

KidStreet



An Outcome Study

Conducted by
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2003

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BACKGROUND

KidStreet is comprised of two community-based licensed centers designed to care for the special needs of children ages six weeks to six years. These children are commonly dependent on medical technology that requires specialized nursing, therapies, and rehabilitative care. KidStreet provides the opportunity for earlier transition of children with complex medical needs out of the hospital setting into the home and community.

A multi-disciplinary team of nurses, occupational therapists, physical therapists and speech therapists work together to enhance the child's physical, psychosocial, and cognitive development. The goal of KidStreet is to maximize each child's potential while at the same time equipping family members with the confidence and knowledge to appropriately care for their child at home. When the child is ready to leave KidStreet, professional staff assist in the transition of child and family to community based services.

Since its establishment, KidStreet staff and families have witnessed numerous developmental miracles among children. Children who were never expected to walk or talk or feed themselves defied the predictions and did it anyway. Much of their progress is attributable to the intensive specialized care provided by the dedicated team of professionals who staff KidStreet.

This study documents outcomes attributable to KidStreet. It includes testimonials from parents who credit their child's progress to KidStreet intervention – parents who claim their children would not have advanced without it. It also includes documentation extracted from KidStreet data-bases that reflect the actual improvements children have made over time.

METHODS

Logic Model

In order to measure KidStreet outcomes, it was important to first conceptualize and understand how KidStreet works. To do this, a logic model was developed with participation and input from all disciplines of KidStreet staff, including management. The logic model lays out program activities in a manner that links them to the ultimate outcomes. In other words, the logic model helps us understand how day-to-day program activities are designed to achieve the program's intended outcomes. Once stated outcomes are revealed, measurement points become obvious.

The ultimate outcome KidStreet wants for its children is an improved quality of life that includes the ability to participate in life and function within their communities in a least restrictive way. Short-term outcomes that lead to the ultimate long- term outcome include things such as kids being able to communicate their needs, kids participating in functional motor play, kids being more self-sufficient, and families being confident in their ability to advocate and care for their children. Activities that lead to these short-term outcomes

include many of the daily interventions performed at KidStreet: structured meal and nap times, occupational and physical therapies, medical care, opportunities for kids to interact with peers, speech therapy, and parent support -- to name a few. The complete KidStreet logic model is included on the following page. Methods used in this study to measure KidStreet outcomes are detailed in the next section.

Data Collection and Analysis

A mixed methods approach that included (1) parent interviews, (2) compilation of existing child acuity data, and (3) interpretation of existing OT, PT, and speech standardized tests was designed to measure KidStreet outcomes:

- (1) Parent* interviews:** The professional evaluator hired for the study developed a nine-question phone interview tool in collaboration with KidStreet professionals. The tool was designed to elicit feedback from parents of children who currently attend or recently attended KidStreet. To be included in the interview the parent's child must have been enrolled in KidStreet for at least six months. Previous enrollees could not have been disenrolled for more than one year. KidStreet management provided a phone list of parents whose children met the criteria. Three professional interviewers, one Spanish-speaking, used the nine-question tool to interview parents over the phone. Parents were initially contacted with a letter from KidStreet to let them know that someone would be calling to interview them. In the letter they were told that their participation is optional and they were guaranteed confidentiality. The promise of confidentiality was reiterated over the phone. Twenty-five parents provided interviews. Only one parent refused. The qualitative data from the interviews was manually coded and categorized. The letter and interview tool are included in the Appendix of this report.
- (2) Compilation of existing acuity data:** Acuity scores were accumulated over the first twelve months of a child's enrollment with Kid Street (for a few children we have less than 12 months data, for some we have more). The twelve-month enrollment period could have occurred during any consecutive twelve-month period between January 1, 2001 and May 15, 2003. Data was available for children of 18 of the 25 parents interviewed in the study. Each child's individual baseline provided the zero point for measuring acuity score deviance. The number of times per month that acuity scores were higher than the child's baseline was plotted above the baseline; the number of times scores went lower than the baseline was plotted below the line. Analysis was performed using an Excel spreadsheet and graphing wizard. See Appendix for data collection forms.
- (3) Interpretation of existing OT, PT, and speech assessments:** Pre and post test scores for the Rosetti Infant Toddler Language Scale, the FRESNO (Functional Recovery Evaluation of Sensory Neurologic Outcomes), the CELF (Clinical Evaluation of Language Fundamentals), and the PDMS (Peabody Developmental Motor Scales) were used to estimate the extent of language, neurological and sensory improvement KidStreet kids achieved over time. Since these standardized tests were developed for typical children, scores for KidStreet children were interpreted and categorized into one of three improvement categories based on empirical evidence shared by KidStreet

