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A Divine Assignment: Church Supports for Caretakers and Children Impacted by Disabilities

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A Divine Assignment: Church Supports for Caretakers and Children Impacted by Disabilities

Cover Page Footnote

English Standard Version Bible, 2001, Mark 10:14-16

A Divine Assignment

Over the past 20 years, my vocation as a behavior analyst has placed me in the lives of children and families impacted by Autism Spectrum Disorder (ASD) and other developmental disorders. Children with autism may have difficulties communicating their wants and needs or understanding what others think or feel. These deficits can result in a child encountering numerous frustrating situations, causing the development of problematic behaviors. As a behavior analyst, I understand behavior as a way of meeting needs and suggest ways of adjusting to replace the problem behavior. I have witnessed my work help children and families experience positive change, and I have gained a wealth of blessings from each child and family I've encountered. The following story tells about my work with a family whose faith and worship were interrupted by their attention to their son, who was diagnosed with autism, and how including a partnership with their congregation was a significant part of the treatment plan.

I received a referral for 5-year-old Riley. He was diagnosed with autism and was non-verbal. Riley's parents were a married couple in their late thirties. According to the parents, Riley was brilliant and seemed to understand everything his parents told him, even though he had never uttered a word. When Riley had difficulty getting others to understand him, he exhibited severe meltdowns and could escalate to hitting whoever was nearby.

Additionally, Riley preferred to be alone and did not want to interact much with his parents or peers. He always searched for the perfect stick to hold, refused to go anywhere without one, and protested if he had to put it down. Reportedly, Riley ran away when adults approached him, fearing that an adult would take the stick. However, he was most at peace and happy when waving his stick back and forth while looking up into the sky.

During the intake process, the parents were most concerned about their son's rigidity surrounding the stick and his meltdowns that often led to aggression. When asked about what they valued as a family and to name a personal goal, the parents revealed their yearning to return to church. The parents said that when Riley was frustrated, his outbursts during worship service were disruptive. They added childcare at church was unsuccessful and always ended with negative feedback about their son's behavior. They were discouraged and stopped attending church. However, they expressed that they would be willing to return to church if there was support for Riley while they worshipped. They tentatively agreed when asked if I could include attending church as a family goal.

I asked the family if they could connect me with leadership at their congregation so that I could assess the barriers. I contacted the youth minister at the Midtown church and introduced myself and my role in supporting the family. I informed him of the family's goal and asked about their resources to help a child with autism. The youth minister was apologetic about the lack of support and excited about the partnership to assist the family and the church. A meeting with church leadership followed.

The Midtown church was a large congregation with over 2,000 members. The church community had two morning worship services, multiple support groups, and a robust youth ministry. The youth ministry had a strong children's Sunday school program and an enthusiastic children's worship service apart from the adult worship service. The children and youth engaged in a fun interactive learning space about God while parents went child-free to worship service. The youth minister admitted that these perks did not exist for the parents and their children with special needs. He reported that many of their missing members from worship service would benefit from a special needs program. The size and scale of the Midtown church showed promise

in having the resources to support many families in their local community. The youth minister expressed that it had been on their heart to develop a special needs program for years, but needed to know where to begin. The church leadership wanted to serve all families impacted by special needs, starting with Riley and his family. The youth minister coined the development of the special needs program as "a divine assignment."

Why start a supportive program for caretakers and their children with special needs?

The Bible says, "Let the children come to me; do not hinder them, for to such belongs the kingdom of God..." (Mark 10:14-15). The youth minister and I shared thoughts about what the verse meant by the word "hinder." Not having support in place for all children is a hindrance. We reasoned that if schools provided accommodations, such as a personal teacher assistant, similar accommodations should exist in the church. Furthermore, the verse says, "for such belongs to the kingdom of God." Jesus is informing us that creating spaces that honor and promote belonging for all children is a necessary responsibility of the church. The youth minister's program for the Midtown church included pairing each child with a trained adult to support them in attending Sunday school and worship service with their peers.

Identifying nurturing spaces

The first step in implementation was to define the spaces in the church building and how they served or did not serve children with special needs. The youth ministry leaders and I began by examining and identifying areas in the church building that could be used as a calming and nurturing space. These spaces would operate as a place a child could go for a break away from crowds and noise or an area when they need to show big emotions. The church provided the funding to furnish and design beautiful spaces with comfortable, child-friendly furniture and calming items. With input from an occupational therapist, sensory tools and gadgets were

purchased that provided comfort. There were two designated spaces at each end of the large building. For children with physical disabilities, structural changes were made to ease mobility around the Sunday school classes and children's church auditorium.

