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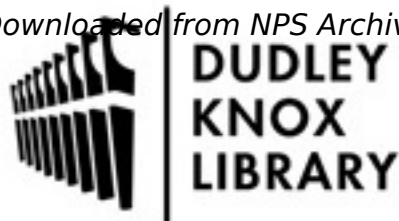
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# Evaluating Community Inclusion: A Novel Treatment Program for Children with Autism Spectrum Disorders

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*A state-funded, non-profit organization developed an innovative inclusion program for children with Autism spectrum disorders and developmental delays, Including Special Kids, which offers activities for children with developmental delays alongside typically developing children in collaboration with well-established local youth programs. This case study examines the ISK intervention program at the original community host sites to determine if the evidence supports a measurable and demonstrable change in behaviors in a real-world setting that may lead to increased quality of life and greater inclusion in the community. Using evidence-based data, we measured the progress of 30 children over 6-24 months. Children participating in the program showed average improvement in all but two function areas and improvement in all composite scores. While these results do not prove program success, they offer an indication that the program helps children learn skills and behaviors to successfully navigate and become part of community-based, after-school recreational programs.*

Key Words: Autism Spectrum Disorders; Children with Developmental Delays; Inclusion Program; Youth Programs; Social Skills in Community Settings

## Introduction

One in 88 American-born children have been diagnosed with autism spectrum disorders (ASDs) (Department of Health and Human Services, 2012), and worldwide estimates indicate 4.3 million people had a diagnosis of ASD in 2009, which is predicted to increase to seven million by 2017. (Global Data, 2010). According to the Mayo Clinic, “Autism spectrum disorder is a serious neurodevelopmental disorder that impairs a child’s ability to communicate and interact with others. It also includes restricted repetitive behaviors, interests and activities. These issues cause significant impairment in social, occupational and other areas of functioning.” (Mayo Clinic, 2014) Children with ASD face social difficulties due to their behavior including their difficulties in communication and social interactions, the fact that they may display repetitive behaviors, and that they often exhibit restricted interest in or participation in activities with other children. Their social skills development trails that of typically developing children, often leading to exclusion from mainstream education and social activities. Rao, Beidel, and Murray (2008, p. 353) found that “children who are deficient in social skills lack the behavioral repertoire necessary to interact with others according to social convention, a deficit that affects both academic and social development.” The prognosis of a child with ASD depends on many aspects of the child’s disorder, including joint attention skills and functional play skills, and more favorable outcomes may result

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from appropriate behavioral intervention and successful inclusion with typically developing peers in community and educational settings (Johnson & Myers, 2007).

While much ongoing scientific research addresses autism spectrum disorders, there are no conclusive solutions available to parents on how to provide the best support for their child's well-being. To a large degree, parents address their children's social interactions through non-profit groups that sponsor a wide variety of programs using recommendations that span the spectrum of possible interventions. While the scientific community is clear that these are not "science-based" interventions, the interventions are widely implemented throughout the general populace. This state of affairs should not be surprising as parents, in the absence of concrete scientific input, try multiple alternatives to help their child. However, it should be of concern to the public; some of these interventions may prove to be better (or worse) than others, but there is no forum for assessing their relative worth. More importantly, some of these interventions may be worth a full-blown medical study to scientifically prove their benefits, but how are they to make the transition from community-based intervention grown out of a geographic community's response to a clinical trial?

One possible solution to this dilemma is to share the findings from non-profit organizations' interventions. This provides a means of allowing the intervention to be judged by other non-profits, the medical establishment, and the general population. It creates a growing body of assessment of community-based interventions. And it allows other non-profit leaders to determine whether or not the intervention is a model they wish to emulate in their communities. Since medical journals resolutely do not publish interventions that do not meet the exact criteria of scientific study (most notably, they object to the lack of a control group – which is almost impossible to have in a community-based intervention), these findings must be published in non-profit journals, which is even more fitting because the implementing institutions are typically non-profits.

This paper presents a case study of a state-funded, non-profit organization that developed an innovative inclusion program for autistic children. Special Kids Crusade (SKC), a 501(c)(3) nonprofit, tax-exempt, charitable organization, was formed to make a positive impact on the lives of children with disabilities and their families, specifically addressing the isolation and discrimination these children face (Special Kids Crusade, 2012). *Including Special Kids* (ISK) is an after-school, community-based intervention, which provides children with developmental delays from ages five through high school the opportunity to interact with a typical mix of peers in small and large group recreational activities. The initial ISK program partnered with well-established local youth programs at two Boys & Girls Clubs (BGCs) and the First Tee golf program. The program now operates at four sites, soon to be five, and program leaders<sup>6</sup> designed the intervention to work with any available after-school host location. The ISK intervention addresses inclusion in leisure-time, community-based activities and aims to help children with ASD function in real-world situations<sup>7</sup>.

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<sup>6</sup> In this research, we refer to the ISK program director, the SKC clinical director, and members of SKC leadership as "ISK program leaders."

<sup>7</sup> The impetus for ISK came from an unusual grant opportunity offered by the California Department of Developmental Services (DDS) through the San Andreas Regional Center (SARC). SARC, is one of 21 regional, community-based, private nonprofit corporations funded by the State of California to serve people with developmental delays, supports individuals and their families who reside within Monterey, San Benito, Santa Clara, and Santa Cruz counties. In 2007, DDS, through SARC, offered to provide start-up funds to stimulate new ideas and new types of program models for individuals with developmental delay; however, DDS stipulated no funding for traditional program models. ISK began with DDS funding

This case study examines the ISK intervention program at the original three community host sites to determine if the evidence supports a measurable and demonstrable change in behaviors in a real-world setting that may lead to increased quality of life and greater inclusion in the community.

