



The 5P- Buzz

NATIONAL SUPPORT GROUP FOR INDIVIDUALS WITH 5P- AND THEIR FAMILIES

A message from the 5p- Society's leader

WRITTEN BY NICK WALLACE

Welcome to 2022!

In the Merriam-Webster dictionary, they define laundry as:

Laundry (noun)

laun·dry | \ 'lɒn-drē , 'læn- \

Definition of laundry

1 a: a room for doing the family wash

b: a commercial laundering establishment

2: clothes or linens that have been or are to be laundered

I'm sure that your family does just as much laundry as mine and has experienced that frustrating moment when all the laundry is done and folded and you find a single sock in the bottom of the basket. Or that dirty towel someone left behind the door. That feeling is how I feel about this past year. Just when we think COVID is all over, it rears its ugly head in the form of a new variant or surging infection rates.

This past year wasn't quite as bad as 2020...but it was close! Once again, our resilience was tested, and we were forced to adapt. Thankfully, we could enjoy some of the things we missed—like going to the theater, seeing our favorite sports teams back out on the field, and doing other activities we loved but missed out on in 2020. We look forward to 2022, hoping that it will bring back more normalcy and opportunities to get our community back together.

Continued on next page.

WHAT YOU'LL FIND IN THIS ISSUE:

MESSAGE FROM THE DIRECTOR

FINDING A SUITABLE GROUP HOME

INDEPENDENT LIVING CENTERS

2022 ANNUAL CONFERENCE INFORMATION

LEARNING TO DRINK TIPS & TRICKS

FINDING ACCESSIBLE RECREATION

A SIBLING'S PERSPECTIVE

TRANSITIONS FOR THOSE WITH 5P-

"LOVING YOU BIG" BOOK RELEASE



The 5p- Society did its best to adapt to the COVID situation this year and still provide education and resources to its members and families. We will continue to do so but have many great events and outreach programs planned for this next year.

For the first time since January 2020, the board of directors is planning in-person events. Regional gatherings are on the horizon; however, the most exciting event is the 2022 Annual Conference in Charlotte, North Carolina. The 2021 conference in Chicago was moved to 2023. Despite that, we know the families in North Carolina are very much looking forward to hosting our first post-pandemic conference. So we ask everyone to cross their fingers, toes, eyes, and anything else so that we can successfully get everyone together!

I will end this article the same as last year because my feelings are the same: Although this pandemic has changed the way we live our lives and will most certainly change how we live going forward, the things we can be certain of are the strength within our community, our ability to innovate to handle tough times, and our resiliency.

I sincerely hope your families have a wonderful 2022. Never forget that you can lean on the 5p- Society during the good and the tough times. We are all in this together.

We're going *digital*

WRITTEN BY SHARI HUFFMAN CAMPBELL

Hey! You may have noticed that the 5p- newsletter has a new name: The 5P- Buzz. More big news! We're also going completely digital. Newsletters will no longer be mailed out; everything is moving online so we can get them out quicker and allow them to be more interactive!

Our aim this year is to include more content, more videos, and more photos. We hope this enhances the experience for our members and those closest to them that they'd like to share the newsletter with.

Of course, a byproduct of going digital also reduces the overall cost for the Society—meaning we invest more in other initiatives that will benefit our members!

To get in on all the **buzz**, send your updated email address to Laura Castillo at director@fivepminus.org.



MAY 1-14, 2022



Calling all Society Members & Friends

Do you have an interesting article you'd like to share or future newsletter content? If so, please contact Mel Sabin at mel5p@outlook.com.

How do I find a suitable group home for my child?

WRITTEN BY EILEEN SHERMAN

Our families face many hurdles as our children get older. We make sure they get the services they need through the stages of their lives. When our daughter, Heather, was born 41 years ago, we had no idea where this journey would lead. We were told her life expectancy was not more than a year; guess they got that wrong. At the age of 20, when she was nearing aging out of school, we had a whole new set of issues. We looked at some group homes, day programs, and other activities for young adults. We kept her at home with a personal assistant who could do things with her when my husband and I were unavailable.

Unfortunately we do not get any younger, and I was approached by a special education specialist regarding placing her in a group home. From our previous tours, I definitely knew what I did not want. I wanted to find a place that would take care of her as well as I did. Here are some things we felt must be part of this experience:

- There must be 24/7 care in the home—some group homes have staff that go between two homes.
- We wanted her to be with young girls that would welcome her and not shun her. We did visits with the other girls before they moved in together.
- We preferred that she have her own room so no one else's belongings were used by her.
- We wanted her to have a day program and activities.
- We wanted to insure communication between staff, ourselves, and the entities that were running the home.