What does a special needs support program need to get started?

Starting a special needs program requires no specialized training or degree. However, the main component is to gather a tribe of compassionate volunteers. The church leadership was speedy in announcing the development of the program and the need for volunteers. Church members received announcements to spread the word and reach out and inform members who may have left the church due to a lack of support for their family's needs. Riley's family was thrilled that their church would begin constructing a special needs support program called the "Buddy" support system. Support for Riley and other children like him was soon to be embraced in the church building.

Training the tribe of volunteers

Over 20 adults eagerly volunteered to serve as a buddy for a child with special needs. Volunteers filled slots for June through August using a virtual sign-up platform on the church's website. The volunteers varied in age; some were married couples wanting to serve together, and a few were new and retired teachers. I provided three one-hour trainings during Wednesday night bible study to prepare volunteers and build confidence. The training informed volunteers on general information on a diagnosis such as autism or ADHD.

Additionally, with the information provided by the parents, we shared the profiles of the children who would need a buddy. The profile outlined their child's likes and dislikes, strengths and challenges. The training included role plays and scenarios that educated volunteers on what to do when challenging behaviors occurred. During one training session, strategies on how to

modify lessons during Sunday school were modeled and taught by the Sunday School teachers. The goal was to have the buddies and their assigned child in the Sunday school class as much as the child could tolerate, offering plenty of breaks.

A home-church communication form was designed for the Buddy program to enhance communication. The parents would complete the simple form to report about their child's morning. Specifically, sharing information about how they slept, ate, or mood/energy. The buddy was given the form to read while transitioning the child to Sunday school. The information on the form informed the buddy of what the child may need to get through their time at church.

On the opposite side of the home-to-church communication form, the volunteer wrote a small description of the child's participation and topics parents could ask the child about. The buddy returned the form to the parent at the end of the church day. The buddies were asked to write up any severe incidents of behavior challenges but not to sweat the small stuff if problematic behavior occurred. The goal was to extend much grace about what to report, as caretakers frequently receive news about what their child did wrong. Besides, there is nothing like receiving a negative message about your child after church service to dampen the spiritual worship experience.

The divine assignment kicks off

Families signed up for the program, so advanced planning for each child could occur. As a result of the outreach, church announcements, and word of mouth, the new Buddy program would serve twelve families and their children. One family expressed to the congregation how life-changing the return of the entire family to church would be. Riley's family boasted about the new church clothes that they purchased to attend worship service. The youth ministry leaders, volunteers, and families exhibited a contagious joy. As church leaders announced the Sunday

program kickoff and acknowledged the volunteers, there was a giant applause, and somebody yelled excitedly, "Let's go!"

The Midtown church celebrated with balloons and treats at the program's kickoff. There were plenty of smiling faces standing by to ease the child-parent separation. The volunteers lined up with smiles, meeting families and the children they would serve. Parents handed over their child along with a completed home-communication form. Parents and caretakers displayed an array of emotions. Some cried others smiled, and a few gave high fives as they timidly walked into the church auditorium.

At the program's start, I solicited an additional behavior analyst to help me support the volunteers. I supported Riley's volunteer more closely due to his high need for support, but I was an earshot away from the other volunteers. The other behavior analyst shadowed buddies in a separate classroom. As the children and their buddies transitioned throughout the building, the smiles and nods among the volunteers were beautiful. There was a feeling in the air that God was pleased.

The Sundays that followed were all successful. Parents showed up, and their children attended Sunday school and church. During June-August, the volunteers received support from the behavior analyst and me, who worked alongside them, observing and troubleshooting. Volunteers received positive feedback and encouragement. A few problematic incidents arose that required extra attention. For example, a 4-year-old girl preferred to worship God in the dark. She constantly darted to turn off all the light switches in the children's church room. Instead of blocking and chasing the young lady, I recommended covering the light switches with duct tape with a visual taped on the wall that said, "lights on." The disruptive behavior ceased, and the young girl focused on playing with puppets instead of the lights.