### **Foundation of the Intervention**

Behavioral intervention programs concentrate on social skills development and behavior modification. Vismara and Rogers (2010, p. 447) state that, to date, behavioral interventions at young ages present the only treatments shown to effectively improve core autism symptoms. Researchers have suggested that if children learn social skills in childhood, they may have a greater likelihood of positive developmental outcomes including peer acceptance [or inclusion], mental health and wellbeing, and academic achievement (Hartup, 1989; Rao, Beidel, & Murray 2008).

Applied behavior analysis (ABA) provides the foundation for most of these intervention programs and addresses social difficulties by helping individuals change their behavior, emphasizing smaller changes in desired behaviors and avoiding reinforcement of unwanted behaviors. In practice, the interventions teach social skills such as referencing (a person's ability to monitor another person's behavior and adapt his or her own behavior according to its effect on others), communicating back and forth with another, and talking at an appropriate volume; behaviors that result in positive social interactions. These skills include not only verbal but non-verbal behaviors needed for individuals to have positive interpersonal communication (Gresham & Elliott 1987). (For more on social skills development see also Rao, Beidel, & Murray (2008, p. 353) and Hartup (1989).) To be included with their peers and in society at large, these children must not just modify existing behaviors, but also learn behaviors that foster group inclusion (Jones and Frederickson, 2010). Of particular interest to this research is the ABA-based model of positive behavior support (PBS). An empirically validated, function-based approach, PBS replaces challenging behaviors with prosocial skills. In a recent study, Leach and Duffy (2009) surveyed best practices in reducing problem behavior and promoting inclusion for students with ASD and found that in most cases, a PBS model is recommended for students with ASD.

These programs typically occur in formal settings administered by mental health professionals. As Lopata et al (2006) and others have shown, often, children can demonstrate specific social skills in the setting in which they were learned but cannot use the skills functionally in their real worlds of school, after school activities, and family interactions. Targeted social skills training groups may have little impact on the overall quality of life for the child or the child's family and community. Other researchers have also suggested that participating in inclusive programs with typically developing peers may improve outcomes for ASD children including greater social acceptance. (See, for example, Fryxell & Kennedy (1995); Guralnick, Gottman, & Hammond (1996); and Halvorson & Sailor (1990)). Further, Carr et al. (2002) suggested that to improve outcomes, activities for people with diagnosed delays must move beyond education and into other community activities that provide opportunities for participation and social interaction with a range of typically developing peers.

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and included children who were SARC clients. As such, each child's family signed a release allowing evaluation data to be collected and used for assessment and evaluation purposes without identifying information.

## **Material and Methods**

### *Intervention Goals and Sites*

The ISK intervention operates in conjunction with established host site after-school programs. The sites are independent of the school grounds, accept children aged six through high school, and are composed of a representative community of peers. ISK and host program staff work to integrate children with ASD into typical out-of-school activities alongside their peers. The goal of the program is to have the children be comfortable attending the afterschool programs on a daily basis (five days a week) for approximately three hours requiring only the same amount of support as a typically functioning peer. ISK leaders were driven by a particular DDS stipulation that ISK could not use a traditional program model. In particular, the ISK leaders had to avoid staffing the program with shadow aides who interacted with ASD participants solely on a reactive basis – only stepping in once issues have arisen. Instead, ISK leaders designed the program to take a proactive approach, embedding an Inclusion Assistant in the activities and groups to create learning opportunities for the child with developmental delays. These learning opportunities are aimed at developing the child's skills so that they can attend community settings like other same age and gender peers. This approach involved training ISK staff as well as host site staff to teach both typically developing children and those with ASD the skills needed to participate together in the community program.

In the next sections we discuss program staffing and training, the skills on which the ISK intervention chose to focus, the measurement and assessment of these skills, and the participant assessment and skill development process.

### *Program Staffing*

ISK leaders hired adults for each program site to teach inclusion techniques to host program activity leaders, adaptive skills to children with ASD, and adaptive skills to peers. They employed inclusion specialists (ISs) and inclusion assistants (IAs) who operated the programs. IAs provided direct support to program participants, helping them develop the requisite skills shown in Table 1 to integrate into the group. They also taught skills and tools to all members of the community. ISs were assigned to a specific site and acted as on-site managers, assisting with training, interacting with IAs and host staff, and talking with parents.

Both IAs and ISs came into the ISK program with experience working with children with ASD, passed strict background testing and underwent 15 hours of continued training, including in-service training and training on developmental disabilities, tools of inclusion, privacy regulations, measurements and assessments and other competencies needed to work in the inclusion program. Training materials are available on request. After the initial training, the IS observed and coached each IA weekly, and the clinical director provided similar support and guidance on a quarterly basis or more frequently, as needed.

IAs and ISs taught host site staff procedures to facilitate social interactions among all children, to include children with developmental delays in host site activities, and to reduce challenging behaviors. Host staff learned to use positive behavioral supports such as moving close by when giving directions, commenting on what the children do correctly rather than spotlighting missteps and simplifying games so all children can participate. In addition, those involved in the program received information from research on typical social and emotional development. Staff implemented strategies appropriate to the goals of each child on an ongoing basis throughout the time period the child attended the program.

