

AFTER SCHOOL SPECIAL

The Experiences of Special Needs Children and Their Families in ICCSD Before and After School Programs

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Introduction

According to the Iowa City Community School District Interagency Agreement with the many organizations that run Before and After School Programs (BASPs) in the district, the organizations providing BASP services formally agree that “All students will have access to a safe and enriching out-of-school program which will assist them to be successful in school and productive members of the community.”

Under “Accessibility,” the agreement further notes that

*Pursuant to the Americans with Disabilities Act (ADA), a **child with disability is entitled to an equal opportunity to participate in before and after school programs.** BASPs will make all reasonable accommodations in policies, practices, or procedures to accommodate children with disabilities, unless accommodations would pose an undue burden or fundamentally alter the nature of the program. **If a BASP program is unable to provide accommodations for a child with a disability, a meeting must be scheduled with the building principal, or their designee, and the District’s Director of Equity before a decision is made to ensure demonstration of an undue burden or a fundamental alteration to the program has been met.** [emphasis added]*

An appendix to the document outlines ICCSD Standards for Out of School Time Programs, which outlines the ways in which out of school time programs (including BASPs) should model positive human relationships, for, by instance, greeting students and parents daily, responding appropriately to the needs of youth, and communicating regularly with parents.

The Interagency Agreement paints a portrait of BASPs that is truly open, inclusive, and supportive of all children. The reality for the parents of children with special needs, however, is quite different. We present below the stories of some of the many special needs children in our district with its BASPs. From children who were bullied or neglected, parents who had to take on extra jobs in order to pay for aides that a BASP required, and children who were simply kicked out of programs, leaving parents scrambling to find and pay for after school childcare, many special needs kids have a very different experience than their peers, and their families face additional and undue burdens. These are some of their stories.

Appended is an annotated bibliography of some resources on creating inclusive out of school time programs.

BASP Experiences from ICCSD Families with Special Needs Children

“If I could go back and do it all again, I would have quit my job to avoid the whole situation.”

My son had a horrible time at every BASP school run program. Four in total. He was never included in activities. He was isolated in another room with a one-on-one para that the school provided for one school year. As soon as they realized what they agreed to, they tried backing out of it. We fought that and won, but it was removed during his next IEP meeting for budget reasons. It was never a good situation and as a working mother, very hard at the time. One program even had the audacity to call me at work and put him on the phone to tell him what to do. The most upsetting was that other kids could rough house, but as soon as Ben got involved, he was being too rough and get pulled out of the group. Why is any kid allowed to rough house? We had preparatory meetings to educate staff of potential problems and the best way to get him to cooperate. We had autism specialists involved as well. I wrote long letters with suggestions. It was all ignored, especially by the staff that was not regularly assigned to him. All in all, it was a terrible experience and very traumatic to all of us. If I could go back and do it all again, I would have quit my job to avoid the whole situation.

“I talked with the principal, the Student Family Advocate, and the school district director of after school programming. No one was able to find a solution.”

My daughter was kicked out of a parent-run, non-profit BASP in another IC public elementary school when she was in kindergarten because I couldn't find a 1:1 employee to cover 2:55-5:30 PM 5 days a week. I would have had to pay that person's salary at \$10.50 per hour. This was in November. I found 3 college students who were ready and willing to work with my daughter each afternoon in the program. However, on Tuesdays and Wednesdays my daughter had no help for a 20 minute period of time, from 2:55 - 3:15. (The college student for those days couldn't get to school by 2:55 due to her college class schedule.) Because of those two twenty minute blocks, the board said no. I talked with the principal, the Student Family Advocate, and the school district director of after school programming. No one was able to find a solution. I was infuriated and stressed out, and very disappointed in our school district. I'm a single (only) parent with no extended family in town to help me out. I finally got my daughter into The Arc after school program and made arrangements for busing. That took two weeks, so I paid those college students to pick up my daughter at school and transport her to The Arc. I LOVED The Arc program and so did my daughter, but it was over \$900 per month (which was probably what I would've spent at the other BASP.). Then in January that same parent-run BASP kicked my

daughter out of the before school program, too, even though there were 2 staff covering up to 9 children, and they were within the 1:15 ratio. I was livid. My child was not accepted by that parent board or program. They had NO empathy, they just didn't want to get sued if my daughter eloped. I had to find another college student to come to our house at 7 and drive my daughter to school at 7:40.

“We were always told we had to hire our own para/person/respite to be with my son...”

We were always told we had to hire our own para/person/respite to be with my son, if he wanted to attend. If I were to pay someone to attend AND pay for the BASP, that would be ridiculous! Not very accessible. My son is 15 now, so this would have been a few years back. Not sure if anything has changed?