* 'Parents' includes biological parents, step-parents, and one custodial grandparent

therapists. Scores for children of 15 of the 25 parents interviewed were available for analysis. Analysis was performed using an Excel spreadsheet and Microsoft Word Tables. Data collection forms are included in the Appendix.

KidStreet

Program Activities		Outputs	Short-Term	Long-Term
Medical Care	<ul style="list-style-type: none"> ▪ Conduct comprehensive nurse assessments ▪ Communicate treatment progress ▪ Administer medications/oxygen therapy ▪ Nourish through tube feedings ▪ Provide anticipatory services ▪ Provide multidisciplinary monthly home visits ▪ Teach kids to help with their own treatments 	<ul style="list-style-type: none"> ▪ Kids' complex medical needs are regularly monitored and addressed by trained medical personnel. ▪ Parents and kids learn to address medical needs at home. 	<p>Kids have fewer hospitalizations, surgeries and ER visits.</p>	<p>Kids are able to participate in life and function within their community in the least restrictive environment.</p> <p>The community receives more exposure to and information about kids with disabilities.</p> <p>Kids have an improved quality of life.</p>
Routine Activities	<ul style="list-style-type: none"> ▪ Provide structured meal and nap times ▪ Arrange developmentally appropriate play ▪ Provide opportunities to interact with peers ▪ Teach kids self-help skills ▪ Expose kids to cognitive concepts and skills 	<ul style="list-style-type: none"> ▪ Kids have a daily structure and consistency. ▪ Kids become more self-reliant. ▪ Kids self-initiate play with peers. ▪ Kids exhibit improved social behavior. ▪ Some kids demonstrate increased cognitive skills or understanding of cognitive concepts. 	<p>Kids communicate their medical, physical, and psychosocial needs.</p> <p>Kids initiate interaction with food.</p>	
Therapies	<ul style="list-style-type: none"> ▪ Provide physical therapy ▪ Provide occupational therapy ▪ Provide speech-language therapy 	<ul style="list-style-type: none"> ▪ Kids learn to explore and interact with their environment through play. ▪ Kids improve gross and fine motor skills. ▪ Kids learn to communicate wants and needs to peers and adults. ▪ Kids improve their ability to process a variety of sensory input. ▪ Kids demonstrate enhanced oral motor skills for feeding, swallowing and speech production. 	<p>Kids participate in improved and functional motor play.</p> <p>Kids are more self-sufficient.</p> <p style="text-align: center;">~*~</p>	
Community/Social Work	<ul style="list-style-type: none"> ▪ Make appropriate referrals to: <ul style="list-style-type: none"> ○ speciality clinics ○ school-based services ○ community services ▪ Help case manage external services ▪ Collaborate with special care clinics ▪ Help schools with IFSP's and IEP's ▪ Advocate for the program in the community 	<ul style="list-style-type: none"> ▪ Kids transition to community-based services in a timely manner. ▪ An enhanced school plan provides a less restricted learning environment. ▪ Kids and their families receive continuity of care. 	<p>Care is family-centered.</p> <p>Families are more confident in their ability to advocate and care for their kids.</p>	
Parent Component	<ul style="list-style-type: none"> ▪ Empower parents to advocate for their kids ▪ Support parents in developing parenting skills ▪ Problem-solve with parents ▪ Hold parents accountable for follow-through 	<p>Parents:</p> <ul style="list-style-type: none"> ▪ develop better parenting skills. ▪ initiate communication regarding their kids. ▪ better understand their kids' needs. ▪ get kids to medical visits more consistently. ▪ secure resources for their children. 	<p>Parents are better equipped to cope with consequences of their child's disability.</p>	

KIDSTREET KIDS

(Note: This section of the report is organized as a series of summary statements highlighted in gray boxes with actual quotes that support the summaries located beneath each gray box. The major theme or category is noted to the left of each gray box and ordered by frequency.)