- We also wanted to know what, if any, fundraising or obligation would be expected from us (some organizations require monetary donations or give or get volunteer hours).

We were lucky we were familiar with the organization that (in conjunction with a larger organization) met our needs. There are always issues that arise, but if the communication is there, most things can be worked out. Our daughter is more independent than she was at home; she helps to prepare meals and she volunteers at a beauty salon in the area. The workers take her for medical appointments and are very well trained and devoted to the girls. She has been there now for six years, and we know she is well taken care of, but of course, no one is as good as mom and dad.

The organizations also helped secure the state funding and put us in contact with the state agency that provides a social worker who monitors and sets up the ISP of goals for each year. The most important advice I can give someone is to make sure you visit and meet with all involved regularly and communicate if you don't think something is right.





Exploring Adult Individualized Education Programs

WRITTEN BY CHRIS HARMS

Hello! We're Chris, Bart, Tyler and Courtney Harms. Our lives have been changed in so many ways by one special young woman named Emma.

Emma was born into our family on January 22, 1993. She was diagnosed with 5p- Syndrome at one month old, at which time the in-home intervention, therapy and numerous goal setting activities began and continued on now for 27 years. She went to an early intervention preschool at age 3 and started attending River Hills School for Special Education at age 5, where she was until graduation at age 21. Since her graduation her goals have been minimal and not as involved as they are with an IEP.

Emma's siblings, Tyler and Courtney, live near and are both presently working in group homes. We live in Waterloo, Iowa, which has a population of about 90,000. We were able to purchase a home three blocks from us where Emma lives with three roommates.

Goodwill provides 24-hour staffing and we were able to be very involved in choosing roommates, Emma's routines, etc. She has lived there for over a year now and loves her house and roommates!

When I was asked to write about IEP's for adults, it got me thinking. My Emma attends North Star's day hab program 2 days/week, has speech therapy at The University of Northern Iowa 2 days/week for most of the year and has goals set for her at her house. Despite all of these goals, I had to think about what goals Emma does have. As we all know, the past few months have been very unusual and difficult for everyone, especially for family members with 5p- Syndrome.

Routines have been disrupted, which makes it difficult to obtain any goals that involve leaving your home!

Her day hab goals are to initiate conversation and put her bag and coat in her locker when she arrives. Her house goals are to help with

cleaning at least once a week, which she does almost daily. She is supposed to walk for one of her goals, but that has been difficult because of the weather and isolation now. She also had a shopping and outing goal, which is not feasible due to "hunkering down," as Emma would call it, because of COVID.

“ I had to think about what goals Emma does have...Routines have been disrupted, which makes it difficult to obtain any goals that involve leaving your home! ”

We have Emma's annual meeting in a couple of weeks to assess her needs and goals for the next year. This will include her supervisors from North Star (her day program) and Goodwill (her group home), her case manager from DHS, Emma, Bart and me. We are planning on talking about goals that can be reached while staying home, such as puzzles, games, crafts or cooking. Bart and I have also talked about including a goal involving healthy eating—something as simple as incorporating more fruits and vegetables into her diet.

Continued on next page.

If there is something you feel is not being done for your adult with Cri du Chat, putting it in writing as a goal makes it more effective, especially in cases where there are numerous staff involved. Emma is verbal and able to manipulate very well when it comes to getting out of doing something she does not want to do, especially if it is someone she does not know very well. Having that goal helps everyone working with Emma to be aware of what she can do. This will also make the staff more accountable for following through with the goal. It also will make it easier for them as far as remembering, "Yes, this is important for Emma's well-being."

The goals should be manageable and beneficial to the person being served. I was talking to my son who works in a local group home. He was voicing his opinion about how the goals set up for some of his clients are not always a high priority for the individual, yet because it is a goal, staff is expected to document on it. A goal doesn't have to be complex. I think of them as adding continuity to Emma's care and making her life the best it can be. To help her to be more confident and independent as she continues to grow as a person.

A bit of rebranding!

WRITTEN BY MEL SABIN

Reading through our recent event sites and other materials, you may have noticed that the 5p- Society is referencing the Syndrome more as **5p Minus (5p-) or 5p Deletion Syndrome** and avoiding the use of "Cri du Chat" or CDC Syndrome.

While the CDC denomination will always have a special place in our hearts, there is a reason for this shift away from the name. In the early days of understanding the Syndrome, one of the common characteristics was identified as the baby or child having a weak or shrill cry, which sounded very similar to a kitten. Hence the name Cri du Chat, which in French means Cry of the Cat.