### *Skills Development*

One of the program goals is to help children build skills so that they can become fully independent members at their host sites. To this end, the ISK program director and clinical director had a series of discussions with host site leadership and determined that three behaviors most upset typically developing peers and the staff of their programs: inability to use the restroom independently<sup>8</sup>, running and yelling. Although these three behaviors were most distressing to the staff and members of the club, age appropriate use of these skills did not necessarily mean that the children would be included in activities or make friends. ISK conducted a simple stakeholder survey, asking host site children and staff, "What makes it hard to be friends with \_\_\_\_\_?" ISK leaders incorporated these observations and the peer-feedback with the existing literature, (specifically: Wolfberg (2003) relating to development of peer engagement; Hart and Risley (1975) who targeted the development of language through incidental teaching; and Stokes and Baer (1977) who developed the paradigm for generalization of skills), and chose nine adaptive skills that pose the greatest challenge to having children accepted in a social group (Table 1: Adaptive Skills).

Once the leaders examined the nine skills in detail, they broke each of them down into a series of sub-skills whose full mastery would lead to achievement of the master skill. For example, "Moving Safely" included mastering the ability to move in a coordinated way first with ISK staff, then with host staff, and finally with typically developing children of the same age and sex. Sub-skills also included moving for the same amount of time as same age/sex peers and being aware of and avoiding other people and objects while moving.

Following Bellini and Hopf's (2007) Autism Social Skills Profile (ASSP), and incorporating aspects of how to teach essential skills from Banda and Grimmert (2008) and Hanzlick, Peterson, and Rogers (2011) as well as other well established PBS methods, ISK leaders developed toolkits to teach these essential skills. The toolkits, which specifically addressed these adaptive skills at 10 levels of skill mastery, were modified and extended to take advantage of group interactions provided by the host setting. For example, ISK staff taught each sub-skill using a set of associated techniques based on the child's level of mastery. For example, children new to the program with little ability to move in a coordinated way would first walk with an ISK staff member around areas of the host site that had very little "traffic." The ISK participant may have held the staff members' hand, while the staff member narrated safety actions (e.g., staying along the perimeter in the gym while others are playing basketball or looking before dashing through an activity). Staff used verbal and visual cues to help the child determine "safe" areas and movement in the host facility. As children progressed, staff used practice situations. These situations mirrored activities like playing "red light" and "green light" to help the child learn when to stop or go. As children began to participate independently, their peers assumed greater roles in interacting, reinforcing positive behavioral changes or addressing staff when an ISK child experienced difficulty. Thus, in teaching these skills, ISK combined ABA methods including peer-mediated strategies, adult-facilitated strategies, and strategies designed to increase initiating and autonomy in a child with autism. (See, for example, Haring & Breen (1992); Kamps, Kravits, Lopez, & Kemmerer (1998); Shukla, Kennedy, & Cushing (1998); Weiss & Harris (2001).)

ISK compiled the teaching techniques for the nine adaptive skills in a series of binders available to all program staff, including the host site. ISK staffing varied depending on needs of the children.

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<sup>8</sup> Neither SKC nor BGCME hold daycare licenses, requiring all program participants to use the restroom without assistance. If a child brought his or her own assistant, he or she was allowed to participate.

**Table 1: Adaptive Skills**

Attending Skills	<i>Using the Restroom</i>	IAs focused on teaching participants how to behave appropriately when in a public restroom. Participants learned how to open and close the locks of the stalls, to use the appropriate number of paper towels, to check for an empty stall and so on.
	<i>Modulating Volume</i>	Participants learned to judge the appropriate volume, depending upon the setting and to use that volume. IAs guided participants to gradually reduce and eventually eliminate loud, unpredictable noises.
	<i>Moving Safely</i>	The IAs spent a great deal of time walking with individual participants around the setting, especially at the beginning of each participant's inclusion. While doing so, each participant learned to move in a coordinated fashion with another person and to avoid objects/people in the path. After mastering walking with an IA, each participant worked on moving at the same speed and frequency as other children of the same age and gender.
Participating Skills	<i>Referencing</i>	Referencing refers to the skill of looking to adults or other competent children for nonverbal cues that help participants know how to behave at a given moment in a given setting. Initially the participants learned to socially reference by turning towards someone calling his or her name. Then they learned to use social referencing to seek out guidance in uncertain situations, and to seek affirmation from significant adults and children <sup>9</sup> .
	<i>Engaging in Activities</i>	Participants frequently entered the program with a small number of preferred, often repetitive activities. IAs carefully scaffolded activities and skills so the participants developed the competencies to engage in a range of host site activities. Participants learned to sample new activities and to be flexible in their choices of activities. In addition, they learned to follow the rules of the activities, both stated and implied.
	<i>Communicating</i>	IAs worked with the participants to increase their ability to communicate clearly their needs and wants with both familiar and unfamiliar people. This communication occurred in the form of gestures, icons, signs or spoken language, depending upon the participant's preference. For participants comfortable using words and discussing ideas, IAs guided them to talk with and to listen to other people. Participants were gradually guided to expand their choice of conversational topics.

