2021
OVC
APPLIED RESEARCH
& BEST PRACTICE
SYMPOSIUM

Helping Children with Disabilities Thrive

Play, Powerful Behaviors, and Full Potential

SCOPE OF THIS RESOURCE

This ebook accompanies the 2021 OVC Applied Research & Best Practice Symposium. It is targeted toward supporting parents, caregivers, and professionals serving children with disabilities, but the principles may apply more broadly. Ideally, it will be used in conjunction with all of the Symposium content - presentations, print materials, coaching sessions, and interactive discussion boards.

For more information, visit ***research.cafo.org/symposium***

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INTRODUCTION

"So God created human beings in his own image. In the image of God he created them..."

Genesis 1:27

INTRODUCTION

Humanity is endlessly diverse. The internet is populated with dozens of websites that can help you find your "doppelganger", or someone who looks just like you. It's incredible to think that - in a world with billions of living human beings - it is the rare instance in which we find two that look alike. Once we begin to consider personality traits, skills, backgrounds, and preferences, the diversity increases exponentially until virtually no two individuals are exactly the same. This diversity reflects the endlessness of God, the countless elements He holds together. (Hebrews 1:3, Colossians 1:16) We can learn more about Him when we engage with people unlike ourselves.

Unfortunately, there is a shadowed side to diversity. Human beings are naturally most attracted to people similar to themselves. Typically, people are more likely to rate people that look like them as more attractive[1, 2], to gravitate toward people with similar beliefs[3], and to live near to where they were raised[4]. *Even if different can be a wonderful opportunity for learning, same is comfortable.* Sometimes, this leads to us to choose not to interact with people who have characteristics or experiences that may be different from ours. Without interaction with diverse individuals, we can quickly start to think of groups of people that share a similar characteristic as being all the same. If we have a negative interaction with a rude young person with a piercing, we might automatically (and unfairly) assume all young people with piercings are rude. In extreme forms, it can lead to prejudice, discrimination, or stigma[5, 6].

People with disabilities often experience this labeling or discrimination[7, 8]. Especially when a disability is visible, other people can think they "know" an individual just by what they see. They miss the layers of characteristics that make up a human life - history, relationships, knowledge, experiences, personality, preferences and more - that all combine to make a unique person. Every individual has inherent worth and dignity and should not be defined by a diagnosis, but instead loved and treated like the child of God that he or she is (John 13:34-35). Taking it a step further, each and every person with a disability should know, without a shadow of a doubt, that they are a beloved child of God with great value and belonging.

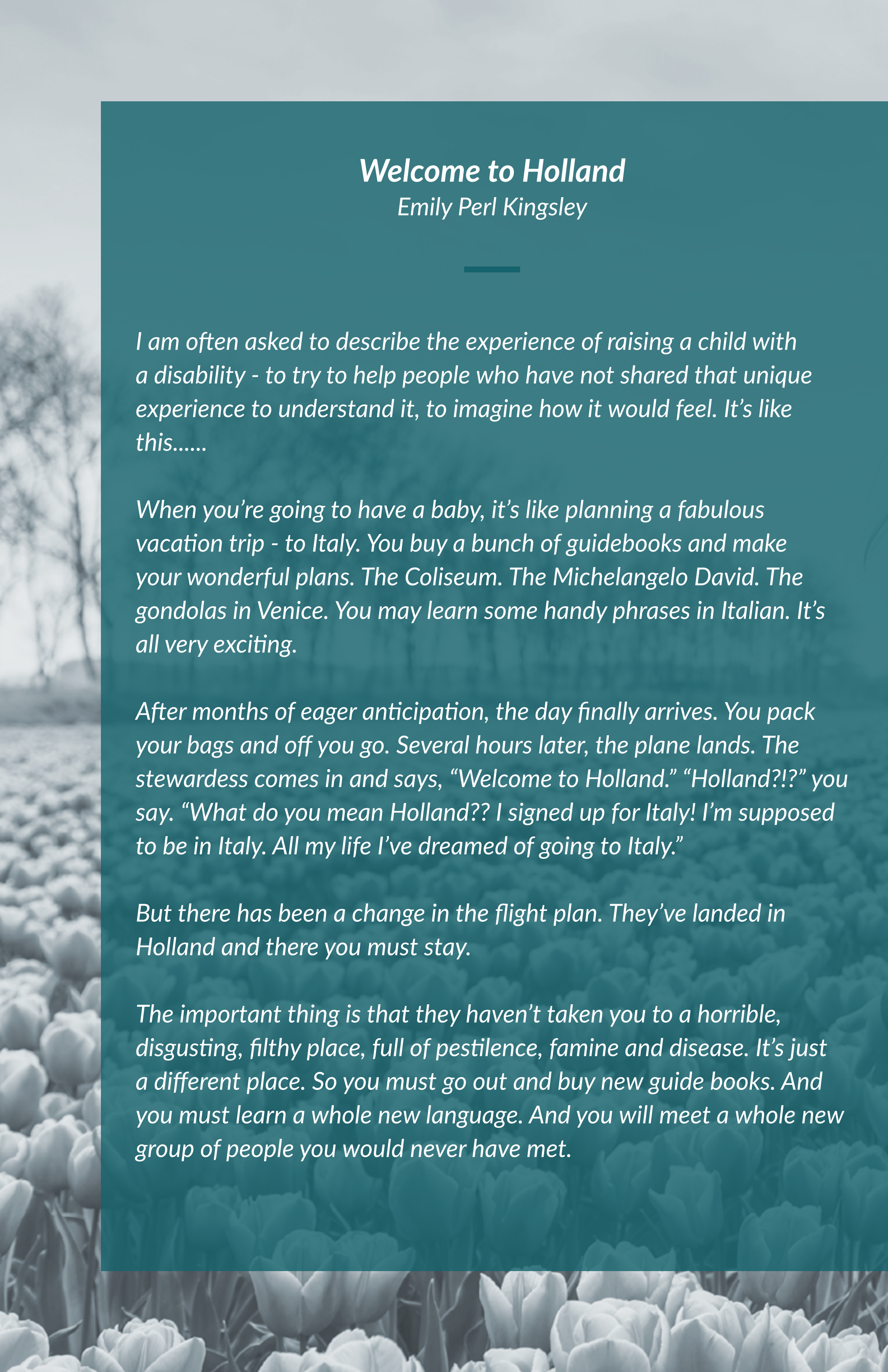
Caring for children with disabilities and loving them well requires patience and compassion. Often, decisions do not come quickly or easily; there are endless hours of research, networking and seeking out resources to best serve the child and family as a whole. For many disabilities, there is limited knowledge about the condition itself, let alone treatment and interventions, and it can feel like resources are scarce.

If you are serving children with disabilities - as a biological parent, adoptive parent, foster parent, kin, teacher, service provider, practitioner, or researcher. ***This resource is for you!***

Our hope is that through this resource, you will feel more understood, encouraged, and informed than you did yesterday.

This book will address:

- *What is a disability and why does the language we use matter?*
- *The powerful, often challenging. behaviors of children with special needs and how we can approach them in a loving, compassionate way that connects rather than frustrates.*
- *The power of play as a tool to communicate and bond with children who have special needs.*
- *Possibilities and hope for the future as children with special needs transition to adulthood.*



Welcome to Holland

Emily Perl Kingsley

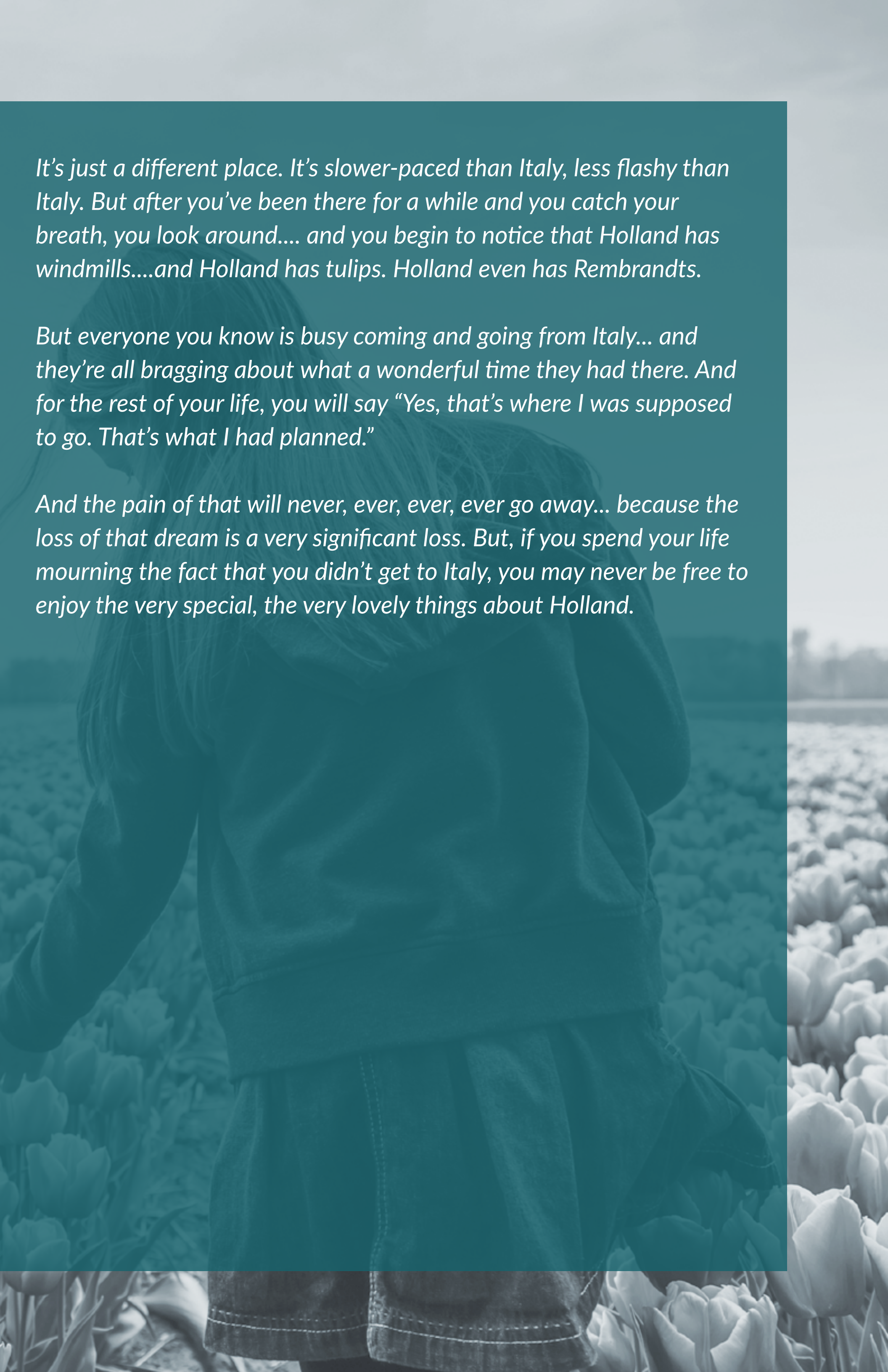
I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this……

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there has been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.