Since those early days, much more research has been done on the syndrome, and we've found that many children do not exhibit this characteristic. In the spirit of inclusivity, we will be referring to those diagnosed with the more medically accurate terminology. We encourage our members to do the same and share this news with your friends and family.

Thank you 5p-Society!

WRITTEN BY KATERI MEZA

Dear 5p- Society,

I am currently a first year student at Stephen F Austin University studying physics and wanted to express my gratitude to the 5p-Society and all the families that support their efforts, which allowed them to award Sibling Scholarships for higher education.

I am honored to be one of the first recipients of the award, which has helped make college financially achievable for us. I am now in my first finals week and packing up to head home and spend the holiday break with Cinnia and the rest of our family before returning for spring semester and completing my freshman year.

Thank you again for the amazing gift of educational support.

Sincere thanks,

Kateri Meza



What are Centers for Independent Living?

WRITTEN BY JOAN STEELE

I am Joan Steele, mother of Kevin, who is 38. He is happy, exuberant, loving, and helpful. He has been in a CILA home for 12 years, but that is another story. I wanted to share a resource that may be helpful for many families.

After retiring from 28 years in public schools as a speech pathologist and reading teacher, I began working part time with a center for independent living. The director had been helping me for about 25 years as an advocate and resource for Kevin. Centers for independent living are designed and operated by people with disabilities and provide independent living services for people with all types of disabilities. These centers are in every state and are authorized by the Rehabilitation Act of 1973. The purpose is to “promote a philosophy of consumer control, peer support, self-help, self-determination, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.”

The core services are independent living skills training, information and referral, transition from institutions, peer counseling and support, systems and individual advocacy, and transition of youth. Some provide more assistance than others, but the staff I work with does a tremendous job of helping with anything. If someone calls with a question, the staff will keep on it until an answer is found. Kevin has had an advocate from this facility prepare for and go to IEP meetings, be my sanity saver and sounding board when he is treated unfairly, locate services, find assisted technology products, provide a list of people for personal attendants and perform background checks on them, and obtain funding to provide an iPad to name a few things.

Consumers of the service live independently or with their families. A few of the services I have helped with in the last year include helping finding and applying for housing; helping and applying for SSI and SSDI applications; arranging delivery of food; counseling and mentoring; starting a swimming program at the local community college; helping with obtaining documents such as a state ID or birth

certificate; going to doctor appointments; setting up systems to promote independence, such as medical notebooks or organizing systems; budgeting instruction; partnering with community services to increase accessibility for consumers; finding counseling and physician services; helping arrange transportation; obtaining grant money for technology, bus passes, cleaning supplies; finding free furniture through a voucher program; locating inexpensive dental care; hooking people up with the state program for technology that rents out equipment and does assessments; and more.

Whatever a consumer requests is attempted to be met. I am not sure that every center would be so conscientious, but help is out there. If you don't know where to start for some service or item, CILS are a great place to start. Google “ILRU Directory of CILS and Associations.” Click on the first result which should be ilru.org and have a map. Click on your state to find locations and contact information for a nearby CIL. I hope your experience is as good as mine.



THE 5P- SOCIETY CORDIALLY INVITES YOU TO ATTEND

7



A Royal Celebration

2022 5P- ANNUAL CONFERENCE

When?

July 14-17, 2022

Where?

Sonesta Charlotte
Executive Park Hotel

FOR MORE INFORMATION, VISIT THE EVENT SITE [HERE](#).



We cannot wait to see everyone at the 2022 Annual Conference in North Carolina! Below are the this year's rewards packages. Please reach out to Laura Castillo with any questions.

Reward packages



King - \$5,000

- 4 Registrations
- 3 nights at conference hotel
- Listing on event website & signage
- Logo on back of event tee



Duke - \$500

- Listing on event website & signage
- Logo on back of event tee
- Social media blast



Queen - \$3,000

- 4 Registrations
- 2 nights at conference hotel
- Listing on event website & signage
- Logo on back of event tee



Duchess - \$250

- Listing on event website & signage
- Logo on back of event tee



Prince - \$2,000

- 4 Registrations
- 1 night at conference hotel
- Listing on event website & signage
- Logo on back of event tee



Knight - \$100

- Listing on event website & signage
- Logo on back of event tee



Princess - \$1,000

- 4 Registrations
- Listing on event website & signage
- Logo on back of event tee



Jester - In-kind donation

- Listing on event website & signage
- Logo on back of event tee



ANGEL AID is hosting an annual Rare Mothers Wellness Retreat from January 21 - March 6, 2022.

