

RETHINKING THE “SOCCER MOM”:  
PARENT FEEDBACK ON COMMUNITY PARTICIPATION, ACCESS,  
AND INCLUSION BY INDIVIDUALS WITH INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES IN GREENSBORO, NORTH CAROLINA

THERAPEUTIC RECREATION AND INCLUSIVE NETWORKS (TRAIN)

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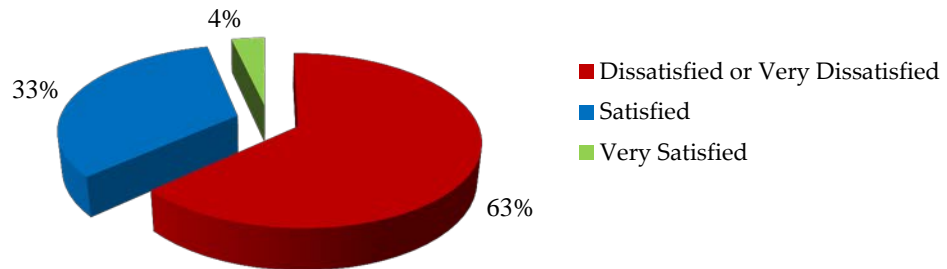
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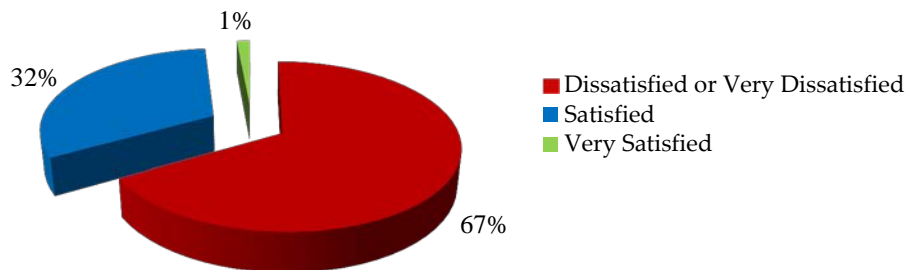
# Greensboro Recreation Needs Assessment for Persons with Intellectual and Developmental Disabilities

The Greensboro Recreation Needs Assessment was conducted to identify the recreation, social, and physical activity needs of individuals with disabilities residing in Greensboro (NC) and surrounding communities. Parents who have a young or adult-age child with a disability were invited to complete an on-line survey designed to gather information regarding the value of recreation in their child’s life, activities of interest, satisfaction with existing recreation opportunities, and their thoughts about inclusive and segregated program options. The survey was completed by 141 parents. Eighty percent of the parents had a child with a disability under the age of 20 years with a wide range of disabilities including autism spectrum disorder, intellectual disabilities, sensory impairments, and multiple disabilities. Parents indicated that recreation was highly valued in the lives of their children (98% identified recreation as “very important/important” and only 2% identified recreation as “not very important”) and had interests across a wide array of activity types. Activities of highest interest were aquatics, music, special events, summer camps, and non-competitive sports activities. Responses regarding parents’ satisfaction with recreation opportunities currently available for their children were alarming due to the high levels of dissatisfaction. Parents were overwhelmingly dissatisfied with the *number* and *variety* of recreation opportunities (63% and 67%, dissatisfied/very dissatisfied, respectively).

**Level of Satisfaction with *Number* of Opportunities Available**

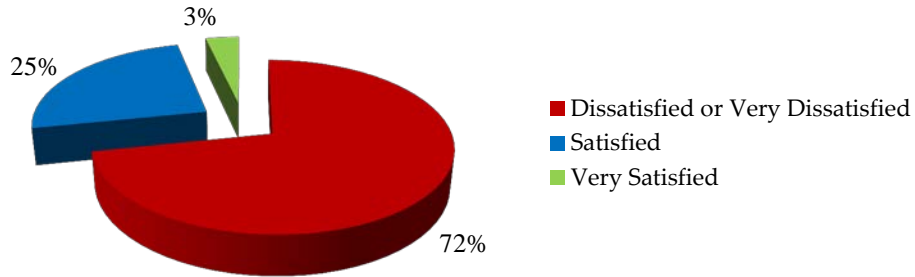


**Level of Satisfaction with *Variety* of Opportunities Available**



Furthermore, 72% of parents were dissatisfied/very dissatisfied with the *opportunities* available for their children to participate in recreation activities with peers without disabilities.