It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very significant loss. But, if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

WHO ARE CHILDREN WITH DISABILITIES?

Children with disabilities are incredibly difficult to categorize, as they represent a large number of individuals with diverse and unique strengths, personalities, interests, and skills. Those factors that would be found most commonly in this group would be found commonly among all children - a need for food, shelter, and security, the desire to be loved, and dreams for the future. They are neither all pleasant nor all difficult, all loving nor all distant, all intuitive nor all disconnected. They are unique individuals with tremendous potential despite their challenges.

What Is a Disability?

Broadly speaking, a disability is a physical, mental or emotional condition that affects the way the body works or develops. In order to be considered a disability, a condition needs to significantly affect a person's functioning[9]. A person who has long-term impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others[10].

While some disabilities are visible on the outside, marked by physical indicators or assistive devices, many are not. In fact, 74% of Americans with disabilities do not require assistive devices[11], meaning their disability is likely invisible. An invisible disability is "a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movements, senses, or activities."[12] Examples of such disabilities are chronic pain or fatigue, brain differences as a result of trauma, sensory processing disorders, mental health disorders, and learning differences. Even when we are not aware, people are often struggling with unseen conditions and limitations. Alternatively, we must be careful not to judge individuals with visible disabilities or assume anything about their own limitations. We must engage in conversation without preconceptions and learn with our ears instead of our eyes.

What a Disability Is Not

A disability is not an identity.[13] An individual has a disability; he or she is not disabled. A disability is not an illness. It is not simply a disease or diagnosis that can be treated with a medication. Nor is a disability temporary.

LANGUAGE MATTERS

LANGUAGE MATTERS

In a world where sensitivities and socially-accepted terms are constantly changing, it is important to be aware of both context and perception. Insensitive language, even when used unintentionally, can make people feel excluded and can be a barrier to building relationships and working together.

The Americans with Disabilities Act National Network has developed Guidelines for Writing About People With Disabilities. In it there are several guiding principles to be used as a starting point when interacting with and speaking about individuals with disabilities:[14]

Guidelines for Writing About People With Disabilities

Ask to find out if an individual is willing to disclose their disability. Do not assume that people with disabilities are willing to publicly acknowledge their disability. Some are not at all, and some are, but not necessarily always, depending on the circumstances.

Ask to find out an individual's language preferences. Some people see their disability as an essential part of who they are and prefer Identity-First Language (i.e. deaf person). Others prefer Person-First Language (i.e. person who is deaf).

In general, refer to the person first and the disability second. When in doubt, use Person-First Language, which acknowledges that a person is not a disability, condition. or diagnosis; a person has a disability, condition, or diagnosis.

Emphasize abilities, not limitations. Empower individuals by emphasizing what people can do instead of what they can not.

Use neutral language - never condescending euphemisms or offensive words. Words such as “victim” and “invalid” portray the person as passive or suggest a lack of something, neither of which are true. Though words like “differently-abled”, “challenged”, “handi-capable” or “special” are sometimes accepted, they are often considered condescending and should not be used.

Resources for Further Exploration

For more information on appropriate language:

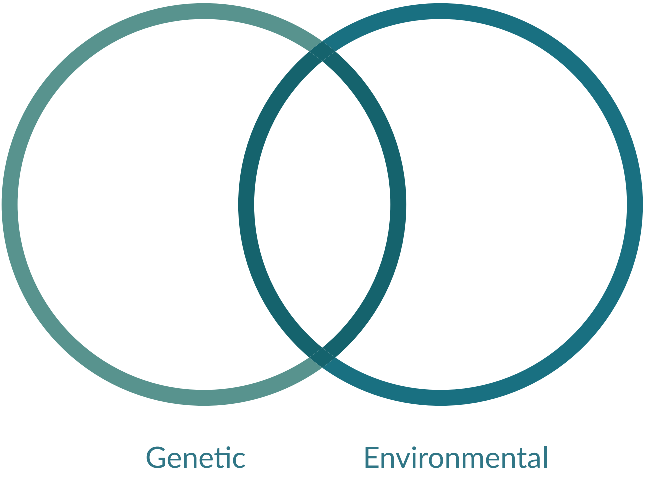
- UN Convention on the Rights of Persons with Disabilities
- Disability Language Guide, **Stanford University**
- **Video:** Katie’s Disability Awareness
- **Video:** Encouraging Caring Behavior

(Adapted from Guidelines for Writing About People With Disabilities, Americans with Disabilities Act National Network)

How Do Disabilities Develop?

Just as each individual disability is different, the ways disabilities develop are also different. Some disabilities are present and diagnosable at the time of birth, others are not immediately apparent or they develop later in life. Some disabilities occur as a result of genetic factors[15, 16]. This can be due to a specific trait or condition being passed from parent to child, or an atypical expression of genetic code. Some disabilities occur as a result of environmental factors, such as an accident[17] or poor nutrition[18]. Sometimes, disabilities, such as learning disabilities, arise as a result of the combination of certain genetic and environmental factors[19].

Cause of Disability



Children with Disabilities and Separation from Parental Care

Having a disability is one of the most commonly cited causes of a child being separated from parental care[20]. Caring for a child with special needs can be challenging for anyone. For parents who may be experiencing extreme poverty, oppression, or their own mental or physical health concerns, it can seem impossible. Sometimes, this experience can lead to child maltreatment[21, 22]. In other instances, it may lead to a parent voluntarily placing their child in alternative care settings. With the right support, many at-risk families have been able to care for their children and themselves, but they cannot do it alone [23, 24].

In some cases, out-of-home placement becomes necessary. Secondary or temporary caregivers must be aware of the child's disability and trauma history in order to provide comprehensive care[25]. When there is awareness on all sides, appropriate support and services can be put in place to best support the child.

Families of Children with Disabilities

Children with disabilities do not exist in isolation. Their parents and caregivers also have a personal experience of caring for someone with a disability. At times, there are tremendous demands on the parent or caregiver, as they may need to become not only their child's caregiver, but also their patient advocate, medical researcher, therapy chauffeur, appointment secretary, etc. Caregivers can quickly become stressed, overwhelmed, and burned out[26]. Even when services are perfectly coordinated, there are still appointments to drive to, specialist bills to pay for, assistance to apply for and often, other children to care for, all at the same time. Socially, parents can feel misunderstood or stigmatized by family and friends and quickly experience loneliness and a shrinking of their support system[27].

Consider a woman who has two biological children. They are school-aged children, and she is working full time to support her family. Unexpectedly, the woman's sister dies, leaving her own young son who has epilepsy without a caregiver. The woman wants to take in her nephew, but his disability prevents him from attending school and requires specialized care. Trained childcare is not available in her community, so she would have to quit her job in order to stay home and provide care for her nephew. She is devastated and feels as if no one can truly help her or understand her situation.

As caregivers of children with disabilities, we may find ourselves in many different roles. We might be the parent of the child who is demonstrating challenging behaviors. Or we could be an outside observer, watching another parent come up against behaviors from their own child. You might be a practitioner helping to care for both of these families. No matter what your role, what is important is that grace and understanding are at the forefront of your reaction. Being able to better connect with their child will be helpful for both of these families. Play is an opportunity to connect - it will create moments for connection and bond caregivers and children together. This connection will prove to be invaluable as families work to stay together, support each other, and allow themselves to imagine possibilities for a bright future.

"Having a daughter with special needs has taught me that God doesn't make mistakes. After her diagnosis, people would tell me and my wife, 'We're praying for healing because God doesn't want her to be this way.' If that's true, then it means that either He doesn't know what's happening or that He doesn't have the power to change it.

Instead, I've had to wrestle with the facts that He is all knowing, all powerful, all good. When I wrestle with this, I come to the end knowing that he didn't make a mistake. She has a purpose, and we've seen glimpses of it. I say glimpses because I know she still has more to do. But she's already shown God to people in new and unique ways."

Father to a child with disabilities

POWER OF PLAY

"Play is the highest form of research."

N.V. Scarfe

POWER OF PLAY

Play is a child's work. Every human being is born with an instinct towards play[28]. Play has been defined as "a range of voluntary, intrinsically motivated activities associated with recreational pleasure and enjoyment".[29] It is a vital piece of human growth and development[30], and has countless benefits for children and adults alike. Play builds self-esteem[31] and social skills[32], improves coordination and motor skills[33], increases attention span[34] and problem-solving abilities[35, 36], while fostering a child's ability to self-advocate[37]. It supports the formation of the safe, stable, and nurturing relationships with caregivers that children need to thrive[38]. Play should be freely chosen, personally directed, and intrinsically motivated[39].