From another family:

We were told the same thing. My son is going into 6th grade.

“BASP through the school system has not been an available resource.”

BASP through the school system has not been an available resource. We go through quite a lot to ensure we have private care for our son before and after school while we work. It would be immensely helpful if the school system had a program that was available to special needs kiddos. Would be happy to pay for care (just not double!).

“...kicked out.”

Due to behaviors when my son was in elementary school he was kicked out.

“...[An inclusive program] should be a given for all students, not a thing we have to fight for.”

On or about October 24, 2018 I was informed, via phone call, that my son would no longer be able attend the BASP at Twain until some unspecified future date when "something was figured out." While I was told verbally that he had been involved in "incidents" and was often asked to pick him up early or told he needed to "take a break" for a few days, I was never informed in writing about what these incidents were or what measures were taken to address them. The one "incident" I witnessed was my son dumping a container of Legos on the floor--not, to be sure, ideal behavior, but which hardly seemed to me grounds for kicking a kid out of a program.

By December, I still had received no word on whether and when my son would be allowed back, and so by that time I had hired a private babysitter at \$15/hour (who stayed through the summer, as there were also no summer programs that would provide accommodations unless I paid for a 1:1 para on top of tuition), and so I wrote again to the BASP director, our principal, and Matt Degner, who was then interim equity director.

I am happy to say that by the next year, due primarily to the hard work of Principal Jason McGinnis, we had an inclusion program for special ed students at Twain that allowed them to attend the BASP. But that should be a given for all students, not a thing we have to fight for.

“He wants to see the day when they tear down his old school because that would put a final end to that chapter of his life.”

It has been hard to come to let go of some of the guilt I feel about putting my now 12-year-old special needs son in a BASP program at ICCSD and leaving him in it when I could find no other options. I have had to try to navigate this world on my own and didn't realize how difficult it would be. I worked two jobs in order to cover the costs of before and after school care when I had to.

When we went to kindergarten roundup, we were told that the BASP was full and that there were no private afterschool programs that would pick up children. I then made the horrible decision to open enroll to a different elementary school. I struggled and struggled to get him a 504 and I could never get him qualified for an IEP. He cried every day of elementary school. The stories that the parents who volunteered in the classroom told me broke my heart.

I felt the BASP program at the school was pretty much my only option. Worst decision I have ever made. One time when he was in kindergarten, I came to pick him up and they had no idea where he was. He was not with the other kids. I was terrified. I found him alone on the playground. He was in the bathroom when all of the other kids were told to go inside so he didn't get the message and just waited outside until he was instructed to go in. One day I went to pick him up at the BASP program one day and he was in the middle of the worst meltdown I have ever seen. No one called. They just left him crying and shaking for hours. No one called me.

He was constantly bullied by another student at the program. When I complained I was repeatedly told that my child was difficult and too sensitive, and nothing was accomplished. I even witnessed the bullying when I picked him up. Every year I tried to explore other options but for single parents who work 8-5, there were no other solutions that I could find.

The worst came when I enrolled him in the summer program with the same BASP program. The kids were often left unsupervised. One time they took a field trip to the city pool. He was changing into his swimsuit in the boys room in a stall because he wasn't comfortable changing in front of the other boys. His bully kept trying to grab his ankles and pulled him out from underneath the bathroom stall. That day when I picked him up at the pool, he didn't even have

his other clothes to change into. I tried to find out where they might be in case they were in the locker room but none of the staff could answer any questions. I took

him home in his wet swimsuit. I would have ended it then and there but at the end of the week they had a planned trip to Adventureland that he was so excited about. All the kids were divided up into separate groups and he was assigned a group with this same bully. I asked the director that they be separated and even though she agreed, he remained in the same group as my son only to continue to tease and bully him the whole day.

I finally could not take it anymore. I was told that there was no way that they could protect my son. Nothing ever happened to his bully. I kept being told that he was just too sensitive.

I made the decision that he would be better off at home alone than at the BASP program. That is how I almost lost my job. I would use my 30-minute lunch break to run to my car, drive to the school, navigate the school pick up line, drop him off at home and return to work. No matter how fast I ran I could not get it done in less than 35 minutes. Heaven forbid we had bad weather that day.

As much as it scared him to be left alone it was preferable to being bullied.

I have many times looked into moving out of Iowa City because of my struggles with the ICCSD but I would need to not only move but find a new job because I worry about being too far away from him if he has problems at school. I always thought that Iowa City would have a great school system, but it has done so much damage to my son that I feel guilty every day. He wants to see the day when they tear down his old school because that would put a final end to that chapter of his life.