**Level of Satisfaction with Opportunities to Participate with Nondisabled Peers**



Parents were only moderately satisfied (48% satisfied/very satisfied) with the quality of recreation opportunities that were available. Parents also indicated their desire for choice in service delivery models (i.e., the availability of both inclusive and specialized recreation opportunities). In response to open-ended questions, many parents expressed keen interest in continuing the dialogue to broaden the scope of recreation opportunities for all members of the community.

Based on this expressed interest, a series of parent focus groups were initiated by the Therapeutic Recreation And Inclusive Networks (TRAIN) grant project at UNCG in collaboration with The Arc of Greensboro. The remainder of this report describes the findings of this focus group initiative.

# Focus Groups to Elicit Parent Feedback on Inclusion in Community Recreation and Sports

## Purpose and Procedures

### Purpose of Project

We hosted 5 focus groups in 2010 comprised of parents of children who had intellectual and developmental disabilities (ID/DD) to share their perspectives concerning their access, participation, and inclusion in recreation and sports opportunities within their communities. Each focus group was designed to engage 5 to 10 participants. Participants resided in Greensboro, NC, or the surrounding area within Guilford County, and were parents of a child with a disability living at home. Sons/daughters of parent participants represented various intellectual and developmental disabilities across multiple age-ranges and socioeconomic status.

### Focus Group Participants

We recognized the myriad family dynamics and living situations experienced by the demographic directly impacted by disability within the community. In our effort to learn from a wide variety of perspectives, each focus group represented a different segment of the population. The first three groups included parents representing families served by The Arc of Greensboro, each typifying children, teen through transition-age, or adult ages. Two subsequent groups included parents from the Autism Society of Greensboro; one with children and the other with teen through transition-age range. There existed some overlap of children's ages across groups to accommodate parents' schedules. The meetings were hosted in the community at the Ted Leonard Recreation Center of the Greensboro Parks and Recreation Department.

FOCUS GROUP	AFFILIATED AGENCY	NUMBER OF PARTICIPANTS	AGE OF CHILDREN REPRESENTED	*DISABILITIES REPRESENTED
1	Arc of Greensboro	8	8-15 years	ASD, ID, DD
2	Arc of Greensboro	8	12-23 years	ASD, ID, DD
3	Arc of Greensboro	10	20-44 years	ID, DD
4	Autism Society	5	5-12 years	ASD
5	Autism Society	5	11-29 years	ASD, ID

\* ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Disability

## **Project Goal**

The goal of the focus groups was to bring parents together to discuss community participation, access, and inclusion of their children with disabilities. It was our hope that these conversations would stimulate development of recommendations and meaningful solutions that could be utilized by individuals with disabilities, family members, service providers, policymakers, and funders to promote greater community participation, access, and inclusion. Focus groups were carefully designed to collect information for future use by those responsible for providing community recreation and sports service delivery opportunities in and around Greensboro. The results should catalyze further community-based participatory research designed to create social change by engaging members of the community who have been underserved. Future discussions will ideally lead to a widespread recognition of the need for recreation and sports programs and activities that welcome everyone, regardless of ability level, in a “zero-exclusion” approach. This focus group effort was not intended to be action-oriented, but rather to raise awareness of the needs of our neighbors with ID/DD and their family members.

## **Description of Focus Groups**

The five focus groups were structured identically. The co-moderators (from The Arc and UNCG/TRAIN project) commenced each group with verbal recognition that our participants were the experts concerning the needs and desires of their children, specifically in light of community recreation, sports, and social activities. It was made clear that our role, as facilitators, was to moderate the groups by asking questions and listening, and not participating in the conversation. The co-moderators used several guiding questions to direct discussions and offered participants freedom to converse about the most salient issues in their lives related to community participation, access, and inclusion.

Over the course of 90 minutes, participants’ interactions included: introducing themselves and speaking about their families, and specifically their children’s recreation, sports, and social interests. This included previous experiences their children had participating in the community, expressing concerns and fears about participation alongside their peers without disabilities, and what might alleviate those concerns. While parents were describing their children’s experiences, we encouraged them to go in-depth about what has been successful as well as challenging, in addition to the benefits of recreation, physical, and social activity. We also asked participants to share their thoughts regarding participation in those activities alongside peers without disabilities. Finally, we offered participants opportunities to make recommendations that could improve community opportunities for their children and other family members going forward.