Play can vary between individuals and cultures, but even then the motivation and benefits remain similar. Children from a more individualistic culture may prefer to spend time alone and participate in competitive activities, while children raised in a more collaborative culture may prefer to play in large groups and dislike competition[40]. Similarly, the roles children choose in pretend play can be a result of their upbringing and surroundings. Those who are raised in rural settings might play farm and tend the fields, while children living in cities might play restaurant and pretend to drive taxis. American and European families tend to emphasize individuality and self-sufficiency in play, while Asian, African, and Hispanic families tend to focus more on group interaction and relationship building[41]. Different cultures also place different emphasis on the value of play and how much it should be prioritized in a child's life.

Generally speaking, there are six stages of play that a child goes through linearly throughout their life and development.[42]

See next page »

Six Stages of Play

Unoccupied play - relatively still and appears scattered; exploring materials around them without any sort of organization; practice manipulating materials, mastering self-control, and learning about how the world works.

Solitary play - entertain themselves without any other social involvement, may not notice or acknowledge other children; able to explore freely, master new personal skills like new motor or cognitive skills, and prepare themselves to play with others.

Onlooker play - sit back and engagingly watch other children playing, but do not join in; children learn a lot by watching others. They learn about the social rules of play and relationships, explore different ways of playing or using materials and learn about the world in general.

Parallel play - children play next to each other but are not really interacting together. For example, two children may drive cars on the carpet next to each other, but their play does not actually overlap. Not really engaging in a social exchange - work side by side on the same activity, practicing skills and learning new methods to engage together.

Associative play - children begin to be more interested in the other players; begin practicing what they have observed through onlooker and parallel play; start to use their newfound social skills to engage with other children or adults during an activity or exploration.

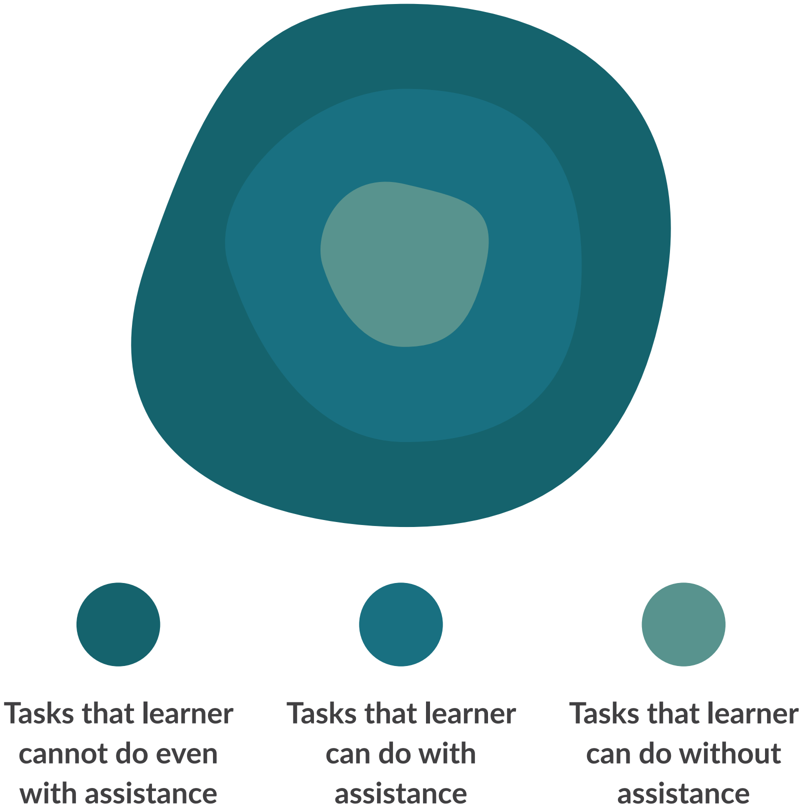
Cooperative play - cooperative efforts between players; adopt group goals, establish rules for play. It's important to remember cooperation is an advanced skill and can be very difficult for young children. Ironically, cooperative play often involves a lot of conflict. This is normal. It is sometimes difficult for young children to share, take turns, and negotiate control in these types of play scenarios. You can support children engaged in cooperative play by staying close and helping them learn healthy expression of emotions and teach them problem solving skills.

It is important to note that the timing of each child's progression through the stages - particularly for those with disabilities - can vary greatly from child to child. For example, one girl who is three years old might begin to engage in associative play with her peers while another girl the same age might prefer to play on her own, showing little interest in collaboration. These stages serve as a measuring stick to assess growth, not to discourage, keeping in mind that each child has different abilities and needs with distinct interests and preferences.

Zones of Proximal Development

If each child progresses at his or her own rate, then how do we know what type or level of development to encourage in our children? One approach is to consider zones of proximal development. Vygotsky (1978) introduced this theory, which says that each individual has a range of ability to perform certain tasks[43]. In other words, one four-year-old child might have the ability to tie his shoes, even though he has not yet mastered completing the task without help. Another child might never be able to tie his own shoes, so his range of ability is different. Proximal activities are skills which an individual will soon be able to accomplish independently, but still needs guidance and practice to be able to do so. As children receive training from invested caregivers and have positive social interactions that allow them to try out these new skills, they are able to move through zones and progress towards achieving their full potential.[44] Learning to ride a bike is a simple example. A child starts off on a bike with training wheels and, at that time, might be able to ride without training wheels if an adult walks alongside, holding the bike upright. However, the child definitely cannot ride the bike without training wheels or adult assistance. In this example, the child's current zone is training wheels, and the zone of proximal development is riding the bike without training wheels.

Zone of Proximal Development[45]



Caregivers to children with disabilities would benefit from approaching challenging behavior with a similar perspective. By understanding where a child is currently, and then evaluating what the next zone of proximal behavior would look like for that child, appropriate behavior and communication can be modeled to move the child toward full development of those new skills. Play is a great opportunity to model these healthy perspectives and interactions.

Supporting Children with Disabilities in Play

While it seems like a simple answer to a complex scenario, play is an incredibly powerful tool when interacting with and supporting children with disabilities.

All children need play, including children with disabilities. Rather than trying to structure and direct a child's play, it is a caregiver's role to support, facilitate and promote positive interaction. Though it may require creativity to facilitate play for children with diverse abilities, much can be done to ensure that accommodations are made and the child is not deprived of important opportunities for play.

Children with disabilities can face barriers to play that children without disabilities do not - limitations that are emotional, social, or physical in nature. Individuals with crutches or wheelchairs might have difficulty accessing play areas, assistive technologies or devices might be difficult to access, and a family's proximity to play equipment could be too far to be practical. A family's financial situation can limit opportunities to participate in recreational activities and social isolation might result in a lack of friend relationships or knowledge of local resources. Emotionally, children might struggle with having the confidence to interact with peers. Community attitudes and stereotypes about disabilities also have the potential to cause struggle and hardship for children with disabilities when it comes to play.[46]

Children with disabilities may have limitations that require modification to play activities, but play is possible for all. There is not a one-size-fits-all approach to play and caregivers should feel the freedom to evaluate what their own child needs and modify as necessary.

There are several types of modifications that can be made to activities to accommodate different types of needs[47]:

Modifications

Type	Support	Example
Environmental	Changes are made to the physical or social environment in which the activity is occurring.	Create clear pathways between activity centers and tape down edges of rugs so that feet, wheelchairs, or crutches do not get caught on the edges as they move around.
Adapting the Materials	Play materials are modified so that the child can easily manipulate them.	If a child has difficulty with stacking rings, simply remove every other ring so they will be easier to grasp and stack.
Simplifying the Activity	Complicated activities are simplified by breaking them down into smaller parts or reducing the number of steps.	To help the child build a more complex block castle, clearly describe the process and draw pictures so the steps are easy to follow.
Using Child Preferences	The child has access to their own preferred materials, activities, or people to encourage the child to play.	For a child who loves cars, create a racetrack theme for a play area or use car placemats in a play kitchen.

Type	Support	Example
Special Equipment	Creative or adaptive devices are used to allow the child access to and participation in the activity.	If a child can not stand up to paint at an easel, replace it with a lap easel that can be used in a wheelchair or while sitting on the floor.
Adult Support	Caregiver or another adult joins the child's play and encourages involvement both verbally and through modeling behavior.	If a child is becoming overstimulated and on the verge of losing control, sit down and join the child's play to calm and slow down the pace.
Peer Support	Peers are encouraged to join a child's play to give encouragement through modeling and commenting, just as an adult would.	For the child who has difficulty with activities that require several steps (such as making a collage or building a castle), pair the child with a buddy so they can participate together.
Invisible Support	Naturally occurring events are arranged within an activity to increase the probability of the child's success.	If a child has difficulty communicating with peers, place picture symbols in the play area so the child can point to them and increase peers' understanding.

One thing to keep in mind when considering play and the child's behavior is this: removing play is not, and should not be used as, a means of discipline. Although there are many ways to administer discipline, the ultimate goal is to teach the child, not punish. Since play serves so many various and important developmental functions, taking away opportunities for play is not an appropriate form of discipline. Rather, it's best to try to relate the discipline to the act itself.

However, there might be times in which play might need to be modified in response to dangerous behaviors. For example, if a child is playing with a pretend sword and chooses to hit a sibling with the toy, it would be appropriate to remove the sword from the play environment for a period of time. Once the allotted amount of time is complete, the child should then be taught or reminded how to safely play with the toy and given the opportunity to practice.

Supporting Caregivers of Children with Disabilities with Play

As adults, we are not accustomed to play as a regular part of our lives, but it is as equally beneficial for caregivers as it is for the children. The positive impact of play will seep into every aspect of the caregiver/child relationship[48]. Play results in decreased stress, increased quality time, bonding and connection, and opportunities for reflection. Caregivers often find that by slowing down and taking time to interact with their children through play, they experience increased motivation to continue parenting and serving through trials.