<p>Why Children Go To KidStreet</p>	<p>Of the 25 parents we interviewed, 23 gave us diagnoses for their children. Severe childhood disorders comprise the list: cerebral palsy, spina bifida, cystic fibrosis, congenital heart defect, failure to thrive, organ transplant and cleft pallet. Because of their disorders children at KidStreet may be on feeding tubes, experience seizures, have paralysis, be immuno-suppressed, be on several medications, be blind or deaf or both. All experience some form of developmental delay as a result.</p>																				
	<table> <tr><td>Congenital Heart Defect</td><td>6</td></tr> <tr><td>Cerebral Palsy</td><td>4</td></tr> <tr><td>Failure to Thrive</td><td>4</td></tr> <tr><td>Spina Bifida</td><td>2</td></tr> <tr><td>Cystic Fibrosis</td><td>2</td></tr> <tr><td>Organ Transplant</td><td>2</td></tr> <tr><td>Pulmonary Disorder</td><td>2</td></tr> <tr><td>Cleft Pallet</td><td>1</td></tr> <tr><td>Unknown</td><td>2</td></tr> </table>				Congenital Heart Defect	6	Cerebral Palsy	4	Failure to Thrive	4	Spina Bifida	2	Cystic Fibrosis	2	Organ Transplant	2	Pulmonary Disorder	2	Cleft Pallet	1	Unknown
Congenital Heart Defect	6																				
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<p>How Long Children Stay KidStreet</p>	<p>Most children who enter KidStreet start enrollment soon after being discharged from an extended hospital stay. Depending on associated birth complications, children may be hospitalized for several months to two years prior to entering KidStreet. Once enrolled the average length of stay is about two and a half years but many children stay three years or more. The average enrollment at KidStreet at any one time is 17 children.</p>																				
	< 12 months	13 to 23 months	24 to 36 months	> 36 months																	
	5%	41%	41%	13%																	

KIDSTREET SERVICES

Services Children Receive at KidStreet

When we asked parents what services their children receive at KidStreet they most often mentioned these three:

- 1) speech therapy
- 2) physical therapy
- 3) occupational therapy

They also frequently mentioned the excellent nursing care their children receive.

Several parents told us that KidStreet professionals taught their children to crawl or walk, prepared them for preschool, helped them learn to interact with other children or simply supported their overall development. Some particularly emphasized various therapeutic interventions KidStreet staff use to encourage oral eating skills.

- *Nurses aggressively monitor his physical symptoms – more aggressively than I would.*
- *They help with everyday things like picking up things, zippers, etc.*
- *[They help with] increasing the quality and quantity of speech.*
- *[They] do food play to encourage him to eat.*
- *He gets sign language instruction.*
- *He receives different types of medications to breathe.*
- *They do school activities like singing, reading, and playing.*
- *[They] help strengthen and coordinate for climbing stairs.*
- *They help with cerebral palsy related muscle tightness.*
- *They're trying to teach him to take baths. He refuses water in any way.*
- *They helped him learn to combat crawl.*
- *They work with cognitive development a lot.*

IMPACT OF KIDSTREET ON KIDS

<p>Overall Profound Improvements</p>	<p>Nearly every parent we spoke to attributed KidStreet with profound improvements in their child. Parents acutely recognize the benefit of the KidStreet experience over what they alone can provide at home. Parents voiced amazement at the unexpected improvements they saw their children make. They witnessed developmental accomplishments far beyond any initial expectations they may have had.</p>
	<ul style="list-style-type: none"> • <i>I'd give my right arm for this kind of care for my child.</i> • <i>He's doing lots of things he wouldn't do if he were at home with me.</i> • <i>[KidStreet is] a blessing.</i> • <i>[I've seen] huge improvements.</i> • <i>He improved so much.</i> • <i>It's so amazing to watch the turnaround.</i> • <i>Her skills are all coming together.</i> • <i>I highly recommend this service for other families.</i> • <i>[There's been] an extreme effect.</i> • <i>It's been a very positive experience – really, really positive. They are a real blessing.</i> • <i>[It's had] a profound effect.</i> • <i>He was behind and they caught him up developmentally. The only area he is behind in is eating.</i> • <i>They were treating her so well with the therapy...they did very well.</i> • <i>She'd be deteriorating if she hadn't gone there.</i> • <i>He's developed so much in eight months there.</i> • <i>The whole experience is positive.</i>
<p>Improvements in Speech and Communi- cation</p>	<p>One of the greatest rewards for KidStreet parents is when their child learns to communicate with them. Many parents who talked with us related remarkable improvements in their child's speech and language skills due to interventions by KidStreet professionals. Even children who are not verbal learn to communicate through sign language.</p> <ul style="list-style-type: none"> • <i>She started talking and her development skyrocketed at KidStreet.</i> • <i>It decreased the need for [an outside] speech therapist.</i> • <i>He's a lot more clear when he talks now.</i> • <i>[She] learned signed language – her communication skills improved.</i> • <i>He may be autistic so he has learned to sign. He's communicating more now than ever.</i> • <i>His communication skills have greatly improved.</i>