## **Focus Group Guiding Questions**

The following five questions were used to frame the focus group discussions. Conversations on these topics allowed the researchers to identify themes that helped organize our report of findings.

1. Tell us about your experiences participating in community recreation and sports. What worked successfully? What challenges have you encountered?

2. What have been the benefits and rewards of participation in community recreation and sports?
3. What dreams and desires do you have for your child in regard to his/her future community participation? Do you have any experiences and/or desires for your son/daughter to participate with his/her nondisabled peers?
4. What concerns or fears do you have about your child participating in inclusive programs alongside his/her nondisabled peers? What would it take to alleviate those concerns?
5. What recommendations do you have for local recreation providers to improve recreation, sports, and social opportunities?

## Findings

### Benefits

Focus group participants noted several benefits to recreation and sports participation that highlight the importance of access to community opportunities, particularly for those with an intellectual or developmental disability. Community activities not only provided outlets for physical exercise, but served as a foundation for the development of social skills, including learning how to interact with their peers without disabilities. Parents expressed desires for their children to experience normalcy in society, including the development of friendships rather than isolation. Additionally, it was noted that community recreation and sports provided outlets for releasing energy and avoiding a sedentary lifestyle, both of which could be challenging for their children. They also expressed joy in the discovery of community opportunities that offered families the ability to experience leisure together, regardless of ability. Inclusive recreation opportunities were also noted as benefiting everyone involved and not just their children with disabilities.

“To have a more blended [socially-inclusive] variety of activities would be so wonderful for her, and something that’s regular and physically challenging to maintain wellness.”

“There is also great benefit from them being able to feed off of children that don’t have disabilities so they can mimic and learn some of their more age-appropriate, developmentally-appropriate behaviors.”

“Even though he has autism, he still needs those health benefits. Because when he turns 40, he is still going to have the same genes as the rest of us have in our family. He needs to have access to exercise and recreation, whether he knows he does or not.”

"I think our local Autism Society has been successful in promoting and securing some available things like Bounce-U, swimming, Natural Science Center, for families to participate. It's just something that parents see as a need when they get together; that they would like to be able to do something as a family rather than in isolation. We had such an isolation between our two daughters because our child without autism was involved in all these activities, but our child with autism couldn't tolerate them. So one of us [parents] had to stay behind with our child with autism while the other one took our child without autism to these activities."

"It's good for the typical kids too. Promoting tolerance and acceptance... Our kids go to Pilot Elementary. And when I think of inclusion, I automatically defer to their program because it is a successful program... and the kids at Pilot who don't have autism are so accustomed to them being there, it doesn't even register on their radar."

### **Lack of Access**

Parents of children with intellectual and developmental disabilities identified problems with accessing recreation, sports, and social opportunities. Guilford County and the Greensboro community have much to offer, but very little is designed to accommodate people with developmental disabilities. Parents expressed frustration with having to continuously fight for access to opportunities in which their children's peers could participate whenever they desired. Parents did not always wish to be the ones having to pave the way for access on behalf of their children. Program access appeared to become increasingly more difficult as children began to reach their pre-teens.

"Our experience about what is available in the community, for the most part, has not been positive. We found a few select things that they have been doing, but we have not found them to be the most welcoming. As a stay-at-home mom and making this almost my full-time job, finding things for them have been quite challenging. We were turned down for group swim lessons. We've been turned down by [name of youth serving organization]. We've been turned down for tennis lessons. And all because of their diagnosis. Even with me saying that they are coming with help, we've still been turned down."

"I would like for it to be less of a fight. To have to dig and scratch and claw for every single little thing that may or may not come down the pipe."

"I can't imagine a parent that has to work, and on top of that, deal with occupational therapists and medical concerns, and then try to find a way to include their child in the community. And forget it if you have financial issues. Where does your child go?"

"So now it's at a point where, why bother to even call? I know that I'm going to get turned down. I'm just going to get upset. I heard that my kids can't be a part of anything."

"They forgot that our children are part of this community. They put everything on us to resolve, if [emphasized] they even let our kids come."