In another example, a 7-year-old non-verbal boy was slow to warm up to his buddy. However, the volunteer discovered that the boy enjoyed a game of chase. The volunteer started their time with a round of chase on the church playground before coming into the Sunday school class. The problems arose when it was time to stop the game of chase and return inside the building. The young boy would cry, flop to the ground, and refuse to come inside. We determined that the volunteer and his paired child would benefit from a visual timer and schedule that gave them both information about each activity and transition. Most importantly, the visual schedule informed him of the next opportunity to play chase with his buddy. The buddy agreed to put three games of chase on the visual schedule. The boy was able to tolerate when the game of chase ceased and looked at his schedule to see what he needed to do inside the building before the next round of chase. Overall, the volunteers felt successful and the buddy system was a blessing for the children and families.

Watching the buddies reunite children with their families after worship was delightful. The positive feedback from the families was immeasurable. Volunteers reported that the children they served nourished their souls. I continued my work with Riley and his family at their home and got a bird's eye view of how happy Riley's family seemed with their spiritual connection to their congregation intact.

Showing signs of weakness

In September and October, the behavior analyst and I faded the support at the church but were available to assist upon request. The youth ministry leaders appeared pleased with how the program progressed. However, November and December produced challenges. The slots for volunteers did not fill up, and few children had buddies available. The director called me to assist her in providing coverage to support some of the children. The director reasoned that the lack of

coverage was due to the holidays and travel. The youth minister claimed that lack of participation and volunteers was common for all of the congregation's programs during the holiday months.

Upon my return to the church to serve as Riley's buddy, the few buddies who were present expressed opinions about the decrease in volunteers. According to the buddies, there needed to be a system that provided a pool of trained people to give the buddies a break. When volunteers didn't sign up or called out, the children had difficulty pairing with the new person. As a result, there was an increase in the children displaying frustration and an increased need for calming strategies. The volunteers shared that a ratio of two buddies for one child on difficult Sundays was ideal.

There were other red flags indicating a breakdown in the program. For example, parents no longer completed the home-to-church communication form, and there was an increase in late arrivals or absences from families. Reportedly, the caretakers appeared increasingly tired, and the children seemed more dysregulated (unable to control their emotions).

The holiday blues

Riley's family had multiple Sundays when they arrived late or were absent from church. When asked how the supports were at church and if they had anything to share. The parents reported that November through January were the most challenging months. According to Riley's family, school schedules are inconsistent and unstructured due to holiday parties. In addition, Riley's sleep patterns change, and problem behavior increases. They described that every winter, Riley awakens at 3 a.m., ready to eat breakfast and jump on his trampoline. The sleep interruption was why they appeared at church late and looked exhausted. They reminded me that

the holiday months are not a good time to decrease support for families but rather increase the amount of help.

Riley had one major incident when he had a new person serving as his buddy. Reportedly, Riley refused to participate in the class's craft activities. The volunteer took away Riley's stick, not knowing the distress it would cause. When the volunteer refused to return his stick and blocked his attempts to leave the table, Riley bit the volunteer on the arm. This unfortunate event caused suffering for the volunteer, embarrassment for the parents, and shame and disappointment for Riley. Though the church cannot plan for every change, a glance at Riley's written profile and support plan (filed in the Sunday school class) would have informed the new volunteer to allow Riley to hold on to his stick and that he could choose a different option if he doesn't want to do a craft activity.

A few families continued to attend church, hoping for the support of the buddy system. Of the 23 volunteers, only four ladies consistently returned each Sunday to serve families that showed up.

The faithful few volunteers

When the holiday fever subsided, the sign-up form for January and February remained slim, with the same four volunteers. The church leaders announced the need for new volunteers at both services and printed it in the announcements. Despite the ask, volunteers still needed to emerge. The four faithful volunteers expressed disappointment in the congregation. As fewer volunteers returned, parents chose to stay home, avoiding the problematic transitions with someone new or fearing a severe problem behavior in which they would have to assist.

The youth minister considered advertising a paid position to non-members to serve as buddies. He reasoned that the decline in families utilizing the program did not justify the paid

position. Perhaps a paid position was unjustified because of the 2,000 church members who had the opportunity to volunteer. Nevertheless, by March, the special needs program quietly dissolved. The youth minister expressed sadness and vowed to reevaluate the program and determine to try again.