<sup>9</sup> "Significant" individuals include parents, teachers and other adults who have an emotional connection with the child. These are the adults that children learn to reference first; later the children learn to discern who is "in the know" in different environments and to reference them.

**Table 1: Adaptive Skills (Continued)**

Collaborating Skills	<i>Cooperating</i>	At the very beginning stages of cooperation, the IAs engaged in very simple play patterns with each participant. These beginning patterns require the IA and participant to do something like roll a ball back and forth or place cards on a stack, where the pattern is a very simple version of turn taking. These patterns helped the participant learn to cooperate with adults and other children; they also formed the basis for all types of group play. As a participant progressed, the IAs expected the child to cooperate, even on non-preferred tasks. The “habit” of cooperation was developed by initially inviting the child to do things that he or she had a high likelihood of doing, and incrementally adding activities that the child had avoided or did not like.
	<i>Regulating Emotions</i>	Most young children have temper tantrums; as they mature, they learn to manage their emotions so as to have few, if any, such outbursts. Children with developmental delays often have intense emotional outbursts long after their peers have learned to express their frustration and anger in socially acceptable ways. ISK participants learned to reduce the frequency, duration and intensity of such emotional outbursts so as to more closely resemble the outbursts of other children of the same age and gender. At the same time they learned to express their emotions in ways so that others could understand and respond.
	<i>Making Friends</i>	This is the most complex skill that the participants developed. Initially the IAs worked with a participant to enter a group of children who were engaged in an activity; simultaneously the IA worked with the group to welcome the participant into the group. The overall goal was to develop a stable and inclusive group (meaning more than one person) that welcomed the participant and with whom the participant learned to enjoy spending time.

For example, children with low skills had an ISK staff member assigned to them while participating in the program while children with more advanced skills had a ratio of two or more children to one staff member. A separate manual for parents details the program itself and all of the policies and procedures for the program. These handbooks are made available to anyone wishing to replicate this program<sup>10</sup>.

ISK program staff members saw these nine skills as being hierarchical, arranged in order from simplest to most complex. In general, participants mastered basic skills before more complex skills were emphasized. However, as with typical development, children and staff worked a little on all skills all the time. From lowest competency to highest, ISK designated three categories of skills based on the nine individual skills. Attending skills came from the first three individual skills (Using the Restroom, Modulating Volume, and Moving Safely), and must have been high enough that a child could show up to the program and handle the group setting. Participating skills, the middle three, (Referencing, Engaging in Activities, and Communicating) allowed children to more fully engage and participate with the activities and routines in the setting. Collaborating skills

<sup>10</sup> Contact Deirdre Hickey Sturm, ISK Program Director, Special Kids Crusade, [deirdre@specialkidsrusade.org](mailto:deirdre@specialkidsrusade.org)



(Cooperating, Regulating Emotions, and Making Friends) described the skills required for working with or collaborating with other people independently within the setting.

### *Individual Measurement and Assessment*

While positive parent feedback on the progress of their children, progress as observed by the IAs, and professional clinical assessments were critical measures of success, ISK leaders felt it was necessary to develop a uniform means of measuring and quantifying progress in an individual. Using data and measurement scales to quantify observed behavioral changes would provide objective, corroborative measures of progress that would permit a triangulation of observations between the parents, staff, and clinical director. The leaders felt that the development, testing, and application of these measures would provide strong evidence-based data about the impact of the program.

An assessment system was needed to serve many purposes including allowing: ISK to report quarterly to SARC on progress of the children; ISK program leaders to understand what skills interventions work; IAs and ISs to also understand and work to improve their skills and interventions; and families to track meaningful progress in their children and to ask intelligent questions about progress. ISK leaders reviewed many types of instruments that provide information on social skills and adaptive behavior for children and adults who have, or are suspected of having an ASD. They found no instrument or combination of instruments that was suitable for their purposes, so they decided to create their own assessment system to measure intervention effectiveness of their critical skills training program. In doing so, they found their ideas most aligned to Bellini's (2006) Autism Social Skills Profile, Partington's (1998) Assessment of Basic Language and Learning Skills - Revised (ABLLS®-R), and Hanzlick et al's work on functional social competence (Hanzlick, Peterson, & Rogers 2011).

ISK leaders constructed an easy-to-understand measurement system allowing individuals to work on the nine skills, describing each skill using 10% improvement increments. Table 2: Evaluation Criteria for Each Skill, shows the levels, where Level 10 means low or very weak skills and Level 1 signifies high or strong skills. While the levels remained constant, program materials provided detailed descriptions of what was meant by the level within the specific skill. This created a scoring matrix as shown in Figure 1 for each child at a given point in time. The matrix rows reflect each of the nine adaptive skills. The matrix columns reflect the level of mastery of each skill (running from 10 [lowest] to 1 [highest]). Every square within this matrix (90 in total) has a detailed explanation of exactly what is meant by that level of mastery for a particular skill. . For example, a score of "5" for moving safely (the dark highlight box in Figure 1) was described as follows:

The ISKer walks and moves safely half the time. The ISKer is able to do this as long as the IA is within 3-8 feet. The ISKer is able to walk in a coordinated fashion with the IA half the time. The ISKer can successfully move with a group half of all opportunities. His/her speed resembles his/her peers half the time. He/she both bumps into people and objects and avoids people and objects. Half of the time, the ISKer moves the same amount as other same age/gender peers. Half of the time, the ISKer moves more often or less often than his/her same age/gender peers. Half the time, he/she moves with intention. Half of the time (51-60% of opportunities), the ISKer moves in the setting like other children of the same age/gender.