“[I]t felt oddly discriminatory that they would make me pay so much extra money to compensate a para because my son happened to be on the spectrum.”

When my son was initially diagnosed, the director of our school's BASP program, which is contracted out to [a local nonprofit], contacted me and indicated that we would have to pay for a para in order to keep him in the program. That felt off to me—he doesn't have a para in the classroom, and it felt oddly discriminatory that they would make me pay so much extra money to compensate a para because my son happened to be on the spectrum.

I inquired about my experience on the Iowa City Autism Community Facebook page and [a school staff member] intervened on my post and asked me to call her. When I did, she explained that [the principal] had worked out a grant-funded sub-program within the BASP that was appropriately staffed to meet the special / behavioral needs of students. She indicated that there was a spot available for my son and that he could continue to attend within that sub-program.

I had several questions as to why the initial conversation regarding [paying privately for] a para even took place, but I put them aside because I was so grateful that he could stay. My son has

had an excellent experience at this BASP, and last year [the principal] encouraged my son's IEP team to document attendance in the program in his IEP paperwork. My son is happy and cared for and is given the support that he needs.

“Although we were confident that all the adults involved had his best interest in mind, there was just no feasible way to continue with the program.”

We were so very excited for our kindergartener to be able to attend our neighborhood elementary school where our two older children had attended and built their incredible love for learning! But as with all siblings, this one was exceptionally different than the other two: extrovert was an understatement!

Although I only work three days per week, we thought BASP would be an extra special time for him, especially since we knew from early on that academics were going to be a significant challenge. Unfortunately, he is also the ultimate imitator, and it didn't take long before we were getting reports from school that he was verbally threatening teachers using words and phrases we knew he hadn't heard before in any of the very controlled, supervised settings he was coming from, let alone that he had any idea what it was that he was saying. He just knew that it got a strong reaction! We honestly had never seen hardly any of the behaviors he was displaying prior to kindergarten. His paraeducator was completely baffled by the changes that occurred over those first three to four months of school.

It also wasn't long before the requests for meetings started coming from the BASP director. Although we were confident that all the adults involved had his best interest in mind, there was just no feasible way to continue with the program. After at least three meetings, both BASP and my husband and I determined it was in everyone's best interest to pull him from the program. Work schedules were rearranged and we were very relieved that within just a few weeks of coming home after school allowed many of the severe verbal behaviors to decrease significantly.

“BASP has simply never been offered as an option for my son.”

BASP has simply never been offered as an option for my son. He is cognitively 18-24 months old and requires the same level of care of a toddler (including not being fully toilet trained). While I recognize that he would require extra care and extra staff, as a dual working household, we have been responsible for finding our own supplemental care for the whole time we have lived in Iowa.

Once he started junior high, BASP was not even on anyone's radar because typical children can look after themselves before and after school; and it certainly isn't part of the high school process. Unfortunately, not all of our children fit the mold of being able to take care of

themselves. It is a huge source of stress to post before and after school jobs on sites like [care.com](https://www.care.com) and [sittercity.com](https://www.sittercity.com) and hope that we can cobble together enough hours and availability of college students for both of us to continue working. It would be enormously helpful to have a BASP for special needs kiddos—especially if it was a reliable and stable source of care for our son during working hours.

“I never trusted those leaders with disabled students after that.”

Twelve years ago I was told the after-school program could not provide the staff that my autistic son needed [and] therefore he could not participate unless I paid for staff. However, that Board member told me his brother could participate. Since I thought that was unfair and would make my disabled son feel left out, neither participated. This limited my ability to join the workforce as well. I never trusted those leaders with disabled students after that.

“We paid the monthly tuition PLUS the difference of a regular staff member’s wage....”

When my son started at [school], we were told that BASP was not available for students with disabilities who required 1:1 assistance because their program could not support it. At the time, I did not look too hard into it because we were utilizing respite from the ARC and we/they had sufficient staffing to meet our daily needs. As time went on, however, staffing became more of a challenge (ARC wasn't able to hire enough staff to cover shifts—still to do this day) and my son became more interested in participating in activities with his friends / classmates.

[Director's name] ran the program at [school] and he was open to discussing how to include my son in the program. The challenge was not how he would participate in the program’s activities, but how BASP would provide a 1:1 staff member solely for him in order to participate in those activities. I inquired with our CCO [Consumer Choice Options] broker who said the BASP program could be hired to provide SCL [Supported Community Living] services.¹ The Director agreed and we met with our DHS case manager and had BASP added to [my son’s] CCO budget for SCL. Although we had approval, it came at additional expense and struggles.