Riley's parents tried taking turns attending different services but ultimately needed help to maintain attendance. When asked how they felt about the program's dissolution, they shrugged and seemed to have anticipated the disappointment. I could also sense they felt ashamed over Riley's biting incident. During my in-home therapy session with Riley, his parents were eager for me to reevaluate a personal goal they had for Riley. The parents wanted Riley to stop holding and waving sticks. They expressed they found it problematic and wanted him to get rid of his sticks. I wondered whether the strong motivation to get rid of the stick was related to the biting incident. Though I disagreed on removing Riley's sticks, I offered to investigate the reasoning behind its appeal.

I began my sessions with Riley the same way, picking him up and swinging him around. He always used sign language to request more swings but never let go of the stick in his hand. After enjoying my swings outdoors, Riley always chose to lie down in the grass, look up, and wave his stick toward the sky. I was curious to understand what he gained from the behavior. I asked Riley to give me a stick and show me how to wave it. Riley smiled big and seemed to blush as he handed me a stick and watched me wave the stick in front of my face. He pulled at me, guiding me to lie next to him on the grass. He modeled holding the stick up toward the sky and rapidly waving it side to side.

When I mimicked his behavior, I was awed by the dancing rays of light that moved back and forth against the cloud backdrop. I noticed the calming effect gained from waving the stick

toward the sunlight. The waving of the thin stick created a lovely contrast of light and dark shadows. The patterns created looked like tiny rays of light dancing. The faster I waved the stick, the more mesmerizing the patterns of shades. I was moved by the broad smile on Riley's face as he watched me engage in a shared experience. I didn't know if he was pleased that he had someone waving a stick with him or if he found it hilarious that I waved the stick the wrong way. I remember feeling enlightened by the experience and thankful for my work. I thanked him for showing me something very cool. The behavior of waving the stick toward the sun provided a lovely visual input that he enjoyed. It was calming to him. It was his flow.

I explained my discovery of beauty in the behavior to the parents and encouraged them to be curious about the seemingly non-functional behavior of their son. I invited them to join their son on the grass. If they show respect for an activity their son loves, he may be open to participating in an activity they want. It was an emotional sight to observe the parents and their son lying on the ground, waving skinny sticks back and forth toward the sky. They all had smiles on their face and giggled.

I believe Riley's posture of looking up to the sky and waving his stick was how he worshiped God. Riley's worship looked different from the average churchgoer's, but as his family and I shared in Riley's experience, the sky and a perfect stick felt just as divine.

Ingredients to develop a sustainable special needs program sustainability.

- 1) Include all church leaders at the table. This program will need moral and financial support from many areas of programming.
- 2) Create an online sign-up for extra help in a Sunday school class (i.e., Survey Monkey).
- 3) Plan for individualized coverage depending on the level of support needed. Some may require a 1:1 ratio, while some benefit from a 2:1 ratio.

- 4) Develop a reinforcement system to reward volunteers. Find out what the volunteers enjoy and reward them with tokens of appreciation and acknowledgment. Plan to incentivize volunteers in November-January.
Designate backup volunteers and include them in the initial training.
- 5) Designate backup volunteers and include them in the initial training.
- 6) Know all you can about the child you will support, including the child's strengths, likes, and dislikes, to build a rapport. Record these things for others to learn about the child.
- 7) To enhance communication, utilize a Home to Church communication sheet.
- 8) Invest in a professional to educate the volunteers about a particular disability or diagnosis. Consult with a behavior analyst to assist in behavior support.
- 9) Identify how the child learns; ask about services or ways they learn at school and try to utilize similar strategies.
- 10) Show them God's love. If Sunday school or worship is overwhelming, allow for nature walks around the building or play outside on the church playground to offer support.

Need more time to be ready for a program? Here are some other ways to support families of children with special needs:

- 1) Ask community agencies to publicize your congregation by adding it to the resource list of providers as a church that respects inclusion.
- 2) Partner with advocates or clinics that serve families with special needs. Offer the space to host a community event. Provide childcare for special occasions, holiday shopping, or date nights for parents.
- 3) Be inclusive during worship service by providing opportunities for a person with special needs to serve and be in front of the congregation
- 4) Create a peaceful space for parents to transition before or during their child's meltdowns.
- 5) Ask families in your congregation what the church can do to serve them better. Ask about their family and what makes their child smile.