Using this measurement technique, ISK leaders and staff created Individual Profiles (IPs) for each child. Every child was scored on each of the nine adaptive skills (the shaded boxes in Figure 1)

**Table 2. Evaluation Criteria for Each Skill**

Level	Adverb	% observed	Skills Focus
1	Typically	91-100	Attendance, Participation & Collaboration
2	Usually	81-90	Attendance, Participation & Collaboration
3	Frequently	71-80	Attendance, Participation & Collaboration
4	Often	61-70	Attendance & Participation
5	Half of the Time	51-60	Attendance & Participation
6	Sometimes	41-50	Attendance & Participation
7	Occasionally	31-40	Attendance
8	Sporadically	21-30	Attendance
9	Seldom	11-20	Attendance w/accommodation
10	Rarely	1-10	Attendance w/accommodation

and these scores were to be tracked over time to determine improvements or possible worsening. One of the most important aspects of creating this measurement tool was describing what “typical” behavior meant for each age and gender represented in the ISK program. ISK staff members used their own observations and those generated from published studies to describe typical skill mastery at different age/gender combinations. Individual Profiles reflected comparison of skills against typical skill and sub-skill mastery. These “typical” skill mastery descriptions and activities used to teach them are available from the ISK program director.

Gerhardt (2010, p. 202) notes “Direct observation of individuals with ASD in social environments can be one of the best means of conducting detailed assessment of particular social behavior of interest, as well as interpreting how responsive an individual is to contextual variables regarding exhibiting particular social skills.” ISK leaders ensured that raters closely followed Jones’ “three desirable conditions: (a) observation and recording of behaviors at the time of occurrence in their natural settings; (b) the use of trained, objective observers; and (c) a behavioral description system involving a minimal level of inference by the observers” (Jones, 1979). As found by other researchers, the use of multi-informant (IAs, ISs, clinical director, host staff, parents) behavior ratings gave ISK better information on social inclusion. (Verhulst & Van der Ende, 2008). Each rater was trained to conduct individual assessments using a detailed rating scale, and the clinical and program directors made frequent comparisons among raters. Inter-rater reliability was high (generally above 90% agreement within one level). For those ratings varying more than 20% between raters, the program director and/or clinical director resolved disagreements by conducting the observation and assessment themselves and working with the original raters to come to agreement.

#### *Participant Assessment and Skills Development*

This study focuses on 30 students enrolled in three different centers. The average age was 11.7 years (minimum 6 years, maximum 16 years) and 77% were male. The average time in the program was almost a year (minimum 3 months, maximum 27 months). Student initial skills assessments are reported in Table 3 and discussed in the Results section.

When children entered the ISK program, the program director conducted an intake interview with a parent, including the parents’ assessment of the child’s skills and a record review of educational and regional center documents (medical records, SARC information, etc.) to set the baseline on the child’s functional and social skills. ISK staff then used a “naturalistic” (Gerhardt 2010, p. 202)

**Figure 1. Scoring Matrix for an Individual Child at a Single Point in Time**

Adaptive Skills	Level of Mastery									
	10 (Lowest)	9	8	7	6	5	4	3	2	1 (Highest)
<i>Using the Restroom</i>										
<i>Modulating Volume</i>										
<i>Moving Safely</i>										
<i>Referencing</i>										
<i>Engaging in Activities</i>										
<i>Communicating</i>										
<i>Cooperating</i>										
<i>Regulating Emotions</i>										
<i>Making Friends</i>										

setting, and direct observation of the children to create individual descriptions and plans for each child. Throughout the program, IAs completed a daily report form on each child. When a child received assessments indicating a level change in a skill, the program director evaluated these “tipping points” to determine whether to record a change in the child’s level for a particular skill. In addition to these daily ratings, the ISK program director evaluated each child every three months, comparing her assessments to those of the IAs and ISSs.

Staff worked to build the skills needed for ISK children to become fully independent members at their host sites. This involved advancing children by changing support and desired skill mastery as they mastered lower-level skills. At the time of the quarterly assessment, each child who met the criteria (improved skills enough) to “graduate” to the next level of independence (from 1:1 support to 2:1 support, for example), moved to the next level. ISK staff collaborated with parents and SARC to create a graduation plan, which included a transition timeline, peer matching, implementation guidelines and evaluation criteria. On the selected start date, the IAs modified their roles. A lead IA guided the child and completed daily report forms while a support IA helped the child learn to navigate the next level successfully. All ISK staff monitored progress or decline in skill levels, providing additional support and information for parents over the transition period. After four successful weeks at the new level, ISK staff set up an official graduation where the child, members of the child’s family and the SARC coordinator attended an appropriate ceremony and/or celebration.