"When [child's name] was little he participated in regular soccer up until about fifth grade. When he was going into sixth grade we decided that, like some of you guys have experienced, when they get to a certain age the regular kids get really strong, and you're afraid that they're going to get hurt or something, but at a younger age it was very successful."

Specialized programs designed specifically for individuals with disabilities were not overlooked during the focus group discussions. However, even many of these segregated programs presented barriers to successful participation. Several parents indicated their children were kicked out of specialized programs due to “behavioral” problems and/or disabilities that could not be accommodated. Others noted the tendency for special-needs programs to cancel their offerings if there were insufficient numbers of registered participants. Several families received support from CAP (a tax-funded program that offers one-on-one assistant care), designed to make inclusive community access easier. However, parents noted that many existing programs designed specifically for participants with special needs were only willing to serve their children if a CAP worker accompanied the child. This policy caused confusion among family members who disagreed with it. Among parents of adult children, transportation to programs was also mentioned as a barrier to participation.

“My son was taking Tae Kwon Do at the [agency name] and it was supposed to be for kids with special needs. And he got kicked out! I guess they felt his skills were not up to par. I was just blown away by that. So, if you don’t fit into ‘special needs’ programs, then where?”

“I don’t know what the problem is in [agency name], but there are so many things that he signs up for, and then the night before, we get a phone call: ‘It’s cancelled. Lack of participation.’ Now what’s the problem? Is it that they don’t get the information out so people can say, ‘Yeah I want to do that.’ I don’t understand why they have to cancel more than they actually provide. That indicates that somewhere, somehow, there is a breakdown in the organizational structure. What is happening that it doesn’t sell? They’ve got to get it out to the public.”

“I’ve become frustrated when things are set up under the assumption that the kids come with a CAP worker. Because I don’t have one. And if you don’t have one, I’ve contacted programs that have just said, ‘then too bad.’”

“Even at the special needs camp you have to send someone to go with your child if you want them to be able to get through the day. That shocked me! Last summer was very stressful because we didn’t have a CAP slot. And in order for them to go to the camp we had to pay somebody hourly to go with our sons to make sure that they were supervised in the swimming pool. That’s ridiculous!”

Members of our community without disabilities have year-round opportunities that offer myriad physical and social benefits; the message we heard continuously from focus group participants is that they desire similar year-round access as tax-paying citizens.

“I think we all want the same thing. We want something extended year-round, not just a season, not just 3 months here, 3 months there, but something ongoing they can look forward to on a weekly basis, so they can look forward to a constant in their lives.”

“I would just like them to have the same opportunities as the rest of the kids in the community and be involved in whatever they choose.”

## Concerns

Several programmatic concerns surfaced during focus group discussions. Parents were consternated about the safety of their children in programs where the leaders and/or staff lacked the training and understanding of how to accommodate them. This dismay extended further, as parents identified problems with programs that were highly competitive, as well as the prevalence of negative attitudes toward their children exhibited by others in the programs. Competition is not inherently wrong, but when participants did not have the necessary skills to “keep pace” with their peers, successful involvement was jeopardized. Parents did not want their children to be “left behind” and subsequently miss opportunities to grow and develop alongside their peers.

“I will admit, being part of any type of recreational activity in [agency name] scares me, because no matter how good their intentions are, they are not trained well enough to keep my son safe. I don’t have confidence in the programs to be able to keep him safe. I cannot gamble with his safety.”

“I thought about putting my daughter in an exercise class. But would they have the extra staffing there? Would there be somebody that would be willing to take the time and effort to understand her and explain things or to watch what she was doing? And, quite frankly, safety is a concern, whether somebody would actually keep an eye on her to make sure she stays until the end of the class and she didn’t just go wandering off. You have one instructor and 30 people in there. Is it safe for her to be there? But to just throw her into something without that support would make me tremendously uncomfortable.”

“I’m really not concerned about the nondisabled peers. I’m more concerned about the adults because it seems like they’ve been placed in an authoritative position and have very limited or no training on how to deal with children with autism. I feel like the training should already be in place.”

“I know these sports teams start at a very young age and are very competitive, but I wish that others would have a sense of compassion so he can participate in some way. He really doesn’t care about winning or losing. We just have to find someplace that isn’t competitive.”