We see you. We recognize the way that you are constantly being pulled in many directions, being asked to give all of yourself to others. We understand you. We know the toll that being a rare disease caregiver places on your heart, mind, body and soul. Join us for M.O.R.E, an intimate retreat for Rare Mothers. Cultivate relief for the mind and body. Connect, transform, and rebuild from the inside out.

M.O.R.E is a virtual retreat guided by professional clinicians and self-care experts, curated especially for Rare Mothers ~ for you. It is a blend of real-world products and virtual experiences. You will receive luxurious self-care items that will be incorporated throughout the workshop. You will gain experience, education and empowerment to help you reconnect with yourself and refresh your soul.

What is Angel Aid?

ANGEL AID provides mental health and wellness services to rare families through sustainable psychosocial training, transformative retreats, and a connective caregiver-to-caregiver multilingual network.

ANGEL AID believes in uplifting rare families by caring for the caregivers, particularly Rare Mothers™ who are the primary caregiver 82% of the time.

To find more please visit their [website](#).

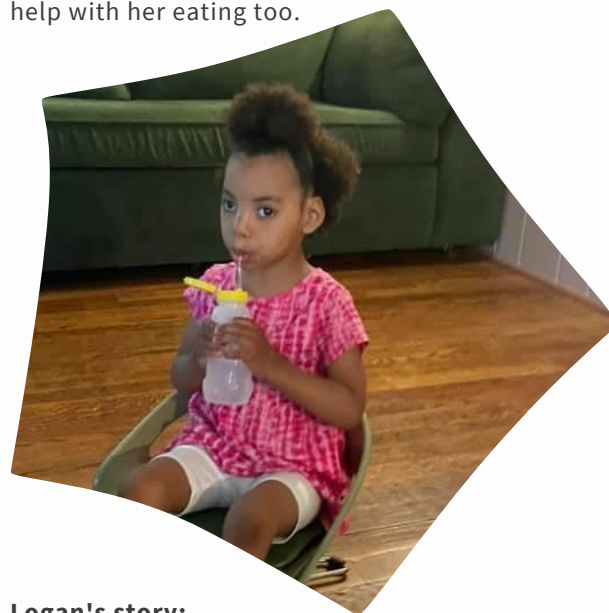
Tips & tricks

WRITTEN BY ARYANA TATUM & MEL SABIN

For our tips & tricks this newsletter, we are focusing on tools to help kids learn the sucking skill.

Sonya's story:

Sonya is learning how to use a straw. It seems to help with the liquid not going down the wrong tube because she isn't tilting her head back. Her feeding therapist used a honey bear with a piece of plumbing tubing for the straw. It is supposed to work where you can squeeze the bear and some water comes up the straw to show her how it works. She caught on right away, and it's been helping with getting her to close her lips more, and hopefully that will help with her eating too.



Logan's story:

Recently, our feeding therapist recommended we start trialing some sippy cups to help Logan with thin liquids. Most of the ones I could find had large openings, which meant the liquids flowed too quickly. Finally, I found the Dr. Brown's Sippy Straw Cup with Silicon Handles. He loved the soft silicon straw, and the handles helped him learn to bring it to his mouth on his own. We love it and would highly recommend!

You can find the [Honey Bear](#) and the [Dr. Brown's Sippy Cup](#) on Amazon!

A sibling's perspective

WRITTEN BY SHARON DEMCZAK

My name is Sharon Barnes Demczak. I am 54 years old and the fourth oldest of nine children. I have been with my husband, Jim, for 33 years and have been married to him for 27 years. We have two children, a son, 19, and a daughter, 17. My oldest sibling, Sandy, is 60 and has Cri du Chat. I have two brothers who are older than me; one is 58 and the other is 56. I have another sister who is 50 years old, then another brother who is 48. The youngest three siblings were adopted at their births; two sisters, one is 42, the other is 41, and a brother who is 34 years old.

Growing up with a sister with special needs was not always easy. I was looked to as the “oldest” daughter quite often. I shared my room with Sandy, took on the role of her playmate, and was often required to look after her when we traveled. When the family would vacation, it was typically my responsibility to watch after her because she tended to wander off. When I was younger, I felt as if she was a burden that I always got stuck with.

As a child, I was often embarrassed by Sandy. Sandy tended to draw attention to herself wherever she went. Her voice was loud, and her claps were even louder. It was difficult for me to understand her behavior and even more difficult for me to understand a stranger’s reaction to her behavior. Wherever we went, people stared. There were times growing up that I resented Sandy for having special needs. I wanted an older sister, and I had one, but not one I could talk to or who could give me advise or guidance.