By making the child the priority of our approach, but also leaving much room for them to make play their own, we can set ourselves and our children up for positive and encouraging playtime. We must intentionally shift our model of play from functional to relational in order to be most effective.[49] Rather than seeing play as a box to check in the course of our day-to-day interactions, play should be built into our routines so that it is happening all the time, even without our children realizing.

Remember, it's supposed to be fun!

“I lost my ability to play when I was a teen, so I was skeptical about playing with my daughter at home. But I found it simple and not at all intimidating. I’ve learned to follow my daughter’s lead. She chooses which toy to play with and how, and I ask to be involved. Typically, she’ll hand me a toy and tell me what to do with it. If I don’t know what to do next, I ask. She tells me.

The challenges have not gone away, but they have shrunk. She and I don’t get so angry with each other, and situations don’t get as escalated as they used to. In my parenting book, I would call that success.”

Play for Teenagers and Adults with Disabilities

Play is important for all individuals - infants to the elderly - and this includes teenagers and adults with disabilities. Depending on the type of disability that a child has, the type and complexity of play can vary. However, as the teenager grows into adulthood, there are ways to guide and support play toward age-appropriate interests and activities. Caregivers can create play scenarios that are modeled after vocational or volunteer opportunities that the teen or adult might have. Games can be modified to include more age-appropriate imagery and used to begin conversations around new ideas or responsibilities. Adolescence is a time full of change when most teens experience a desire to fit in with their peers. During this time, play can be used as a tool to open lines of communication between caregiver and teen or adult to really understand desires and insecurities. The focus of this time together should be on connection and communication, bonding and creating a safe place for the individual who is likely experiencing new feelings and ideas at every turn.

Key Practices and Principles for Play

Whether play is free of structure and guidance or thoughtfully designed to accomplish a specific purpose, it is equally beneficial and vital to development. Play offers a low-risk, low-stress environment in which children can encounter and overcome challenges. This gives them confidence in their ability to face new or challenging situations without triggering an excessive stress response. With an increasing emphasis on academics and technology, it is important to remember that free play is the training ground for appropriate developmental progress in young children. For children with disabilities, play may not come as naturally or progress in the same way as others, but it is still a vital piece of childhood.

(Adapted from Created to Heal, CAFO)

This information can provide helpful foundational knowledge but may leave parents and caregivers wondering where to start in facilitating play for their children. As we learn to play with the children we care for and serve, there are three main principles to keep in mind:[50]

1. **Manage Your Expectations**
2. **Set the Scene**
3. **Support and Guide**

See principles »

Play Principle 1: Manage Your Expectations

Instead of worrying about how you think the child should be playing or what you expect them to do with a certain toy or in a specific situation, let the child decide. When children have control of a situation, they learn to listen to their own cues and promptings, making learning developmentally appropriate for them, while also fun and engaging.

How?

1. Fix your focus on what is best for the child. At times, we may be tempted to push children to play in ways that we enjoy, or in ways that align with our dreams for them. They may have wildly different interests or abilities. Allowing them to lead in play can reveal what they love and are good at.

2. At the same time, it is entirely appropriate to expose them to a wide variety of play-type activities. Consider multiple types of play, including physical, board games and puzzles, jokes and riddles, music, art, manipulatives, social games, and more. Offer the opportunities but be okay with them not being interested.

3. Ignore chronological age and consider developmental stage instead. Even if most 8-year-olds are able to engage in a certain type of play, expectations should be reframed for each individual child. Kids almost never benefit from

us comparing them to others. Even if they are years "behind" in play, meeting them where they are at can help them grow and enjoy themselves.

4 Identify the child's zone of proximal development. For example, if a child can put together a 4-piece puzzle, he or she might be ready to try a 6-piece puzzle. If a child enjoys coloring, they may be interested in painting. If a child plays well with a sibling, a next step might be learning to play with a friend. If a child is completely nonverbal or struggles to interact, peekaboo may be an option.

5 Figure out what makes a child laugh and do lots of it. Jokes, hide and seek, pretending to fall over, etc.

Resources for Further Exploration

For more information on appropriate language:

- **Video:** Stories of the Power of Play, **Tracy Imbach**
- **Video:** "Ian" A Story of Playground Inclusion
- Parents and the Zone of Proximal Development, **Think Parenting**

Play Principle 2: Set the Scene

Create opportunities and give the child freedom to explore likes and dislikes. We live in a world full of variety and wonder; share it with the child and allow discovery.

How?

1. Think about the child's interests and what related activities have not been explored yet. Maybe the child loves boats but has never created one of his own. Or maybe he has, but he has never played with it in the water. Build a boat and find a puddle to float it in.

2. Go to a different park than usual and if the child is comfortable, join in on other groups of children playing together.

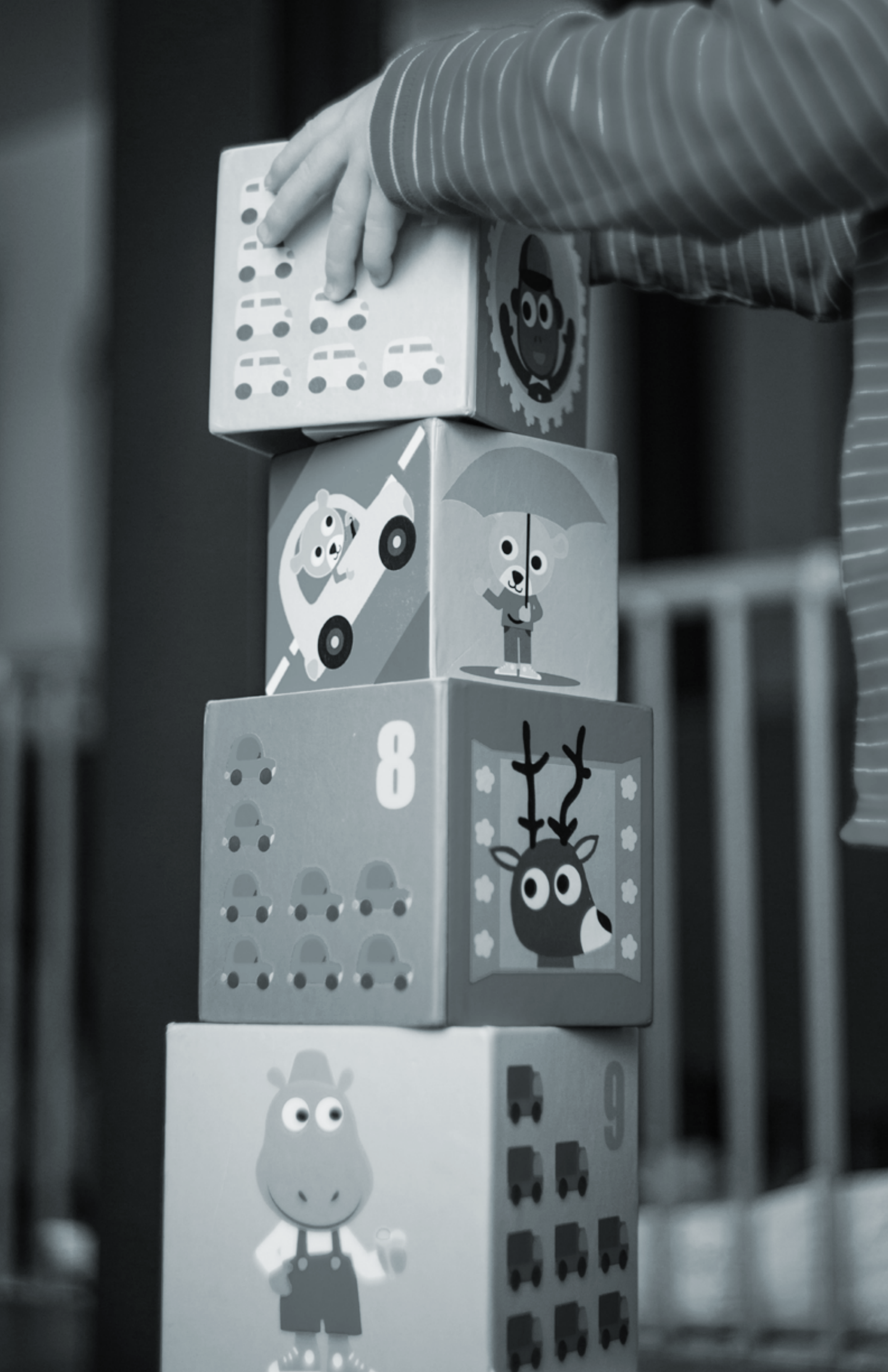
3. Take the long way home and make observations about the new surroundings out loud as you walk together. Invite the child to point out interesting details or favorite sounds or colors too.

4 Consider adaptive materials and devices to make sure the environment is comfortable for the child and conducive to play. For example, a child in a wheelchair might prefer to sit in a beanbag chair. Instead of standing at an easel, a child might prefer to sit at a table with a whiteboard.

Resources for Further Exploration

For more information on appropriate language:

- Play Resources, **Global Playground**
- Creative Play Activities for Children with Disabilities: A Resource Book for Teachers and Parents , **Lisa Morris & Linda Schulz**
- Toys & Games Usability Evaluation Tool , **TUET**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Play Principle 3: Support and Guide

Just like parents support a child learning to walk by providing a steady hand when needed, being present and engaged in the child's play gives you the opportunity to support them when they need it. The child might need help learning a new skill, emotional support exploring a new environment, or new ideas and inspiration from their favorite adult. As the child grows and develops, your support can help them reach new heights.

How?

1. Begin by observing and becoming aware of the areas where the child needs support or modification, and where they need encouragement to step outside of their comfort zone.

2. Keeping in mind what you've learned from your observations, create time and space and a care-free environment for the child to play. Arrange the day in a way that allows plenty of free time to use their imagination and explore their own interests, and provide age-appropriate toys or art supplies.