“My concern is people’s reactions. We have had that problem. People would actually tell her that she was ‘retarded.’ You still have some people who target them, point, and whisper. And she knows that people can be cruel, and she knows this is just human nature for some people. But it still hurts!”

“Educating your family is hard enough, let alone somebody who thinks their kid is just so spectacular and special that they are on this team and they are the top scorer. And here’s your child, and ‘that’s the kid who is dragging everyone down.’ And then the parents start whispering things. That is what led me into individualized sports. That way he can still be competitive once he becomes proficient, but I don’t have to worry about him interfering with anybody else’s progress.”

## Family roles

Parents desired to step away from the exhausting and perpetual roles of having to be active participants themselves, who are required to provide additional support for their children. In many cases, parents had to actively participate in an activity alongside their children in order for a child to participate with his/her peers. For these parents, being a “soccer mom” literally implied playing soccer alongside their child. This provided no opportunity for these parents to socialize or connect with the other parents on the sidelines. Furthermore, they were concerned about the impact that their continued presence would have on their child’s experiences and peer relationships. Also, many questioned whether they would be able to continue in this literal “soccer mom” role as they grew older, even if they had the interest and physical ability to do so.

“It is exhausting to be a parent of two special needs children. We run non-stop, 24/7, 365 days a year. We are never given a break. So while the other parents are sitting down on the sidelines watching their kids play, we’ve got to be out on the field; we’ve got to be running up and down the field. We never get to sit down and enjoy the game. We want to take some pictures of our kids playing too. Or we want to be able to enjoy our kids, to sit down on occasion and talk to another parent. We never get to be the one that sits down. It’s non-stop! That social piece for us is extremely hard to accomplish, especially with parents of typical kids. When do we have time to have that conversation? If they’re going to play hide-and-seek at the park, I’ve got to play hide-and-seek too.”

“They allow your kids to participate if you provide all the support. You provide all of the assistance so that your kids can play, because they’re not going to do it for you. You can pay us and we’ll take your money, but you have to do everything.”

“It may be okay at five or six for mommy to play with you, but at 10, 12, 13 years of age, it’s not going to be okay for mommy to be running down the field with you. Do you know what that is going to do to their self-esteem? They’re going to be outcasts at that point.”

Family members of individuals with disabilities need to be able to assume roles other than being the sole source of support for their children in community activity. Parents are experts about their children, and it is important to understand that they are assets of substantial aptitude to assist service providers. However, much of the exhausting weight of the responsibility to ensure successful participation needs to be lifted from parents’ backs.

“Number one, I think they were just open to my child with the right attitude. They said, ‘we will figure this out.’ Instead of, ‘this is on you to figure out,’ it was, ‘we’ll figure this out together.’ So I even asked them ahead of time what will you be doing at the meetings so I can help my child. They gave me some information ahead of time so I can prepare my child.”

“And they need to get feedback from us parents. And what would help me, if I’m coming to your program, is ask me, ‘Okay, tell me about your child.’ And then this information should be relayed to the person who’s going to have direct interaction with my child. So this person already has a snapshot; all these little cues that will help when you work with him. And I now feel comfortable because they know this about him.”

## What parents believe agencies should do

Focus group participants noted that practitioners and agencies need to not only listen to families for guidance, but to value them as tax-paying citizens with a desire for equal access and opportunity. Parents were quick to point out that the overall population of individuals with intellectual and developmental disabilities, including autism spectrum disorder, is growing rapidly, and it is simply smart business to not exclude this demographic. Individuals with a disability and families often network with each other; consequently, information concerning what is successful, and conversely, what does not work, quickly spreads among families, friends, coworkers, and other community members. However, when there are appropriate community recreation and sports opportunities available, they are largely unknown to parents. The need for a centralized resource list and/or point-of-contact was addressed across the focus groups. As for existing programs, simple modifications or adjustments such as the implementation of additional training for staff members, or securing additional assistance (whether hired or volunteer), could go a long way in ensuring successful participation by any member of the community.