IMPACT OF KIDSTREET ON KIDS

- *KidStreet helped her in all areas: motor, speech, sign language, fine motor skills...*
- *He got sign language from nowhere else but there.*
- *She began to sing and speak and count.*
- *He speaks more and has improved greatly.*
- *She makes some noises now and says, 'Mom.' She lets you know when she's hungry.*

Gains in Social Skills

Another area many parents commented on when asked about the impact KidStreet had on their child was social skills. They appreciate the gains their children have made in learning to appropriately interact with their peers. According to some parents, their children have advanced developmentally due to the peer influence of other children – potty training, for example. Children have also overcome stranger anxiety and learned to demonstrate endearing behaviors like giving hugs and blowing kisses.

- *His interaction with other kids has made him more accepting of himself and others.*
- *He interacts with other kids now – at home daycare he didn't.*
- *She has a peer group and friends now.*
- *She has gained from interaction with other kids. She learned from them – like potty training.*
- *He makes more eye contact now than before [he was enrolled at KidStreet].*
- *Now he gives hugs.*
- *He made immediate friends with all of the professionals.*
- *He's picked up behaviors from other kids.*
- *Socially she did fantastic. She overcame her stranger anxiety.*
- *She gives hugs and blows kisses.*
- *He's transitioning to kindergarten.*

Improved Gross Motor Skills and Muscle Strength

Parents reported several incidences of their children's improved command of their physical beings. Included were a wide range of examples from improved head control to standing up alone to riding a bike.

- *He started to roll over and stand up.*
- *He can stand in the 'stander' for 45 minutes now.*

- *He can control his head much better now.*

IMPACT OF KIDSTREET ON KIDS

	<ul style="list-style-type: none"> • <i>Overall muscle control is improved.</i> • <i>She learned how to ride a bike</i> • <i>She could not sit or crawl [when she came to KidStreet]. Suddenly she stood and crawled and sat.</i> • <i>He can [now] get up alone – and he tries to put his shoes on and can dress himself.</i> • <i>I've seen her be able to move and activate switches with her head.</i>
<p>Eating Better Eating More</p>	<p>Nearly half of all the KidStreet parents we spoke to mentioned improvements in their child's eating behaviors. For some kids the success was in getting food up to their mouths. For others it meant further weaning off the feeding tube or simply an increase in the variety of foods taken.</p> <ul style="list-style-type: none"> • <i>He's eating better and throwing up less. He eats like any other three year old now and less through the tube.</i> • <i>Her eating has improved. She will eat at KidStreet and tries hard and eats different things.</i> • <i>He now touches food to his lips.</i> • <i>He has had many gains in eating since transferring to the KidStreet YMCA.</i> • <i>He's eating much more by mouth.</i> • <i>He still has problems eating but now is much more independent.</i> • <i>Before he did not want water, food, or any flavors. Now he is more normal.</i>
<p>Fewer Illnesses Fewer Hospitalizations</p>	<p>Between one-third and one-half of parent interviewees told us they believed their children experienced fewer sick and hospital days due to the interventions they receive at KidStreet. Because KidStreet nurses are skilled in detecting subtle changes and vigilant in conducting twice daily assessments, they are able to detect subtle problems before they become bigger problems. Kids avoid an office visit or possibly even a hospitalization because of their acute skills.</p> <ul style="list-style-type: none"> • <i>The daily assessment is so beneficial. They know when it is a typical cold and when it is much more.</i> • <i>She is healthier. They spot problems sooner.</i> • <i>They know he is sick before I do. It really helps keep him healthy.</i>