I did not like having friends over to my house. I was often afraid of how they would react to Sandy. Once a classmate did come to my home; we were maybe 9 or 10 years old. I remember Sandy coming up to her and giving her a big hug. My friend screamed, ran to the bathroom, and locked the door. She refused to come out until her mom came to get her. The neighborhood kids, mostly boys, loved Sandy though. She was just another kid in the mix in their eyes.

The older I became, the more my resentment dissipated, and my

admiration for Sandy grew. I learned Sandy did not choose to be this way but that God made her in His own special form. When I was in eighth grade, working towards my confirmation, I was required to preform community service. I choose to work at my church as an aid to the faith formation instructor for the special needs children’s class. Sandy, of course, was in this group. I learned a great deal through this program.

There are many spectrums of special needs, and all are uniquely special and blessed as God’s children. One of the priests at the church had a love for the special needs program and wanted to expand it. He started a weekly social for teenagers with special needs. He asked for volunteers to assist with his new program. As I had already been working with most of these children, I offered to help. This is where I truly began to build my bond with Sandy, that no one to this day can penetrate.

As a young teenager, my parents looked to me to look after Sandy once again. Her school offered a summer camp program, which Sandy attended each day throughout the summer.

On Wednesdays, they would take all the campers to Loyola College’s indoor swimming pool. The Baltimore Colts football team worked out there and would volunteer to help the campers who could not swim. If they were not able to assist on a particular day, the camper was required to have a swim buddy, or they could not attend.

Continued on the next page.





That's where I came in. After all, it was summertime. What else did I have to do? I enjoyed those Wednesday trips to the pool so much, that I became a full-time camp aid. Every summer after that, Sandy and I would go to camp together.

The older I became, the more I wanted to spend time with her. I took Sandy everywhere. We went shopping, to the zoo, bowling, the movies, and even to the bars dancing, after I turned 21. I did not care one bit what anyone thought or said. We loved being together and having fun. And to me, that was all that mattered. I learned that that one friend of mine who rejected Sandy, so long ago, was the exception to the rule and not how most people behaved.

When I started dating, it was without exception, that the guy embraced Sandy. I was not going to stop including her in my life just because a boy felt awkward; gratefully none did. They each grew to

love Sandy just as we all did.

I knew Jim, my husband, was the "one" very early on in our relationship. One of our strongest connections was our similarities in our family life. My cousin was deaf; his sister was deaf. My sister had special needs; his cousin had special needs. He loved spending time with Sandy. We would take her on trips with us, take her to baseball or football games or whatever she wanted to do. Sandy adores Jim, and Jim adores her.

My children have been raised knowing the strong bond and love that I have for Sandy. They have seen how I treat her, how their Dad treats her, and have always been encouraged to ask questions and to speak their minds.

I have been a participant in the 5p- Society conferences for nearly 20 years and was a host family when it was held in San Antonio a few years ago.

To say that caring for Sandy has been my calling from God is an understatement. I love being an advocate for Sandy as well as an advocate for anyone who has special needs. Awareness and education are the keys to making this world a better place for everyone. I feel I am now being called to help the newer, younger siblings navigate their own journeys, good or bad, as they grow up with a sibling with special needs.

2021 Hall of Fame

At the 2021 Annual Conference, we announced our 2021 5p- Society Hall of Famers. Congratulations! To nominate candidates for the 2022 Hall of Fame, please email [Laura Castillo](mailto:Laura.Castillo).



JAMES CHALMERS
SUPERHERO OF THE YEAR



GLORIA GRIFFIN
GRANDPARENT OF THE YEAR



MELISSA SABIN
PARENT OF THE YEAR



KAILA HOFFMAN
SIBLING OF THE YEAR

Tutus, traps, and tucks: Our journey finding accessible recreation

WRITTEN BY HEATHER MEZA

When Cinnia was diagnosed, our lives were already fully engulfed in therapy and specialist visits, so despite already being a toddler, we hadn't even begun to approach the idea of activities and sports. The next year or so continued to move along with our busy schedule doing therapy basically every day and adding in special needs preschool. And then Cinnia turned 4, therapy slowed down a little, and she began to express an interest in dance, so we tried. We are blessed to know a very welcoming program and signed up. While Cinnia lasted the entire school year, there were many unpredictable ups and downs, and ultimately it ended in her refusing to go near the stage during the recital despite all our best efforts to let her explore and acclimate before it was stage time. After dance, Cinnia was again not interested in activities for a while, and just when she began exploring again, Covid restrictions halted EVERYTHING!