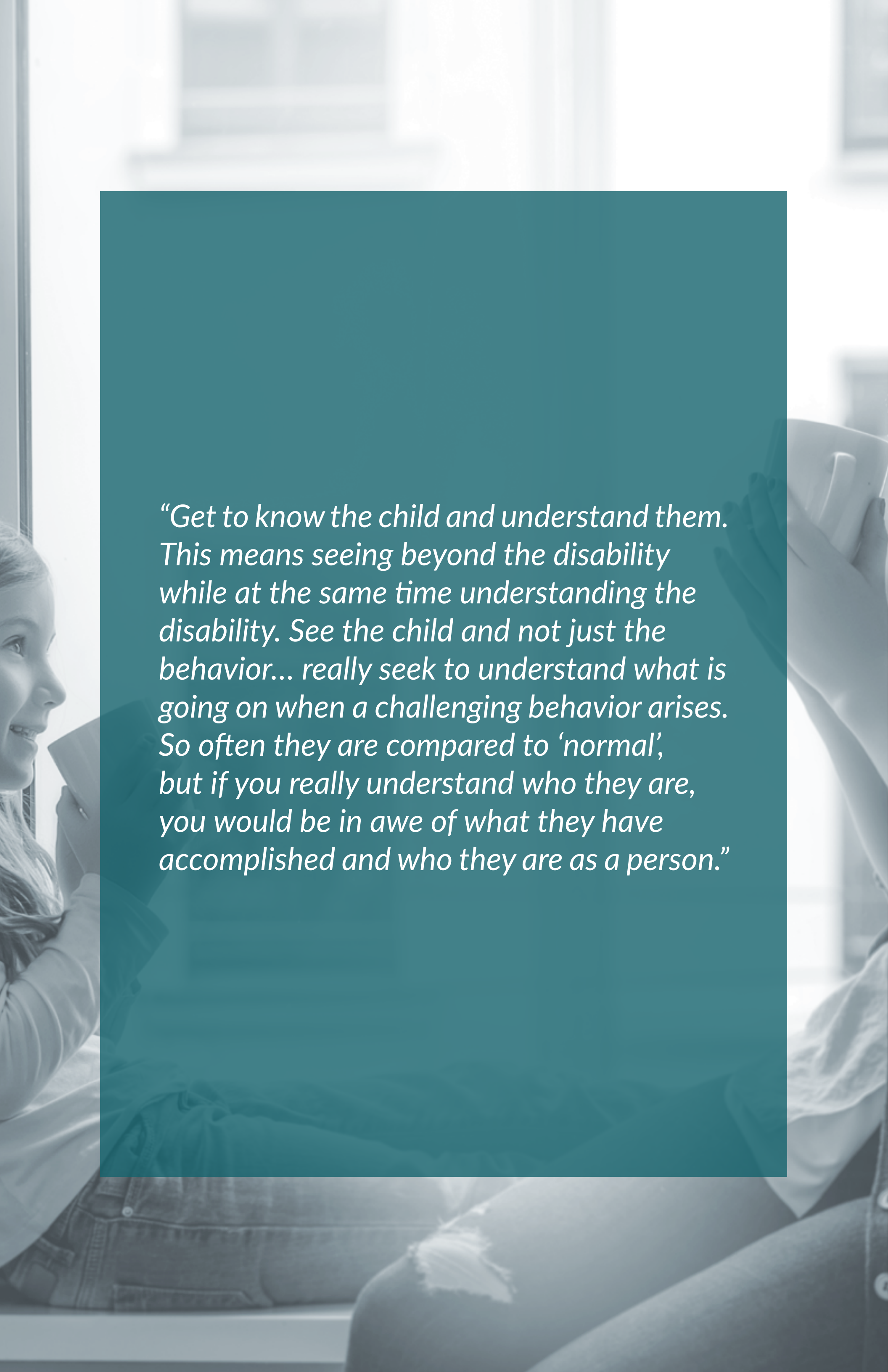
3 Keep in mind the disabilities that might hinder collaborative play. For a child with a hearing impairment, sit on the ground, face to face with the child. For a child with limited mobility, allow plenty of time for the child to rearrange objects and complete movements without jumping in to help. Allow the play to happen at the child's pace.

4 Remember that you must also be able to step outside of your own comfort zone. Many adults have forgotten how to play and it will take some relearning!

Resources for Further Exploration

For more information on appropriate language:

- Guidelines for supporting children with disabilities' play, **Sciendo**
- The Out-of-Sync Child Has Fun, Revised Edition: Activities for Kids with Sensory Processing Disorder , **Carol Kranowitz**
- The Out-of-Sync Child Grows Up: Coping with Sensory Processing Disorder in the Adolescent and Young Adult Years, **Carol Kranowitz**



“Get to know the child and understand them. This means seeing beyond the disability while at the same time understanding the disability. See the child and not just the behavior… really seek to understand what is going on when a challenging behavior arises. So often they are compared to ‘normal’, but if you really understand who they are, you would be in awe of what they have accomplished and who they are as a person.”

POWERFUL BEHAVIORS

> *“Beneath every behavior there is a feeling. And beneath each feeling is a need. And when we meet that need rather than focus on the behavior, we begin to deal with the cause, not the symptom.”*
>
> *Ashleigh Warner*

POWERFUL BEHAVIORS

All children have a range of behaviors as they learn and grow. These behaviors begin to form at birth and continue throughout the lifespan, guided by an innate need to connect and gain mastery over life, and taught through interactions with others.[51] Some behaviors are winsome and received positively, such as pleasant conversation, creativity, curiosity, or affection. Other behaviors may serve a purpose but be much less palatable to those experiencing the behavior. These can include noncompliance[52], aggression[53, 54], hyperactivity[55], antisocial conduct[5657], destructive action[58], self-injury[59, 60], extreme tantruming[61, 62, 63], and sleep difficulties[64, 65]. We will refer to these collectively as powerful behaviors.

Some needs that might underlie powerful behaviors include:

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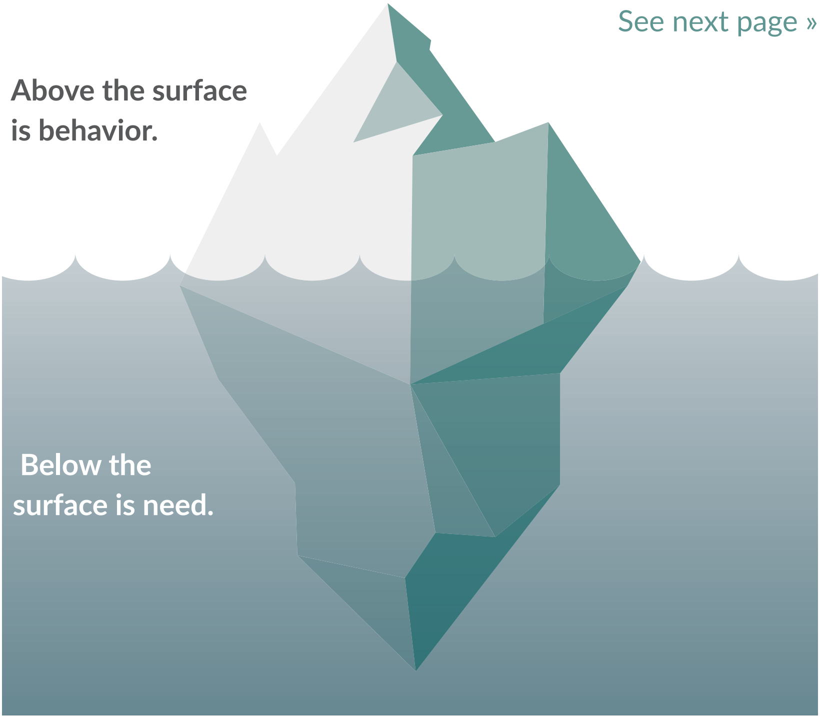


Needs that Underlie Powerful Behaviors

1. **The need for physical care.** There are several basic physiological needs that humans have: food, shelter, clothing, water, air, and sleep[66]. When those needs are not met and a child experiences hunger, thirst, illness, and exhaustion, acting out is likely to occur[67].

2. **The need for security.** All human beings need to know they are safe before they can function and develop appropriately. If a child is unsure of the safety of a person or place, they may be more likely to express their distress through powerful behaviors[68]. When children experience anxiety and do not have appropriate coping skills to deal with it, acting out is often the natural response[69].

3. **The need for structure.** Children need routine and to know what to expect. When their life seems chaotic or without reason, they may respond poorly. Asking children to transition from one activity to another with no warning is one common precursor to powerful behaviors[70].

4. **The need for attachment.** In a healthy attachment cycle, a child expresses a need, and the need is met by their caregiver. A strong bond is built on the foundation that the child can trust the caregiver to meet their needs. This process forms the foundation for mental health. When a child's basic needs are not met, the result is chronic distress. This child has not formed trustworthy connections with a caregiver and has not been taught how to self-regulate. In this case, the child turns to the behaviors that they do have - challenging behaviors - to try to form a connection[71].

5. **The need for communication.** Every human has a need for relationship and communication. When communication is difficult or impaired, there is much frustration. Challenging behaviors can be the outward expression of that frustration or an attempt at alternative communication, often both[72].

6. **The need for affect regulation.** As a child grows and the brain matures, a set of processes develop to use for managing and expressing emotions. When a child's development does not follow the typical path, either due to trauma or disability, regulation of emotions and behaviors can become very difficult[73].

7. **The need for attention.** Children may use challenging behaviors as a means to get the attention that they desire, often because they are desiring some level of control over a situation. By acting out and demanding attention, they feel a sense of agency or involvement that did not previously exist[74].

8. **The need for autonomy.** The desire for independence is universal. To go a step further, it is essential for human wellbeing[75]. When a child's sense of self or individuality is taken away, challenging behaviors are likely to occur as an attempt to establish their own sense of self.[76]

As a caregiver of children from hard places, challenging behaviors can be discouraging. In many cases, they can also be distressing for the child. For children who benefit from additional behavioral, emotional, and learning support, this can often be further exacerbated[77]. However, for children living with disabilities, like those who are not living with disabilities, behavior is just one of the many ways to communicate and connect with the people in their lives[78] [79]. For children who have disabilities, it may be used more frequently if they are having trouble communicating. In these scenarios, we must look at the behaviors and try to recognize the motivating needs behind them. Often the answer will be connection, relationship, and the need for acceptance and affirmation.