**Analyses**

In this study, we used three-month assessments to capture true changes in skill level and avoid the noise of daily variations in behaviors that were not considered real changes. We constructed descriptive statistics and regression models from the panel data to study the skill level changes for each child over time. In addition to the nine individual skills, we developed five composite scores: a composite of all nine skills, a composite of all skills excluding Using the Restroom, a composite of attending skills (Using the Restroom, Modulating Volume and Moving Safely), a composite of participating skills (Referencing, Engaging in Activities, Communicating), and a

**Table 3: Descriptive Statistics, n=30**

Variable	Mean	Std. Dev.	Min	Max
<b>Basic statistics:</b>				
Average age	11.70	2.67	6	16
% Male	0.77	0.43	0	1
No. With Attender classification	11			
No. With Participator classification	9			
No. With Collaborator classification	10			
Average months in program	11.80	8.07	3	27
<b>Functional/behavioral skills scores:</b>				
Using the Restroom	2.57	1.80	1	8
Modulating Volume	4.84	2.57	1	10
Moving Safely	5.41	2.52	1	9.25
Referencing	5.40	2.66	1	10
Engaging	6.25	2.38	1.5	10
Communicating	6.05	2.50	1	9.75
Cooperating	5.97	2.29	1.33	9.75
Regulating	6.33	2.37	1.2	10
Making Friends	8.36	2.01	1.33	10
<b>Composite scores:</b>				
Composite score:	5.69	1.88	1.29	9.13
Composite score not including restroom	6.05	2.06	1.32	9.52
Composite - attending skills	4.15	1.92	1.17	8.17
Composite - participating skills	5.89	2.22	1.4	9.8
Composite - collaborating skills	6.87	1.98	1.29	9.42

composite of collaborative skills (Cooperating, Regulating Emotions, Making Friends). We refined our global analysis by categorizing participants based on their skill levels on entry to the ISK program. The three categories were the Attenders (those who had sufficient skills in Using the Restroom, Modulating Volume and Moving Safely to enter the program, but no higher), the Participators (those who had sufficient attending skills plus some mastery of Referencing, Engaging in Activities and Communicating), and the Collaborators (those who had sufficient attending and participating skills plus some mastery of Cooperating, Regulating Emotions and Making Friends).

Fixed effects models were appropriate because we assumed that something within individual children, the unique characteristics of the individual, might impact or bias the predictor or outcome variables that measure program effects. We needed to control for this to evaluate the program, thus we held constant (or “fixed”) characteristics of each child that did not change over the time period of the study. These were level of intelligence or other individual characteristics. We developed these models including all children with ASD in the program, in total and by entry skill group.

## Results

Table 3: Descriptive Statistics shows basic information about the ISK participants and the average skill levels of all children at the time they entered the program. For example, children averaged

2.57 for using the restroom and 8.36 for making friends, where 1 is the best possible score and 10, the worst. Overall, average skill scores increased (reflecting poorer skills) as skills became more complex. Table 4: Descriptive Statistics by entering skill classification, shows baseline skill scores for children by their entering classification (attenders, participators and collaborators). Children who enter with attending scores average approximately “8” on most skills; participators average about closer to “6,” while collaborators average under “4.”

In Table 5: Fixed effects models estimating effects of program participation on skills for all participants, we present analyses of changes in each of the skills over time. The coefficients shown are average changes in skill level for a 12-month increase in program attendance, with corresponding p-values (\*\*\*)  $p < 0.01$ , \*\*  $p < 0.05$ ). The third column shows the standard errors for the regression coefficient. The fourth and fifth columns show the constant terms and standard errors for the constants.

We found that overall, children participating in the program showed average improvement in scores in all areas except using the restroom and cooperating ( $p < 0.05$ ). We also saw improvement in all composite scores. For example, the 12-month effect on skill improvement for moving safely was 1.0 ( $p < 0.01$ )<sup>11</sup>, meaning that on average, children in the program improved by one point over a 12-month period. In fact, these children improved their scores, on average, of one point or greater for modulating volume, moving safely, and making friends. They improved their scores, on average, more than half a point for referencing, engaging, communicating, regulating emotions, and for all the composite scores. These children came into the program with high average scores for using the restroom, so perhaps they had less need or ability to improve in that

**Table 4: Descriptive Statistics, by Entering Skill Classification**

Variable/Observations	Mean skill scores		
	Attenders	Participators	Collaborators
Observations	11	10	9
Using the Restroom	3.64	1.78	2.14
Modulating volume	6.84	4.41	2.86
Moving Safely	7.63	4.83	3.35
Referencing	7.27	5.48	3.01
Engaging	8.29	6.64	3.32
Communicating	8.57	5.17	3.94
Cooperating	7.82	6.01	3.64
Regulating Emotions	8.13	6.62	3.82
Making Friends	9.67	8.39	6.74
Composite Score	7.55	5.48	3.65
Composite without Using the Restroom	8.03	5.97	3.73
Composite - Attending	6.03	3.67	2.39
Composite - Participating	8.04	5.76	3.39
Composite - Collaborating	8.54	7.01	4.66

<sup>11</sup> Note that improvements in scores are measured by a decrease in the score because 1 is the highest score and 10, the lowest. However, to keep the results understandable, we report all improvements in positive terms.