Cinnia recently entered kindergarten and has shown a consistent love for kicking a soccer ball around. We searched high and low for an all abilities type program with no luck. Eventually, the decision was made to register in the local "recreational" league for the fall season. Jason and I had a lot of excitement and nervousness about this, but we pressed on. The night of the first practice was awful for us. Cinnia was confused and overstimulated because this program does level practices not just team. The coaches didn't understand why she wasn't listening, the teen helpers were disinterested, and the other kids her age had ZERO interest in her. It was also quite obvious that these kids were only recreational because they were too young for the travel league. This level was definitely NOT all ability friendly.

After a few emails and even social media comments, I was able to discuss my concerns with a board member who then offered to allow her to play down a year. This was a big choice because it meant a new team and going against our hopes of being with her peers. Jason and I decided to give it a try before giving up completely because at that point Cinnia did not want to go back. We talked to her for the entire week about a new team, calmer practice, and small field. Despite a comforting phone call with the new coach, we arrived at practice week 2 very anxious. Quickly we found the difference to be night and day. Our new coach took time to redirect Cinnia, let her explore drills her own way, and gave her lots of encouragement. We left practice with a new outlook and an excited Cinnia!

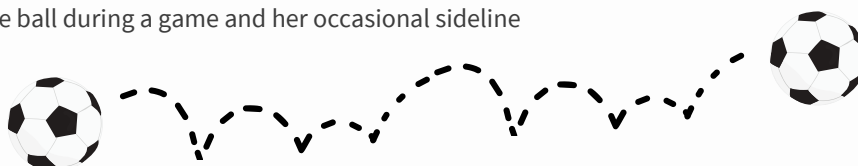
The season continued to challenge her, and there were tears shed, some refusal, but overall a lot of happiness and participation. Her coach continued to value her and allow her to play as much as she tolerated, despite never touching the ball during a game and her occasional sideline meltdowns.



He made it a point to ASK her if she wanted to play, got on her level, and let her go back to the bench anytime she was done. Practices let her shine and show off her actual skills.

In the end, the season was a success for Cinnia. She was awarded best effort on her team, she only has good things to say about being a "soccer team athlete," and we got to see her enjoy an activity with her peers, on her terms. Sadly, she will not be eligible to "play down" the next season, so the cleats and shin guards will be retired until she is old enough to participate in the all ability programs in our area. BUT we are looking forward to trying an all ability cheer program at a local gym.

We will always seek to have Cinnia involved in activities as long as she has an interest, but the reality is at 6 years old, she is already at the mercy of coaches who don't mind losing to let kids play, or we have to find a dedicated all ability group which does not give her the same experience as her peers.



Transition: Some things to consider

WRITTEN BY DENNIS CAMPBELL



Most people think of "transition" as preparing for life after school. It is, but for our kids, it starts way earlier. Transitions by definition are the process or a period of changing from one state or condition to another. For individuals with Intellectual Disabilities, transition (or any change) is often traumatic. For individuals with 5p deletions, transitions occur in: Early Childhood, Kindergarten, School to Adult Life, or even from one room to the next.

There are many books written about transition, but for this article, let me try to just pose the questions you need to consider as you help your loved one become the best and happiest they can be. Let's talk about the "w"s. Who: will they live with, have for friends, depend on for support, and most importantly, who will they be? (Back to that later). What: will they do for fun or meaningful activities (how will they spend their days), what resources will they have (family, friends, monetary, or other things)? Where: will all of this occur and when?

I prepared teachers to work with students with disabilities for about 20 years. If I had to break down the most important thing I taught, it would be to assist individuals in being as independent as possible. Shoot for total independence and provide the supports they need to get as close as you can. I have also been the dad to someone with disabilities for over 30 years and have to admit that I have often failed in that. I could spend a lot of time talking about the reasons for that, but the important point is to be aware that as a parent it is easy to not let your child be as independent as they can be.

Keep independence in mind as you go through this process—it will greatly impact their future.

The Transition Process on paper is really quite simple: Identify Interest, Set Goals, and Take Action to achieve those goals. Then periodically review how it is going, adjust as necessary (remember life happens and can throw a monkey wrench in those plans), be flexible, review again, and revise when necessary. Like I said, it's simple on paper. Preparation for transitions begins with an understanding of the individual and setting goals that are realistic. Remember the old adage: "Failing to plan is planning to fail."

There are several programs/strategies that are available to help with this process. Some I am aware of are: Person Centered Planning, Circle of Friends, Futures Planning, and Making Actions Plans. Whichever method you choose, being it one of these or something else, the important thing is to include as many people who are part of your child's life as you can in the process, for example, siblings, other family members, teachers, friends, and any other relevant professional. If you can find someone trained as a facilitator in this process, that would be great. A facilitator can help to ensure that everyone's input is included and will help the team come up with a plan. They also let you stand back and be part of the team. As a parent you can do the planning yourself, but the input from others can be very helpful and often offers options you may not have considered. The bottom line is, of course, in the end you are still in charge. For those who are, shall I say, very controlling, it can be a challenge to let go, and a facilitator can make this a little easier.