When children have emotional, cognitive, or speech barriers, sometimes their method of expressing themselves can be through challenging behaviors. For children living with disabilities, this might be the easiest or most effective way to get their needs met. These behaviors are often intense. Through the intensity of a tantrum, physical behaviors, or speech, a child can get a parent's attention[80][81] the quickest. For individuals with intellectual and developmental disabilities, behavior is often an expression of emotion rather than a manipulative effort.[82] Many individuals with intellectual and developmental disabilities are minimally verbal or cannot express their emotions in an appropriate manner, but instead use their behavior to communicate their emotions. When caregivers focus only on the disability, the actual emotional issue can be missed. When we shift our mindset from challenging behaviors to authentic communication, we can create a space to understand where our child is coming from and what they need.

Disruptive behavior is often motivated by unrecognized anxiety - when a child does not feel safe, secure, stable, or connected.

Many times, a child will not even have the ability to identify the feelings they are experiencing internally, but react to the underlying stress by becoming oppositional or aggressive.[83] Other children, particularly those who are younger, can shut down or become clingy when experiencing anxiety.

Many children with disabilities struggle with affect regulation, defined as "the attempt to alter or control one's mood or emotional state so as to maximize pleasant experiences and minimize unpleasant ones."[84] As we develop, we learn that we experience emotions in response to things that happen to us. There are a few options for how we choose to respond when we experience emotions. We can act out or shut down, neither of which is ideal. In a healthy reaction, we are able to have self-awareness and manage our response[85]. Children with disabilities often have little or reduced ability to self-moderate, and therefore respond with powerful behaviors instead of a more balanced reaction.

However, there are many other times when children with disabilities are very aware of their reactions and can anticipate how caregivers will respond. Just like a child without disabilities, by paying attention to actions and responses, they sometimes learn that powerful behaviors result in extra attention or getting what they want. In this case, it is the adult's responsibility to be aware of what is going on and reframe interactions so that the child learns to communicate in other healthy and appropriate ways, in order to achieve the desired outcome.

How to Address Powerful Behaviors

No parent or caregiver relishes challenging behaviors in their children. We want to raise children who will be the best version of themselves, and who will be able to interact well with others. We want to give them the best possible start in life.

For children with special needs who have been separated from parental care, this can be especially difficult. We want to be gracious and aware of the hard things they have experienced. We want to be trauma-informed in our approach, avoiding anything that would frighten or cause distress to our child. At the same time, we are tasked with helping them to grow into the fullest version of themselves so they can fulfill the plans God has for them. As with all children, this requires character development and training.

When addressing powerful behaviors, we can follow this process:

1. **Identify the root causes of the powerful behavior(s).** What is below the surface of the conduct? If possible, when the child is calm, ask her what she needs. Observe what precedes the behavior. Keep track of when the behavior occurs in relation to food, rest, activities, and interactions (Check out Thumsters, a behavior tracking app). Ask other adults in the child's life about what they see.

2. **Connect before correcting.** Character training is only effective in the context of a healthy relationship. Have you been spending enough time with the child outside of responding to powerful behaviors? Have you gotten on his level and helped

him calm down completely before responding to his powerful behavior?

3. **Cast a vision of the child's identity.** Every child is made in God's image (Genesis 1:27), for a specific purpose (Romans 12:4-8). God has a good plan for her (Ephesians 2:10, Jeremiah 29:11), and He can be trusted (Proverbs 3:5-6, Romans 8:28). Frequently, children with powerful behaviors get so much negative attention that they can begin to believe they are inherently flawed. Help the child to conceptualize herself as good and powerful and full of potential.

4. **Accuse the behavior, not the child.** Work with the child as a team to "outsmart" the behavior. Very often, powerful behaviors may be distressing to the child. Ask the child what is motivating him to act in this way and make a plan together for getting his needs met in a different way. Make the behavior the bad guy, not the child, as in, "It seems like [anxiety/ fear/ control/ frustration] really got the best of you that time, huh? What do you think we can do to outsmart it next time you are experiencing these things?"

5. **Celebrate successes.** Every success, even tiny ones. If the child would usually tantrum for four hours, and this time it was only one, that is worth celebrating! If the child would usually hit another child for taking her toy, and this time she only yelled, we can celebrate the improvement. Helping the child see her own growth can motivate her in the journey to overcoming her powerful behaviors.

Children with disabilities, especially those separated from parental care, may be experiencing a number of these causes simultaneously. It will take time to untangle the various interwoven needs that underpin a child's powerful behaviors. Start with one type of behavior and work on that. Look for the victories, which will give you momentum for the journey. Shake off the attempts that do not go as planned. Keep your focus on the improvement you are seeing rather than comparing the child to someone else. Be his or her biggest fan.

Every child wants to get their emotional and physical needs met and children living with physical, behavioral, cognitive, and communicative disabilities have the same desires. Challenging behaviors are often an attempt to communicate those desires. The good news is this: just because children are exhibiting challenging behaviors now, does not mean that they will continue in the same way forever. We, as caregivers, are tasked with teaching them to communicate those needs differently, in a positive and safe manner[86].

Powerful Behaviors Principle 1: Build the Relationship

When kids have a lot of challenging behaviors, it can be easy to focus on them and their behavior all the time. We start to say things like, “She’s difficult” or “He’s a tough one.” Focusing on the hard parts and allowing them to define the child can break down the relationship quickly. Instead, focus on the positive.

How?

1. Figure out what you love about the child. Ask yourself questions like, “What is my favorite thing about her personality?” and “What do others love about her?”

2. Spend quality one-on-one time with the child. Put aside all your stress and concern and questions about both the present and the future. Spend dedicated time with the child focusing on your relationship and bonding. Choose an activity that you both enjoy or want to explore.

3. Get to know them. Really get to know the child - not the behaviors or reactions or outward appearance, but their true heart and desires, likes and dislikes.

4. Develop positive rapport and seek to have positive experiences together. Shared moments lead to deeper connection. Do something together that neither one of you has done before.

Resources for Further Exploration

For more information on appropriate language:

- Attachment After Adversity: Building Resilience Through Relationship, **CAFO**
- I Love You Rituals, **Becky Bailey**
- **Video:** Positive Interactions, **KERA**

Powerful Behaviors Principle 2: Alternatives for Communication

Identify more positive, effective alternatives for communication.

How?

1. First, encourage the child to take a deep breath (or three). As soon as everyone is calm, communication is automatically more clear and effective.

2. Be mindful of the nonverbal cues and gestures that you are sending, as well as receiving. Nodding, pointing, and eye contact are effective tools, particularly for children with disabilities.

3. For children who are not able to be as verbal as they would like to be, sign language is a great option. There is a learning curve as the child and caregivers would need to learn an alternative language, but it could be well worth the time invested.

4. Create a system using objects, pictures, or symbols that can be used by the child to communicate basic wants or needs. Rather than having to use words or sign language, the child can simply point.

5. Consider communication tools like pen and paper, keyboards and tablets, or custom assistive devices. These are particularly useful for children who have speech or hearing limitations.

Resources for Further Exploration

For more information on appropriate language:

- 5 Activities to Improve your Child's Communication Skills, **Special Needs Alliance**
- **Video:** When You Feel So Mad - Daniel Tiger, **PBS Kids**
- **Video:** Using Objects to Develop Choice Making
- Guidance: People with Communication Aids, **Communication Matters**
- **App:** AutoVERBAL PRO Text-To-Speech, **Bridging Apps**

Powerful Behaviors Principle 3: Identify Realistic Expectations

1. Consider: Based on the current circumstances, what is appropriate behavior for the child? Do not compare the child to other children at a similar age or position. Instead, focus only on the child and their own specific goals.