**Table 5: Fixed Effects Models Estimating Effects of Program Participation on Skills, All Participants**

Adaptive Skill	Ave. 12- mo change in score		s.e.	Constant	s.e.
Using the Restroom	0.36		-0.021	2.315***	-0.213
Modulating Volume	-1.13	***	-0.019	5.227***	-0.193
Moving Safely	-1.00	***	-0.022	5.815***	-0.220
Referencing	-0.65	**	-0.021	6.083***	-0.212
Engaging	-0.61	***	-0.016	6.349***	-0.166
Communicating	-0.48	***	-0.015	6.258***	-0.151
Cooperating	-0.18		-0.020	6.335***	-0.205
Regulating Emotions	-0.84	***	-0.017	6.909***	-0.177
Making Friends	-1.17	***	-0.019	8.359***	-0.195
Composite Score	-0.63	***	-0.012	5.962***	-0.122
Composite without Using the Restroom	-0.73	***	-0.013	6.385***	-0.128
Composite - Attending	-0.53	***	-0.015	4.394***	-0.152
Composite - Participating	-0.58	***	-0.013	6.219***	-0.133
Composite - Collaborating	-0.73	***	-0.014	7.213***	-0.144

\*\*\* p<0.01, \*\* p<0.05

area. There is no ready explanation as to why children did not show an improvement in cooperation skills.

For the next set of analyses, we calculated the average effect on skill score for children in the program by categorizing them in terms of their initial skills. Table 6: Fixed effects models estimating effects of program participation on skills by entering skill category, shows the effects on skill score using the attenders (lower), participators (middle) and collaborators (higher) categories (representing the spectrum of skills from simplest to most complex).

The estimations for children who entered the program with low skill levels, the attenders, show improvements in average skill scores for two of the three simplest skills; the effects on modulating volume (1.26 points over 12 months;  $p<0.01$ ) and moving safely (0.84 points;  $p<0.05$ ). Interestingly, children in this group showed a statistically significant improvement in making friends score (0.80;  $p<0.01$ ) despite that being the most complex skill to master. They also showed a significant improvement in the composite score not including restroom use (0.47;  $p<0.05$ ).

For children who entered the program with mid-range skills, the participators, we found strong average effects on the more complex skills of regulating emotion and making friends (1.36, 1.52;  $p<0.01$ ) as well as on all composite scores (0.55, 0.68;  $p<0.05$  for attending and participating composites and for all other composites (0.78 on overall composite, 0.91 on composite without restroom use and 1.15 on the collaborating composite;  $p<0.01$ ). These children also showed strong average improvements in scores for modulating volume, moving safely and engaging (0.94, 0.97, 0.83;  $p<0.05$ ). Given this group's mid-level skills, it seems appropriate that the children made their greatest improvements in collaborating skills (the highest level) and overall composite scores.

**Table 6: Fixed Effects Models Estimating Effects of Program Participation on Skills, All Participants by Entering Skill Category**

Adaptive Skill	Attendees (Lower skills)				
	12-mo effect		s.e.	Constant	s.e.
Using the Restroom	-0.97		0.043	3.163***	-0.466
Modulating Volume	1.26	***	0.031	7.276***	-0.334
Moving Safely	0.84	**	0.034	7.512***	-0.374
Referencing	0.38		0.030	7.770***	-0.331
Engaging	0.53		0.024	7.856***	-0.258
Communicating	0.33		0.016	8.548***	-0.172
Cooperating	-0.37		0.033	7.506***	-0.358
Regulating Emotions	0.17		0.026	8.294***	-0.279
Making Friends	0.80	***	0.021	9.482***	-0.232
Composite Score	0.32		0.019	7.497***	-0.208
Composite without Using the	0.47	**	0.019	8.022***	-0.204
Composite - Attending	0.37		0.028	6.005***	-0.305
Composite - Participating	0.41		0.018	8.058***	-0.198
Composite - Collaborating	0.20		0.020	8.427***	-0.214
Obs	55				
Individuals	11				
Participants (Middle skills)					
	12-mo effect		s.e.	Constant	s.e.
Using the Restroom	-0.21		-0.016	1.401***	-0.158
Modulating Volume	0.94	**	-0.036	4.032***	-0.365
Moving Safely	0.97	**	-0.039	4.821***	-0.399
Referencing	0.82		-0.038	5.690***	-0.382
Engaging	0.83	**	-0.032	6.061***	-0.323
Communicating	0.35		-0.029	4.917***	-0.298
Cooperating	0.46		-0.036	6.390***	-0.367
Regulating Emotions	1.36	***	-0.030	6.964***	-0.308
Making Friends	1.52	***	-0.035	8.023***	-0.354
Composite Score	0.78	***	-0.021	5.353***	-0.215
Composite without Using the	0.91	***	-0.023	5.838***	-0.229
Composite - Attending	0.55	**	-0.021	3.446***	-0.216
Composite - Participating	0.68	**	-0.024	5.540***	-0.247
Composite - Collaborating	1.15	***	-0.026	7.181***	-0.262
Obs	44				
Individuals	10				
Collaborators (Higher skills)					
	12-mo effect		s.e.	Constant	s.e.
Using the Restroom	0.72		-0.031	2.114***	-0.271
Modulating Volume	1.18	***	-0.024	3.313***	-0.208
Moving Safely	1.42	***	-0.036	4.221***	-0.316
Referencing	0.97		-0.045	3.626***	-0.399
Engaging	0.37		-0.03	4.054***	-0.263
Communicating	1.05	**	-0.039	4.116***	-0.348
Cooperating	0.89	***	-0.024	4.144***	-0.212
Regulating Emotions	1.42	***	-0.031	4.312***	-0.274
Making Friends	1.34		-0.056	6.798***	-0.493
Composite Score	1.03	***	-0.018	4.083***	-0.158
Composite without Using the	0.97	***	-0.025	4.234***	-0.222
Composite - Attending	0.86	***	-0.019	2.880***	-0.172
Composite - Participating	0.78	**	-0.029	3.906***	-0.260
Composite - Collaborating	1.15	***	-0.026	5.050***	-0.245
Obs	31				
Individuals	9				
*** p<0.01, ** p<0.05					