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So to recap, the important pieces are to promote independence, get input from multiple people familiar with the individual, be open minded, and develop at least the beginnings of a plan. Before or during this process, you should explore what the local options are for adults with disabilities. For example, agencies that work with adults with disabilities, living options in your area, and government resources that are available. Things that should be included get back to those “w”s. Who is the individual? If they have a 5p deletion, they probably have communication issues, some behavioral concerns, can be lazy, but also understand a lot more than you think, and have the ability to manipulate people to get what they want (this can be an asset). They are also very social and can adapt to new environments but may need some help with that. Remember to think about who they are currently and who they become. Although you can’t predict this, you can make sure you understand their strengths and challenges. By doing that you can help them learn to increase those areas of strengths and make those more challenging areas less of an issue. If their manipulating helps them become more independent, great; if it keeps them from doing for themselves, not so great. The key is to gather as much information as you can as you plan. Good decisions are based on good information. Over the years I have talked with parents who said, “If we only knew about something, we would have made a different choice.” I always remind them that they chose based on the information they had at the time. If you are thorough in gathering that information (data), and choose based on that, you can be comfortable that you did your best.

One way to make transitions smoother is a process where you teach to the next environment. Take them to the new school, classroom or program, visit a group home, or an adult program. Talk about what is going to be different and also how great it is going to be. Boost those expectations. All the way through school remember academics are important, but to be able to function as independently as possible when they leave school should never be forgotten in your IEP’s. Little is known specifically about outcomes for students with 5p deletions. Just like there is a spectrum of abilities with the syndrome, the opportunities available in adulthood are also a spectrum. So, let’s move on to “what.” What should include how they will spend their days and with whom. Options again are a spectrum; they can go from competitive employment, supported employment, workshops, or day activities. Again, shoot for the most independent of those options for your child. In that way you can be comfortable that you gave them the best shot you could.

All of these should be considered as part of IEP’s in school. There are training opportunities also after high school. Recently, college programs have been developed for individuals with disabilities primarily through the Think College network. Other programs are run through agencies like the ARC and Independent Living Centers.

Again, get to know what is available in your area. Many are provided through Medicaid. Your child should be eligible for Medicaid. When they turn 18, Medicaid is based on their resources not yours. They also should qualify for Social Security. Apply just before they reach 18 for Social Security, and they will in turn refer you to Medicaid.

That “what” entails where they will spend their day. But also, you need to consider where they will live. Many, if not most, individuals with 5p- will live longer than their parents. So, considerations for where they will live should be part of the planning. Options could include at first with parents (we don’t want to let go), but after that it could be with other family members, friends, in an apartment by themselves or an apartment with support from an agency, a group home, or other independent living environment. When that move or transition comes into play should be considered. There are many adults with disabilities living with elderly adult parents. Obviously, the parents’ ability to provide care is a consideration. One thing that many families don’t always take into consideration is when a parent passes away, their child not only has to deal with that loss, but may require that they move to a new environment, creating a double whammy of loss.

As you consider where they will live, also think about things like taking care of a household. Can they prepare their own meals? Can they follow directions and microwave or heat already prepared meals? Let them be as independent as possible. How will they get around? Can they use public transportation? Will someone take them where they need to go, or will they pay a ride share company like Uber or Lyft? Are they able to protect themselves and be safe? What about friends and even a special friend? As an adult they have the right (and ability) to have a sexual relationship. You want them to be happy but not be exploited.

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If you are not familiar with the term, this is called Self-determination, being able to make choices for yourself that you consider important and meet your values. Teaching self-advocacy skills are also important.

How will they manage money and resources? If they are receiving benefits like Social Security and Medicaid, there are income and asset limits. Look into Special Needs Trusts, the Able Act, or similar programs. Make sure family members are also aware of these. Grandma or Aunt Sally may have their hearts in the right place in leaving your child an inheritance, but if it isn't protected by a trust of some sort, those assets will cause them to maybe lose benefits. The 5p Minus Society has that information available. Finally, when they turn 18 in most states, they are legally an adult.

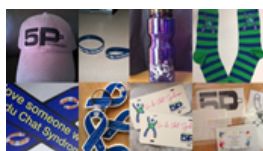
Each state has a developmental disabilities council and a protection and advocacy agency. To find resources in your state, a good place to start is the Administration on Disabilities, the federal agency that supports many programs.