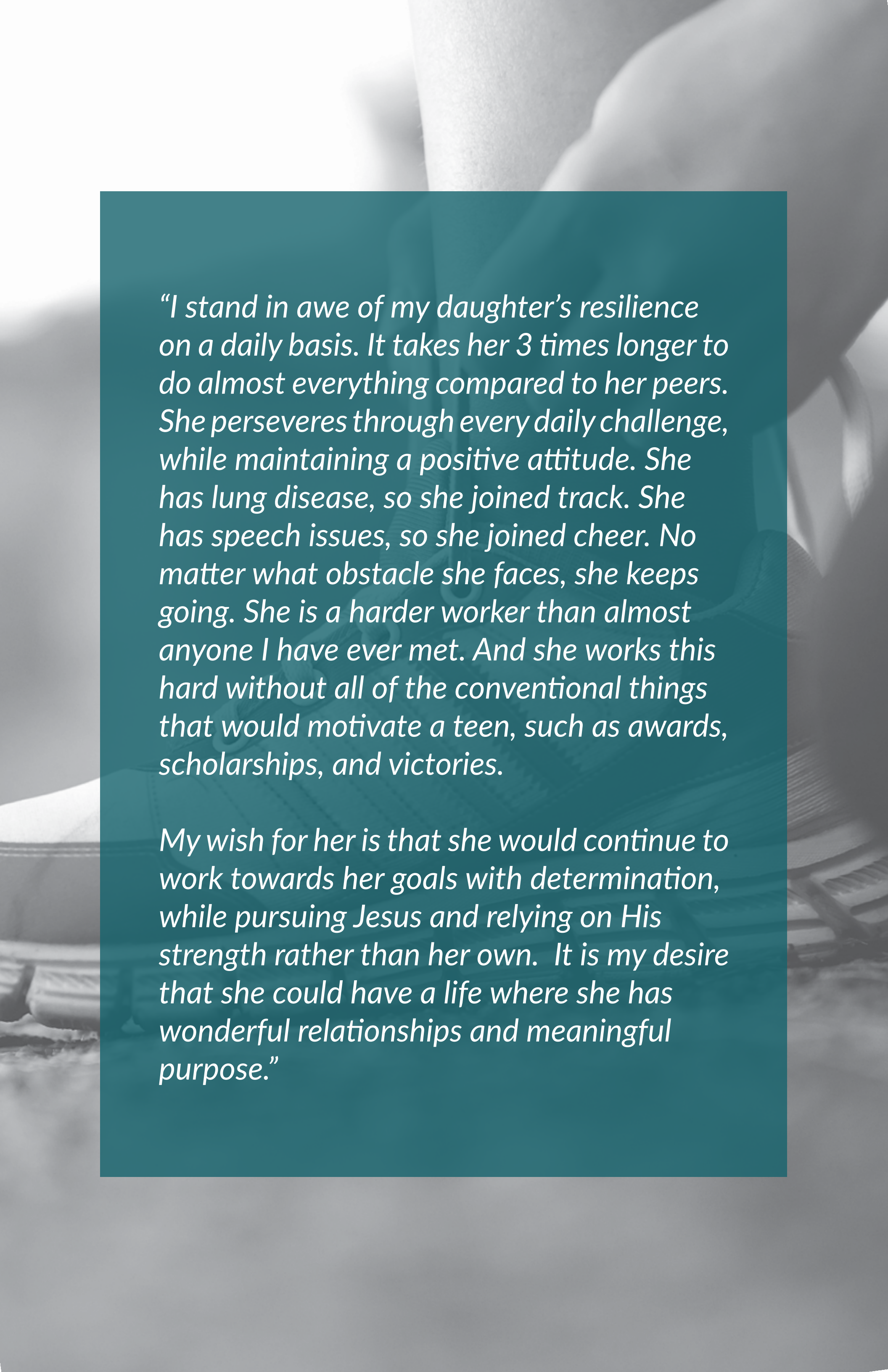
2. Think about next steps for growth. What is the next reasonable step for the child and how can we help her get there? If the child bites himself when frustrated, rather than attempting to stop the biting completely and all at once, encourage the child to bite a stress ball instead. Once he is consistently biting the ball instead of self-harming, then encourage the child to squeeze the stress ball instead of biting it.

3. Collaborate with the child's support system of loved ones and professionals to determine how the child can be holistically encouraged towards more appropriate behavior. Consistency between caregivers will be greatly beneficial to clarify expectations for all.

Resources for Further Exploration

For more information on appropriate language:

- **Video:** Can't vs. Won't, **Mandy Howard**
- **Ecourse:** Supporting Children with Challenging Behaviors Positive Solutions for Families Workshop **, Child Development, Inc.**



“I stand in awe of my daughter’s resilience on a daily basis. It takes her 3 times longer to do almost everything compared to her peers. She perseveres through every daily challenge, while maintaining a positive attitude. She has lung disease, so she joined track. She has speech issues, so she joined cheer. No matter what obstacle she faces, she keeps going. She is a harder worker than almost anyone I have ever met. And she works this hard without all of the conventional things that would motivate a teen, such as awards, scholarships, and victories.

My wish for her is that she would continue to work towards her goals with determination, while pursuing Jesus and relying on His strength rather than her own. It is my desire that she could have a life where she has wonderful relationships and meaningful purpose.”

POSSIBILITIES

‘For I know the plans I have
for you’ declares the Lord.’

Jeremiah 29:11

POSSIBILITIES

All parents have hopes for their children. Depending on the personality and experiences of the parent, those dreams could relate to carrying on a family legacy or excelling in a certain profession or even having a certain number of children. Many parents have the expectation that their children will grow up to be independent, self-sufficient adults. In reality, few children go on to live the lives their parents imagined. For children with disabilities, especially those who have been separated from parental care, the difference between dream and reality may be even more stark. As our children transition to adulthood, the process may require a reworking of expectations for both parent and child, as well as a process of grieving dreams in order to joyfully embrace the future God has created.

Surprising Grief

The transition from childhood to adulthood is always significant. For children with disabilities separated from parental care, it can be especially complex. For both parent and child, it may emphasize the difference between the child's capacities and those of their peers in ways that may have not been obvious before.

Many children with disabilities and their parents are surprised by unexpected feelings of grief as the child transitions to adulthood. For the child, it may become clear that dreams they once held - independence, graduation, getting married, etc. - might never be a reality. For the parent, the reality often looks much different than they first expected when their child was born or placed in their home. While many friends are becoming empty-nesters and celebrating exciting transitions with their children, those transitions often happen in very different ways for those who are caring for children with disabilities. Between the ages of 18 and 22, resources become much fewer and less accessible. Programs, therapies, and financial support that were available for their entire childhood are now inaccessible as an adult. There are so many new considerations and stresses. While working through these new challenges together, the caregiver now must consider, “How do I give my adult child independence while also providing the necessary support?”

Future Considerations

This can all feel incredibly overwhelming. Parents and children alike may want to avoid the conversation, assuming that options will become clearer as the child ages. However, being proactive is key. Having conversations and identifying available services is vital.

As an individual with disabilities begins to make the move from child to adult, there are several considerations for their future[87]:

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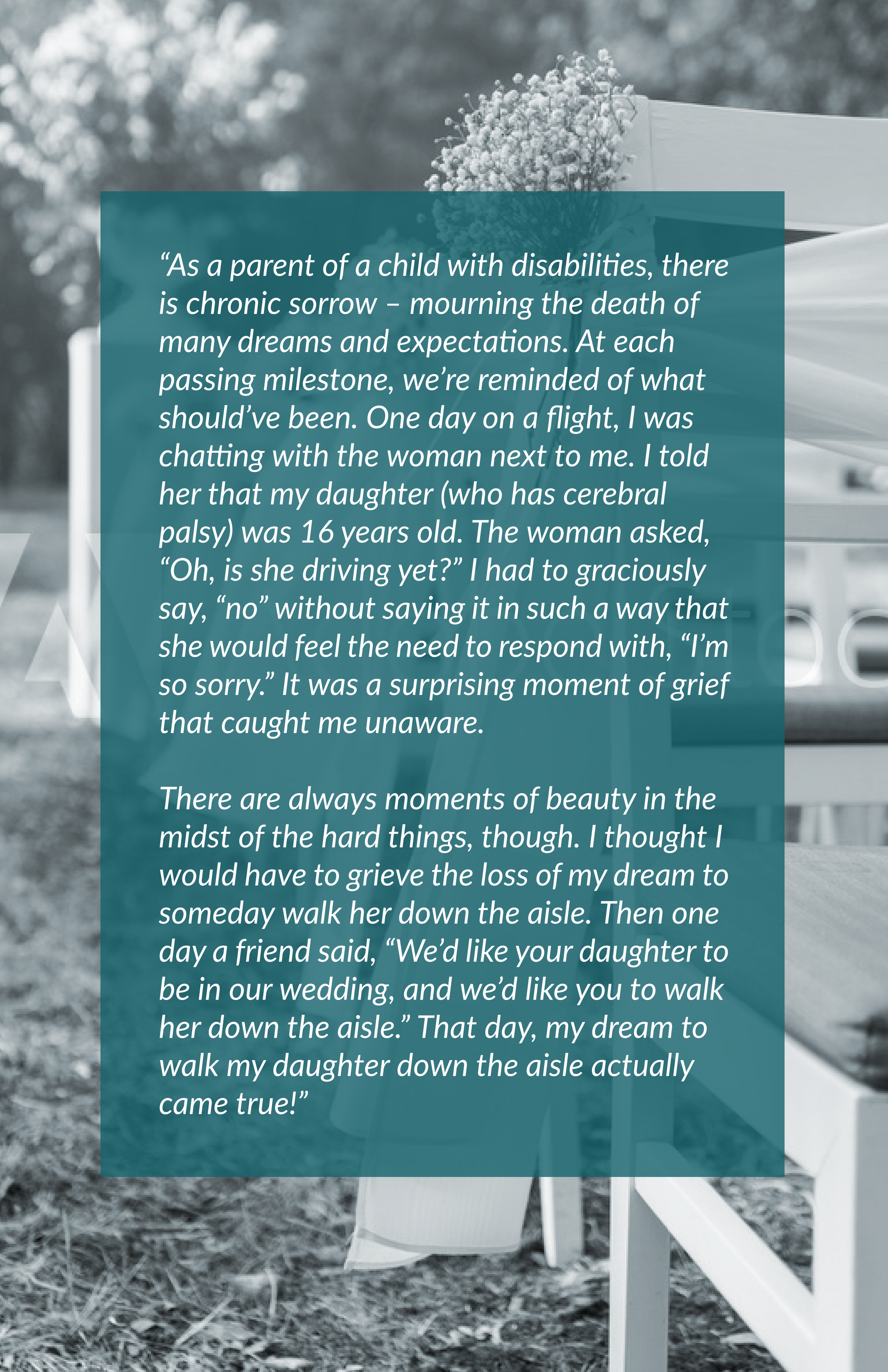

“As a parent of a child with disabilities, there is chronic sorrow – mourning the death of many dreams and expectations. At each passing milestone, we’re reminded of what should’ve been. One day on a flight, I was chatting with the woman next to me. I told her that my daughter (who has cerebral palsy) was 16 years old. The woman asked, “Oh, is she driving yet?” I had to graciously say, “no” without saying it in such a way that she would feel the need to respond with, “I’m so sorry.” It was a surprising moment of grief that caught me unaware.

There are always moments of beauty in the midst of the hard things, though. I thought I would have to grieve the loss of my dream to someday walk her down the aisle. Then one day a friend said, “We’d like your daughter to be in our wedding, and we’d like you to walk her down the aisle.” That day, my dream to walk my daughter down the aisle actually came true!”

Considerations for Their Future

1. **Relationships.** Who are, and will be, the important relationships in his or her life? Who is trustworthy?