1. We paid the monthly tuition PLUS the difference of a regular staff member’s wage: [for example] staff paid were \$8/hr and the \$13 deemed necessary for 1:1 staff to cover feeding, toileting, etc. This averaged an additional tuition fee of \$5/hr on top of the monthly tuition.
2. BASP did not have enough staff to cover all 5 days per week as offered. We paid the full tuition and extra per above, but they only had enough staff to cover 2-3 days per week.

¹ Supported Community Living and Consumer Choice Options are among several programs and supports offered to qualifying families through the Medicaid waiver overseen by the Iowa Department of Human Services: <https://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers>.

3. If staff were not available or needed to be pulled to cover staff shortages, we were informed that my son could not attend because they'd pull his staff member to cover other openings.
4. Field trips—[there was] no accessible vehicle. [My son] had to bring his own van and BASP staff or [director] would drive my son to activities separate from everyone else if he wanted to participate. If I could not drop his van, he was left out. There were times where I would haul my bicycle in the van to drop him and the van off and then ride my bike from [school] to work.
5. School paras could not work at BASP with students on the school dime because BASP is not a school sanctioned program, the district only allows BASP to use their facilities.

My son loved attending and [Director] did his best in accommodating, but it did come at a financial cost to the family and his Medicaid program. I would do it again if it meant my son being involved with his peers.

After School Programs for Special Needs Populations

Afterschool Alliance. “America after 3PM: Special Report: Afterschool in Communities of Concentrated Poverty. Washington, D.C.: Afterschool Alliance, 2016.

<https://eric.ed.gov/?q=after+school+programs+AND+special+education&id=ED582319>.

While this report primarily addresses other barriers to after-school care, specifically in high poverty areas, it also addresses the barriers faced by parents of students with special needs in finding quality, affordable after school care.

Fetter-Harrott, Allison, Amy M. Steketee, and Mary Dare. “Boosting Inclusion for Students with Disabilities.” *District Administration* 44, no. 10 (September 2008): 63–65.

An overview for school administrators of the legal obligations to make after school activities including extracurricular activities and after school programs available and accessible to students with disabilities.

Haney, Michelle R. “After School Care for Children on the Autism Spectrum.” *Journal of Child and Family Studies* 21, no. 3 (June 2012): 466–73.

<http://dx.doi.org/resources.kirkwood.edu/10.1007/s10826-011-9500-1>.

An overview of the lack of after school programs that provide quality care for autistic students and of the hardships faced by parents of autistic students seeking after school care for their children. The article concludes with some practical suggestions for creating high quality, workable, affordable after school programs with accommodations for autistic students.

Hayden, Deidre. “Inclusion Tool Kit.” San Francisco: Special Needs Inclusion Project, 2010.

<http://www.snipsf.org/wp-content/uploads/2011/08/v2010Inclusion-Tool-Kit-Sept-update1.pdf>.

An extensive guide to creating inclusive programming in before and after school settings, summer camps, and more, including not only applicable laws but also standards and benchmarks for inclusive programs, sample policies, plans, interview questions, and an extensive list of resources, both national and California-specific.

Maryland Disability Law Center. "Together Beyond the School Day: Including Youth with Disabilities in Out of School Time Programs," 2012. <https://www.disabilityrightsmd.org/wp-content/uploads/2012/10/OST-final-for-website.pdf>.

A guide for parents, program directors, and youth on the laws governing out of school time programs (including those provided by schools, for and nonprofit agencies, and civic and religious institutions), how to design inclusive programs, and resources for parents on how to work with programs to ensure their child's needs are met and that their rights are respected. Includes a listing of community and national partners, though most are Maryland-specific.

Dawn Leann Mollenkopf. "Students With Disabilities in 21st Century Community Learning Centers: Inclusion Issues for After-School Programs." University of Kansas, 2002. <http://www.proquest.com/openview/643a7509cb9336a56d08dcfebd10b9eb/1?pq-origsite=gscholar&cbl=18750&diss=y>.

A dissertation covering the issues facing organizations who receive 21st Century Learning grants in providing equitable and inclusive services for students with disabilities in after school programs.

Smith, Kara. "The Need for Skilled Inclusion in Out-of-School-Time Programs: Kids Included Together Responds." Kids Included Together, 2016. https://www.kit.org/wp-content/uploads/2016/09/OurWork_WhitePapers_TheNeedforSkilledInclusion.pdf.

A white paper from a San Diego-based nonprofit that now works with 21st Century Community Learning Centers nationwide. Smith outlines the importance of inclusive programming and the challenges that families face in obtaining out of school time care for special needs children and the ways in which current programs are unprepared to accommodate students with special needs.