- *They find illnesses before I am aware – like a new medication that was elevating his heart rate.*

IMPACT OF KIDSTREET ON KIDS

- *He's in the hospital less because the nurses are so vigilant about his care.*
- *They picked up illnesses quickly and protected her by not allowing sick children around her.*
- *She's hospitalized less. They also helped me learn about tapping and doing percussions.*
- *Nurses at KidStreet are very aggressive about his medical care. They pay attention to all of his symptoms.*
- *The nurse there even diagnosed large adenoids.*
- *They taught him to know when a breathing treatment is necessary and to tell the teacher.*

More Self Confidence

Some parents noticed the increased self-confidence their child achieved as a result of participating in KidStreet.

- *He's more confident and self-assured.*
- *They helped her with confidence in general. It led to her walking and doing better in general.*
- *He takes the initiative more. He does things more on purpose than by accident.*
- *He sees the professionals as his extended family. It gives him security.*

Learning to Walk

About a third of the parents interviewed attributed their child's learning to walk to KidStreet intervention. For two little boys the motivation was to be able to walk like their other friends at Kid Street. One boy is learning to walk without braces.

- *He's working on walking with no braces.*
- *He has started to walk. He saw other kids doing it and wanted to walk just like them.*
- *They got him a Gait Trainer. He wouldn't be walking without it.*
- *He couldn't stand up when he started – now he's walking.*
- *He's walking now. He decided on his own to learn because his friends were walking.*

IMPACT OF KIDSTREET ON KIDS

<p>Greater Tolerance for External Stimuli</p>	<p>Some parents whose children have an aversion to outside stimuli noticed an increased tolerance to light and noise since being enrolled at KidStreet.</p> <ul style="list-style-type: none"> • <i>Her tolerance level for any situation is 100% better.</i> • <i>Now we can take her anywhere. She used to startle terribly at new situations.</i> • <i>They expose her to so much that she tolerates things better.</i> • <i>He's starting to desensitize to noises, lights, and other stimuli.</i> • <i>He's learning how to manage himself and calm himself.</i> • <i>She's into lots of lights and music and vibrations [now].</i>
<p>Stability Normalcy</p>	<p>KidStreet provides stability for children, particularly those in foster care. Parents feel it creates an environment where children with special needs can feel a sense of normalcy.</p> <ul style="list-style-type: none"> • <i>He's been in many homes but they (KidStreet professionals) are a constant.</i> • <i>The stability was critical to her continued growth while she was switched around in foster care.</i> • <i>If she were at home she would be more isolated with no daily structure.</i> • <i>It gave him a perspective that he was normal.</i> • <i>He developed a sense of normalcy.</i>
<p>Lack of Improvement</p>	<p>Two of the 25 parents interviewed commented on their child's lack of improvement while at KidStreet.</p> <ul style="list-style-type: none"> • <i>He was sick a lot and caught a lot of bugs from the other kids.</i> • <i>None of his OT or PT goals were met.</i> • <i>He regressed in eating when he was paired with a child who ate less.</i>

IMPACT OF KIDSTREET ON PARENTS

Parents
More
Informed
and Aware

When parents were asked about the help they receive from KidStreet, the most frequent answer given was that they (parents), feel more informed about their child's condition and therefore better able to participate in his or her care. Parents feel comfortable asking questions of KidStreet nurses and therapists and like the regular reports their kids bring home. Because of the rich communication stream provided by KidStreet professionals, parents feel a sense a partnership in making important decisions about their child's plan of care.

- *I couldn't have done it without them. The daily assessments were wonderful even when she wasn't scheduled to be there – I would run her in before the weekends.*
- *I call them whenever I have a concern.*
- *I communicate a lot with [KidStreet] professionals. They show me how he's doing and what he likes to play with.*
- *We collaborate. They (KidStreet professionals) tell me what they see; I let them know what's going on at home and we make changes together for what's best for him.*
- *I can get their impression when I have conflicting information.*
- *They keep me in touch with what they are doing.*
- *They sent progress reports daily telling us what he is doing and how to continue at home.*
- *I felt more prepared and aware as a parent. They (KidStreet professionals) were informative.*
- *I like the reports they (KidStreet professionals) send home regularly.*
- *They're (KidStreet professionals) good about returning calls.*
- *They (KidStreet professionals) answered our questions and helped us set up home therapy.*
- *They (KidStreet professionals) helped explain what was causing the eating problems so I understood better.*