   [See the Healthy Relationship Workbook from The Arc.]

2. **Guardianships.** Does the child need help making important decisions? Who will help?

   [See more on guardianships from Friendship Circle.]

3. **Living Situation.** Where will the child live? Can he or she live on their own or do alternative arrangements need to be made?

   [Read about Kathryn's independent living story, as told by her mother from Special Needs Alliance]

4. **Budgeting & Spending.** Where will the money come from and how will it be managed?

   [Download Cents and Sensibility: A Guide to Money Management by the Pennsylvania Assistive Technology Foundation.]

5. **Health & Safety.** What precautions need to be taken to keep the child safe and healthy?

   [Learn more about Community Safety for individuals with disabilities from the Waisman Center]

6 **Personal Care & Dressing.** Can the child take care of their own personal hygiene needs?

[Learn more about teaching an older child with disabilities about hygiene from Friendship Circle.]

7 **Meal Planning & Grocery Shopping.** Does the child know how to make healthy choices and prepare meals for himself?

[See these healthy tips to make meal planning easier from Disability Horizons]

8 **Laundry & Household Maintenance.** Is the child able to complete household chores independently?

[See this checklist of chores the child can complete at home now to prepare for employment and the transition to independent living from SeekFreak.]

9 **Community Involvement, Social Skills & Recreation.** What will the child do in his or her free time?

[See more in this education tool on Recreational Activities for People with Disabilities from CME Toolkit.]

Future Planning

Planning for a dependent child's future will look vastly different for every family, but also very similar in many scenarios.

Consider how they will make decisions, build relationships, decide where to live, cover their expenses, and occupy their free time (including support services).

The Arc's Center for Future Planning has developed a tool to be used to help guide discussion as you plan for all of these pieces of adult life. The Plan Center has also developed a Future Planning Tool to be used by individuals with disabilities as they, with their support system, plan for the future.

Relationships

As with all humans, relationships with others are vital for adults with disabilities, but also have potential to result in harm. Adolescents and adults with disabilities experience abuse at a rate about three times higher than individuals who do not have a disability[88]. It is important to provide education about healthy relationships, how to identify people who are safe and unsafe, and to create a support system of trustworthy individuals who can be turned to for help and guidance. Guidelines should be discussed regarding interactions with individuals in the community, healthy family relationships, friendships, and dating and marriage. Understanding their own personal physical and emotional boundaries is important, as well as concepts such as consent and safety when interacting with others on the phone and internet.

Be sure to talk about:

- *His or her community support system - who is part of it?*
- *Who are the most significant friendships in her life?*
- *Does he desire a romantic relationship? If so, what is he looking for in a partner?*
- *What are his or her personal physical boundaries, both generally and in a sexual nature? What will happen if boundaries are ever pushed or violated?*
- *Does she understand the meaning of the word "abuse"? Who will she tell if she ever feels unsafe?*
- *How are the phone and internet used safely and appropriately?*

Finances

Probably the most often considered (and worried about) element of a child's future is finances. Many of the decisions for a person's future depend on money and the ability to fund things like shelter, costs of daily living, and the expenses associated with support services. By doing some research, planning ahead, and setting up the appropriate accounts and aid, you can ensure the child will be taken care of with a stable financial future.

Here's what you can do:

- *Connect with government offices and learn what options are available for adults with disabilities.*
- *Explore healthcare options to determine what is best for the individual transitioning to adulthood.*
- *Choose a trustee to help the individual with financial decisions if necessary.*

Career

Though there are some disabilities so extensive that an occupation is impossible, in most cases, there's a job or volunteer position for everyone. It has been found that work-based learning experiences are hugely beneficial to individuals with disabilities[89].

- *Through a work-based learning experience, the teenager or adult will:*

- *Develop an understanding of different occupations in order to make informed career choices.*

- *Increase knowledge of specific occupational skills and workplace settings.*

- *Gain career readiness skills, including the "soft skills" that employers look for in entry level workers.*

- *Establish a work history and connections that can aid in future job searches, with minimal risk to the employer.*

- *Experience emotional health benefits as they build independence and self-confidence, and as they feel more purposeful90.*

- *See increased school attendance, decreased dropout rates, reduced school suspensions, and increased school engagement.*

- *Although official work services opportunities might not be available in your community, consider informal alternatives. Could the young adult help a local farmer or sit with a neighbor at her vegetable stall? Does the young adult have a hobby that would transition well to a means of income?*

Independent Living

Once finances are in order and the child transitioning to adulthood has occupational opportunities, whether volunteer or paid, it comes time to address their living situation. For some, they will never have the ability to live independently. For others, it is a definite possibility, most likely requiring some degree of assistance.

There is a variety of living scenarios for adults with disabilities, such as:

- *Living with parents or family members*
- *Skilled nursing facilities (for those who need around-the-clock care)*
- *Staffed assisted living facilities*
- *Supported living/group homes (with other individuals with disabilities; not staffed)*
- *Low-income housing (for those who are able to live on their own or with a friend)*
- *Rent or own*

When making decisions regarding housing - where the young adult transitioning to adulthood will live - there is no one-size-fits-all approach. Most importantly, consider the individual needs and desires, and seek to find the least restrictive, but also safe, option.

Key Practices and Principles for Possibilities

Beginning to plan for the future for a child with disabilities can be overwhelming and bring many unexpected emotions for everyone involved. Some might have very clear direction, while others do not even know where to begin. As you begin the planning process, there are a few key principles to keep in mind.

See next page »

Possibilities Principle 1:
Take Care of Yourself

As a caregiver, be sure to pay attention to your own stress and emotions. As you work tirelessly to ensure each child receives the love, care, and resources they need, it's vital that you do the same for yourself. Consciously enter this phase with abundant grace for yourself, the child, and the entire care team you have so carefully built. Children who are most successful as adults are those who have a strong community and support systems. Each piece must be healthy in order to be strong as a whole. In order to care for the child well and support them through the transition to adulthood with potentially increased independence, caregivers need to check in with themselves first.

How?

1. Ask yourself questions like: How am I feeling about the upcoming transition? What are the things that I am most excited about? What are the things that have brought unexpected sadness or disappointment? Then talk about your thoughts with a trusted supporter.

2. There is power in community. Seek out other parents and caregivers of children with disabilities - find groups in person or online, ask professionals involved in the child's life about meeting with other caregivers, etc. Share your stories and be willing to learn from others who can relate.

3. Spend time taking care of yourself. Take a walk. Make a cup of tea. Read the book you have been wanting to read.

4. Invest in other significant relationships in your life. Go on a date night with your spouse. Make time for friends. Bake cookies with your children or grandchildren.

Resources for Further Exploration

For more information on appropriate language:

- Relationship savers for parents with special-needs kids, **Today's Parent**
- How to Find Your Purpose as a Special-Needs Family
- Sibling Relationships and Special Needs, **Greater Good Magazine**
- **Video:** Self-Care: What it Really is - TEDx, **Susannah Joy Winters**
- Charting the LifeCourse Learning Community, **Lifecourse Nexus**

Possibilities Principle 2: Plan Practically, Together

This process should be centered around the individual whom you are planning for. Start with conversations to really understand what his or her dreams are, then set reasonable goals as a team.

How?

1. First ask the child what he or she dreams of. “If anything is possible, what would the future look like?”

2. Consider the child’s interests and hobbies. Play is a great way to explore these areas. During imaginative play, what does the child communicate in terms of preferences for certain roles, jobs, and desires?

3. Volunteer together. Explore possibilities for work-based learning experiences and be willing to be a part of it if the child would prefer your support.

4. Choose a tool to guide you through the planning process.

5. Plan as a team. Gather all of the important people in the individual's life to discuss and brainstorm together, allowing for collaboration - family, friends, practitioners, teachers, mentors, etc.

6. Understand that the plan can always be revisited and changed. Just because a situation is one way now, does not mean it will not change in the future. Be flexible.

Resources for Further Exploration

For more information on appropriate language:

- Five Critical Areas To Strengthen Your Child's Skills for Adulthood, **Friendship Circle**
- Future Planning Tool, **The Arc**
- Future Planning Tool, **The Plan Center**
- Employment for People with Special Needs, **Christopher & Dana Reeve Foundation**
- American Association of People with Disabilities Career Center
- Person-Centered Planning Process, **National Parent Center on Transition and Employment**

Possibilities Principle 3:
Do Not Compare to Others

Remember that the process of planning for the future can look very similar, but also very different, from person to person. There is no competition or race, it is simply an individualized plan that is in the best interest of the person who is making the transition to adulthood. There is always a tendency to look at other teenagers or adults and compare where they are in life to where the child we care for is currently. However, this is not fair or productive. By focusing on the child we care for and thinking only of what is best for them, we set up everyone involved for success.

Resources for Further Exploration

For more information on appropriate language:

- Become a Self-Advocate, **Christopher & Dana Reeve Foundation**
- Person-Centered Planning Guide
- It's My Choice, **William T. Allen**

CONCLUSION

"The true measure of any society can be found in how it treats its most vulnerable members."

Gandhi

CONCLUSION

Just as no two children are the same, no two disabilities (or combinations of them) are the same. Each child requires personalized care and support, as well as a thoughtful approach, from his or her caregiver. Some children with disabilities have experienced trauma or adverse experiences, some have not. Many have been able to remain in the care of their biological parents, but unfortunately, some have experienced alternative placement. The interactions of their experiences and disabilities are just as diverse as they are, which can cause frustration in caregivers because no two interventions are the same either. Behaviors can be challenging, communication can be difficult, and planning for the future can be discouraging.

However, as Gandhi said, “The true measure of any society can be found in how it treats its most vulnerable members.” As caregivers, we have the opportunity to choose to believe in the inherent value of the children we serve every day. We can approach them in love and prioritize connection over all else. We can utilize play as a means to connect and bond with them, and we can have hope as we dream of their futures full of possibilities.

Endnotes

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