We observed that children who entered with the highest skill levels showed improvements in their average scores, but at both ends of the spectrum. Interestingly, they made significant improvements in scores for modulating volume and moving safely (1.18, 1.42;  $p < 0.01$ ). In mid-level scores, they also showed average improvement in communicating (1.05,  $p < 0.05$ ). At the upper end, they improved significantly in two of the three scores (0.89 for cooperating; 1.42 for regulating emotion;  $p < 0.01$ ). As might be expected, this group showed significant improvements in all composite scores: overall, 1.03,  $p < 0.01$ ; composite without restroom use, 0.97,  $p < 0.01$ ; attending skills, 0.86,  $p < 0.01$ ; participating skills, 0.78,  $p < 0.05$  and collaborating skills, 1.15,  $p < 0.01$ ).

## **Discussion**

Across groups, we noticed that cooperating and communication were significant only for children who entered with higher-level skills (the collaborators). We might speculate that the program needs modifying so that it helps children who do not already have high skills improve in these areas. In addition, referencing improvements were weak or nonexistent across groups, so program leaders plan to evaluate more closely the processes and assessments used to teach and capture referencing skills. In general, these children came into the program with high average scores for using the restroom; thus we do not find our lack of improvement in using the restroom over time problematic.

In general, our results seem to support the finding by Rao et al (2008) that social skills training programs should differ in their approaches to learning and adaptation of skills relative to cognitive and verbal skills of children with ASD. Certainly our analyses show different patterns when we grouped children by their initial skill levels. And while these early results do not prove program success, they offer an indication that the program helps children with ASD learn skills and behaviors that allow them to successfully navigate and become part of community-based, after-school recreational programs.

### *Limitations*

There are a number of limitations in this work that should be acknowledged. First, observed improvements in friendships, social skills and other skill measures do not prove that children actually are more included or have higher quality of life. We have every reason to believe this is true, but this study does not provide empirical evidence making that connection. Secondly, the program is not a clinical trial, and the “control group” consists only of “typical” behavior based on research and development literature and the behavior of “typical” children at the community-based facilities. In addition, many children in the program had secondary diagnoses that likely affected their ability to learn and adapt behavior. Finally, even though this dataset is a time series of data on each participant (and thereby ensures that the individual level changes are controlled) and ISK leaders made every effort to maximize inter-rater reliability of learning and adaptive behaviors, the possibility of rater bias cannot be ruled out (i.e. the rating changes amongst the population). Nonetheless, the study provides insight into the potential participant level benefits on children who participated in this community-based, inclusion program, illustrating program effects not readily found in the literature.

## **Conclusions**

In this study, we examined the Including Special Kids (ISK) Program, a novel treatment program developing better social skills and inclusion among children ages five through high school with autism spectrum disorders (ASD). This study reports the initial results of program effectiveness.



Using evidence-based indicators, we measured the progress of a population of 30 children over 3-24 months. We captured the effectiveness of multiple aspects of the ISK program across different types of participants. Although attenders, participators and collaborators showed some improvement relative to their entry-level skills, those children who began the program with at least mid-range skill levels tended to show the most improvement. These initial findings support the idea that the methods, measures and evaluation techniques created for the ISK program result in positive outcomes in terms of being included in mainstream, out-of-school activities.

Our study of this community-based inclusion program suggests that ISK had a meaningful effect on the skills ASD children need to be accepted in and to participate with groups of typical children in out-of-school activities. This initial assessment yielded encouraging results for community-based inclusion programs, which merits further, in-depth study. An ideal result from this initial work would be that this program is selected for further rigorous scientific study to empirically prove and document the benefits that this initial study highlights. This would require two main pieces of research. First, the measurement tool that is proposed in this study would need to be fully vetted as a valid measurement tool by documenting its reliability and validity as well as its sensitivity, its interpretability, and its ability to minimize responder (rater) bias. The next step would be to run a clinical trial including a control group in which the participants receive standard care. Since this is a community-based intervention and does not have pharmaceutical backing, the considerable expense of a clinical study would need to be borne by a public agency. In order for a funding source to be found, initial findings and excitement about the possibilities needs to be generated. We hope this study can help lay these foundations.

In a larger sense, we hope that this study encourages other community-based interventions (in ASD or other interest groups) to develop measures to show where and how their interventions provide benefit. Those who operate non-profit community based interventions likely have little or no time to concern themselves with additional measures that would another layer of data and reporting (and probably training, documentation, and analysis) to their already busy schedules. These same program managers witness individual cases of success but often do not have time or know how to set up evidence-based, objective data, which is necessary to convince others of their success. Other community organizations and other funders need to see the potential power of an intervention; the best way to encourage wide adoption is to provide proof of the potential for success.

Finally, although medical journals will not publish the results seen in a community-based intervention, those working in other non-profits and community-based organizations will be an eager and appreciative audience. These individuals merit the ability to assess and judge how well an intervention may work in their community. With sufficient grass-roots experimentation and implementation, the scientific community and potential clinical trial funders can be encouraged and enticed to run the clinical trials to provide conclusive proof of efficacy.

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