*“We need to raise awareness somehow. A community leader made a comment to me that funding for people with special needs will not be available because the issue is not widespread and it does not affect as many people as other community needs. They have no idea! It affects the parents, siblings, and the extended family. They thought it was all about the child and that’s where it ends. That’s simply not true.”*

*“I hope they realize that they are turning away a lot of people with that kind of attitude. And we know people; we talk. It’s not like the number of kids with autism is going down. And all it takes is one bad experience, and everybody we know, knows about it. And there goes your program. So if they want our business, they need to be accommodating.”*

*“Have a point-of-contact where parents or participants could go to and say, ‘How can I participate? What exists?’ Maybe that person could also work with the various groups within the department to develop programs or be aware of other program resources.”*

*“Training is key because parents aren’t willing to put their kids in programs unless they know that highly-trained individuals exist.”*

*“You’re going to have to reach out to us now, at this point, because there is such a bad reputation. I can’t imagine trying to enroll my kids in anything that [agency name] has. It’s really disgusting how they’ve treated our kids. So, at this point, I’m saying, you come to us and tell us that you will serve our children. You contact us at the Autism Society. You come to a meeting and say that we can include your children, we’re welcoming you guys, and tell us that you have changed. There needs to be some initiative on their part to make us feel welcomed. You’re talking about a long time of shutting us out.”*

Parents also made many comments and several recommendations for how agencies should adopt a “zero-exclusion” approach to programming, where participants are not excluded based on their labels or problems. They offered specific ideas for staff members and program instructors in order to implement successful programs for a significantly broader range of individuals.

“First of all, when we call you, don’t tell us, ‘we’ll have to see if your kid can participate... just stop putting obstacles in our way. That’s the first thing I think you need to do. ‘Okay, how can we help you and how can we include your child?’ Welcome our kids.”

“Anticipate that there will be parents calling about children who might have special needs. Train the person who’s going to answer that phone and figure out what it is they need to do when that parent calls and says, ‘I have a child with autism and I would like him to be in your swim lessons. Can we accomplish that?’ And you say, “Absolutely! Let me put you in touch with... whatever we need to do and let’s make this work.’ Not, ‘Well, I don’t know.’”

“What I have found when working with some staff is that not everybody is going to be trained and not everybody is going to have experience, but the people that are willing to learn and gain that experience by working with my child, I’m cool with that. But it is hard to find somebody willing to.”

“The instructor does not have special training on how to work with children with autism. He just has a willingness to take a step back and observe [child’s name] and try to understand him; try to meet him on his level. And that has worked really, really well.”

## Concluding Remarks and Recommendations

### Summary

These focus groups offered parents a platform to voice their concerns about local opportunities, or the lack thereof, for their children with intellectual and/or developmental disabilities to successfully participate in recreation, sports, and social activities. The importance of having access to such opportunities was emphasized by parents who were very familiar with their potential benefits. Parents who have seen their children’s peers without disabilities profit from community recreation and sports—yet have not witnessed similar opportunities for their children—expressed strong desires for similar and ongoing opportunities. They expressed frustration over the lack of community options for their family members with disabilities that should occur with regularity as is readily available to most other community members. Existing programs were criticized for not successfully accommodating individuals with disabilities and an unwillingness to learn how to make accommodations. Parents were concerned for the safety of their children under the supervision of staff who lacked the necessary training and had negative attitudes toward individuals with significant disabilities. This creates barriers that parents grow weary of, and consequently avoid, resulting in segregation and exclusion. Perhaps it is time for parents to be parents, and “soccer moms” to be designated drivers to activities, rather than goal scorers alongside their children on soccer fields and designated runners on softball fields. Now is the time for recreation and sports service providers to take responsibility for accessible and accommodating program design and begin to implement programs and enhance experiences for all participants.

## **Recommendations**

Many community recreation and sports programs and services designed for typically-functioning individuals can be adapted or modified to successfully include any child, regardless of ability. Members of this community with disabilities do not deserve to receive a lower prioritization for access to these opportunities due to labels or limitations, especially within taxpayer-supported programs. It is important not to perceive this population as having a lower social status, but rather to recognize the potential for equal access to the benefits gained through participation in these activities. Parents are an invaluable resource to offer expertise and education about their children, and service providers will identify great value in developing mutually-beneficial partnerships with families. It is foolhardy to ignore the collective voice of parents in this demographic who are yearning for their children to grow and develop as typically as possible alongside their peers without disabilities. As one parent emphatically stated, "We're setting these kids up to fail because they're not part of anything. The more you can expose them to, the more they can find something. If we don't do something, it's going to be a burden on society later on." And as another parent confidently added, "There is a way to include every child!"