol noticed the most significant improvements. However, Carol says, "It is very difficult to get therapists to work with an older student."

Carol believes that Keith would benefit from additional and significant communication interventions. She has the desire to see Keith involved in interventions focused on improving social skills so he can develop stronger relationships with people in his community. ■

He struggles to articulate well, to select appropriate pronouns, and to choose correct subject and verb agreement. Although Keith was enrolled in speech therapy from the age of two to the time he left high school, challenges remain.

Discovery

Individuals with Down syndrome can more effectively communicate when their speech and language development is supported. Under the direction of Paul Yoder, Ph.D., a professor of Special Education and a Vanderbilt Kennedy Center investigator, two studies were conducted to gain insight into how to best support speech and language development in children and adolescents with Down syndrome and other intellectual and developmental disabilities.

The first study, "More is Better," determined that young children with Down syndrome need more frequent early intervention services than they typically receive to support their language development when they are learning to talk.

The second study, "Clear Talk," determined that therapists need to match the type of speech therapy to the child with Down syndrome, so that children with Down syndrome can improve their ability to make their speech understood by strangers.

More is Better

In the "More is Better" study, investigators explored the effects of an early communication intervention called Milieu Communication Teaching in children with Down syndrome and other intellectual disabilities who were between the ages of eighteen and twenty-seven months.

Results

- After receiving nine months of treatment, toddlers with Down syndrome who received Milieu Communication Therapy daily (five times per week for one hour) could say an average of seventeen words, while those who received Milieu Communication Therapy on a weekly basis (one time per week for one hour) could say only five words.

Recommendations:

Typically, young children with Down syndrome receive about one hour a week of speech therapy in early intervention services. Best practice would suggest that toddlers with Down syndrome will achieve more optimal spoken language outcomes if they receive five hours of speech therapy per week.

Discovery

Clear Talk

In the “Clear Talk” study, investigators compared two types of speech therapy in children with Down syndrome who were between the ages of five and twelve. One type of therapy simply involved the adult saying, or recasting, what the child just attempted to say using adult pronunciation. The other type of therapy was a commercially available treatment package that speech pathologists commonly use with children in an attempt to improve the accuracy of their speech. Speech therapists provided one hour therapy sessions twice a week for six months at each child’s school. These were individual sessions with a speech-language pathologist.

Results

- Over the course of the study, most children made gains in producing speech that could be better understood by a stranger.
- More importantly, children who were good imitators when they started treatment benefited more from receiving the treatment that simply involved the adult recasting or saying what the child attempted to say with correct pronunciation than they did from receiving the more common approach to speech therapy, which does not include recasting.

Recommendations:

Typically, school-aged children with Down syndrome receive up to one hour a week of speech therapy. This is usually provided in a group setting. Best practice suggests that some school-age children with Down syndrome (those who can already imitate adult models of speech) will make the most gains in making themselves understood by strangers with two individual one hour sessions per week in which the adult repeats what the child just attempted to say using adult pronunciation.

In Summary

The research summarized above shows that receiving early communication intervention daily instead of weekly will help young children with Down syndrome learn to say more words. Receiving recasting treatment two times per week for one hour in individual sessions will help some school-age children with Down syndrome speak in a way that can be better understood by a stranger. Although this level of service provision may not be provided to children with Down syndrome as “regular practice”, research suggests that it would be “best practice.”

Recommendations

What can Parents do?

- Advocate for your child to receive the type and amount of treatment that research has shown will help them to achieve better outcomes. Click here to locate a Certified Speech-Language Pathologist: www.asha.org/findpro/
- Support your child's communication development at home by saying what you think your child is trying to say or by repeating what your child says using adult pronunciation. In the "More is Better" study, parents learned strategies from the book *It Takes Two to Talk*. You can also learn strategies to support your child's communication development at home from your speech-language pathologist.
- Children with Down syndrome are at greater risk for vision and hearing challenges, which might have an impact on their ability to learn to communicate. Request referrals to pediatric ophthalmologists and audiologists who have experience with children with developmental disabilities.
- Reach out to Down syndrome advocacy groups to find guides, friends and confidants that will support you along the way.

What can Clinicians and Educators do?

- Review the research articles provided in the resources section of this booklet. They suggest that children with Down syndrome can achieve better outcomes if they receive more intervention than they typically receive, even when they are still very young.
- Share these research findings with others, like your administrators, clinic coordinators, and third party payers, to discuss how children with Down syndrome can receive more therapy.
- Currently there is no commercially available curriculum for Milieu Communication Teaching or Recasting. However, manuals for these treatments are available from the authors of these studies upon request. Contact courtney.taylor@vumc.org.
- You can match school-age children to the best speech treatment approach using a simple test of imitation ability. Insert link to DAVI.

What can Legislators do?

- Educate themselves and create and advance transformative legislation that encourages insurance companies to pay for sufficiently rigorous communication therapy schedules.
- At present, there is no legislation encouraging insurance coverage of speech language therapy for children with Down syndrome.^{1,2}

¹ See a 2015 bill, called Ava's Law, passed in Georgia for an example of comprehensive insurance reform legislation for children with Autism Spectrum Disorder.

² The Developmental Disabilities Assistance and Bill of Rights Act of 2000 states that "Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities," and that self-determination is consistent with the rights quotes above (109.a; 101c.1). Activities that advance self-determination should result in a person having the ability to communicate (102.27.A).

Resources

STATE

Vanderbilt Kennedy Center: vkc.vumc.org

Vanderbilt Kennedy Center Research StudyFinder: vkc.mc.vanderbilt.edu/StudyFinder

Down Syndrome Association of Middle Tennessee: www.somethingextra.org

Tennessee Early Intervention Services: www.tn.gov/education/article/teis-eligibility

Locate a Certified Audiologist or Speech-Language Pathologist: www.asha.org/findpro/

Gigi's Playhouse: gigisplayhouse.org/nashville/

NATIONAL

Down Syndrome Education USA: www.dseusa.org/en-us/

National Down Syndrome Congress: www.ndsccenter.org/speech-and-language/

Down Syndrome Education Online: www.down-syndrome.org

National Down Syndrome Society: www.ndss.org

JOURNAL ARTICLES

Yoder, P., Woynaroski, T., Fey, M., & Warren, S. (2014). Effects of dose frequency of early communication intervention in young children with and without Down syndrome. *American Journal on Intellectual and Developmental Disabilities, 119*(1), 17-32. www.aiddjournals.org/doi/abs/10.1352/1944-7558-119.1.17

Yoder, P., Woynaroski, T., Fey, M., Warren, S., & Gardner, E. (2015). Why dose frequency affects spoken vocabulary in preschoolers with Down syndrome. *American Journal on Intellectual and Developmental Disabilities, 120*(4), 302-314. www.aiddjournals.org/doi/full/10.1352/1944-7558-120.4.302

Yoder, P., Camarata, S., & Woynaroski, T. (2015). Treating speech comprehensibility in students with Down syndrome. Manuscript submitted for publication.

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~Christy (parent)

“I think if we had not had the early intervention and related services, his communication would have affected his education. I’m so glad for the people who shared with us early on to concentrate on speech.”

~Elise (parent)

Vanderbilt Kennedy Center for Excellence in
Developmental Disabilities
vkc.vumc.org

Tennessee Kindred Stories of Disability
kc.vanderbilt.edu/kindredstories/

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