So, in closing, this is just a rough overview of the process. My intent was to get folks thinking—long term for those of you with younger kids, and for those of us already there, perhaps some things you hadn't considered. Just remember, planning and setting goals are a good thing. Even if at the last-minute life gets in the way and you have to change course, you will be more ready to revise and again review.

Want to shop?

When purchasing items on Amazon, make sure you go to AmazonSmile at <https://smile.amazon.com/> and choose to support 5p- Society (Lakewood). The 5p- Society gets a small % of what you purchase. Every little bit counts, and we are grateful to you for your participation.

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Managing stress in 2022

WRITTEN BY MEL SABIN

Hello 2022! We are all still dealing with a global pandemic, disruptions to schedules, and the ability to socialize and get involved in activities outside the house. Most of us are also juggling jobs, relationships, and errands, all on top of having children or family members with special needs.

So this is a reminder to take a deep breath and incorporate a few ways to make your life easier and better in 2022. Here are some tips to manage stress better this year:

- **Build in as much routine as possible.** Even with all the COVID craziness and everyone being cramped together all the time, find ways to make it feel like you are "getting up" and then "coming home." Maybe that is scheduling activities or time spent in specific rooms in each day. Maybe it's scheduling in breaks or fun time.
- **Schedule time for self care.** I love doing face masks on Sundays or going to get a manicure.
- **Start a new tradition.** Logan and I do PJ Sundays. We even go shopping in our jammies. Less laundry for me and just that little bit of laziness makes it seem like we're taking a mini vacation.
- **Do something once a week to give your mind a break.** Maybe it's drowning out everything and everyone blasting music. Or reading a book for 20 minutes. Personally, I listen to podcasts or turn on Netflix.
- **Give yourself permission to rant and rave.** Sometimes you just have to let it out. Don't be mean; that will just make you feel worse. Definitely voice your frustrations and—pro tip—come with a suggestion that could relieve the issue.

Here's to less stress in 2022!

"Loving You Big" just released

WRITTEN BY LEAH WITMAN MOORE

When I first received Jordan's diagnosis ten years ago, I looked up every book I could find about raising a child with special needs. As an English teacher, words were how I made meaning of the world around me. I found some books—many that provided strategies about how to raise a child with a disability; however, I wasn't as interested in learning more tips. My home was already a rotating door of therapies. I didn't need to know more about the logistics of how to get her into the grocery store; I wanted to read how people felt trying to do it. I wanted to connect to the other caregivers who needed to talk about what no one saw—what was it really like below the surface to raise a child with a rare disability?

I felt isolated. Tired. And a manicure wasn't going to cut it. I needed more of a community. When I discovered the 5p- Society, I immediately connected to people that understood my story and could help me more than the doctors. Through our shared storytelling, I not only learned how to connect my child more to the world around me, but also to navigate through my own understanding of her diagnosis.

One day, after a long day of teaching, I decided to take the advice I share with my ninth graders. Tony Morrison writes, "If there's a book that you want to read, but it hasn't been written yet, then you must write it." So, I sat down and started to write the book that I needed to read.

About nine years later, *Loving You Big* was born. It is the book that helped me to understand how to balance the joys and sorrows of raising Jordan and her twin brothers. Without understanding why, I hoped I could love the disability out of Jordan. That with enough resourcefulness I could discover the right experts to help her find her way in the world. However, through writing, I learned there was nothing about Jordan that needed to be changed. It was the world that needed to be different. People are able to see their own experiences in print and share them with a loved one to explain what it feels like for a day to walk in our shoes. I hope readers will find validation in their own struggles, experiences, and questions and recognize they are a part of a larger community. That by reading my story, they will feel less alone in theirs.

Loving You Big can be purchased at Amazon, Barnes and Nobles, Target, local bookstores, or anywhere online where books are sold. Also, you can visit www.lovingyoubig.com to download a free PDF of the book club guide or to sign yourself up for the Spotlight Series—dedicating to celebrating the stories of other families.





PO Box 268
Lakewood, CA 90714-0268

Return Service Requested

Toll: (888)970-0777
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Fax: (562)920-5240
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Dear 5p- Society Member,

We are trying to eliminate or reduce how much snail mail we send out. One of these ways it to send the quarterly newsletter electronically. You are currently on our mail list. The emailed version has animations and videos. If you would like to receive the newsletter electronically, I will need you to send me your email address.

Please let me know if you prefer the newsletter to be sent to you via snail mail or if we can remove you from that list and send it to you electronically.

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Warmly,

Laura Castillo
Executive Director
5p- Society
PO Box 268
Lakewood, CA 90714
(888) 970-0777
director@fivepminus.org