IMPACT OF KIDSTREET ON PARENTS

<p>Parents Know How to Better Care For Child At Home</p>	<p>Parents told us they learn many things from KidStreet nurses and therapists that help them better care for their child at home. Not only do they learn how to identify signs of impending illness, provide breathing treatments and insert feeding tubes, but they also learn how to parent their child, play with him/her, feed him/her, and understand when to let go of being overly concerned.</p>
<p>Increased Parent Confidence</p>	<ul style="list-style-type: none"> • <i>[KidStreet professionals] give me tips on what to do at home to help him.</i> • <i>OT and PT [therapists] are clear and concise about how to carry out treatments at home.</i> • <i>They [KidStreet professionals] give me ideas about what toys he likes and activities he likes to do.</i> • <i>They[KidStreet professionals] taught me not to protect her too much.</i> • <i>I learned CPR, breathing treatments and inserting a G-tube.</i> • <i>They[KidStreet professionals] helped me know when to keep him home and how to care for him.</i> • <i>[KidStreet professionals] taught me parenting skills.</i> • <i>[KidStreet professionals} taught me how to play with my child.</i> • <i>I have gone to conferences at KidStreet and they say what he would be able to do and I make notes.</i> • <i>They [KidStreet professionals] let me know what to do here in the house.</i> • <i>They[KidStreet professionals] taught me how he likes to be treated and what he doesn't like and how to know when he is ill.</i> • <i>They[KidStreet professionals] taught me how she likes to sleep on a platform with her head down.</i> • <i>I know better how to help him eat now.</i> • <i>They gave me pointers on feeding, structuring his schedule for feeding and being consistent.</i> <p>Several KidStreet parents feel supported by the professionals who care for their children. Parents say they have developed confidence in their own ability to care for their children through the encouragement and support provided by KidStreet nurses and therapists. One mother said she worries less; another is more at ease with why her daughter entered the world.</p>

- *KidStreet professionals were a huge emotional support for me and my husband. They gave us suggestions on how to handle her behavior problems.*

IMPACT OF KIDSTREET ON PARENTS

- *When I have questions they [KidStreet professionals] reduced my worry, answered my questions.*
- *I feel more confident and more comfortable -- more at ease with my daughter entering world.*
- *They [KidStreet professionals] gave me confidence that I've done a good job of getting son where he is. I feel good.*
- *I feel much more adequate feeding him too. It was a battle before to even get him to eat one bite.*
- *I feel much more confident and comfortable.*
- *I have increased self- esteem.*
- *They [KidStreet professionals] give me lots of encouragement.*

Parents Have An Advocate

A few parents related stories about the advocacy work that a KidStreet professional had done on their behalf in medical and school settings.

- *They helped me understand how the medical process works.*
- *I got all types of information for when I go to the hospital – what a virus is, different types of nebulizers, etc.*
- *They [KidStreet professionals] arranged an ISP meeting and connected me with people to transition to the school.*
- *They [KidStreet professionals] helped us do paperwork at the hospital – it's hard because English is our second language.*
- *She [KidStreet professionals] spent time with me and came out to the home and helped me.*

No Help To Parents

Although the overwhelming majority of parents we spoke with had nothing but praise for KidStreet, two disgruntled parents shared negative remarks. One felt she received no assistance in transitioning her child from KidStreet to the outside world. Another felt judged and deceived when KidStreet professionals called Social Services regarding her child's situation.

- *They dumped my child out of the program and didn't help me find services outside.*
- *They made it more stressful for me. They assumed a lot and accused me of over-feeding her.*
- *They didn't understand her syndrome and blamed us for her problems.*

They got nosier and pried and called Social Services.

HOW KIDSTREET HELPS PARENTS EXTEND CARE TO THE HOME

Feeding Children At Home

Parents find particularly helpful the strategies that KidStreet nurses and therapists recommend to encourage children to eat. Making sure their child gets enough nutrients as they learn to eat regular foods can challenge parents of special needs children. Kid Street professionals help parents transition children to self-feeding behaviors when appropriate and find foods that are agreeable to child and parent.

- *They [KidStreet professionals] helped with transitioning off the bottle to the Sippy cup.*
- *They [KidStreet professionals] helped get him to eat at the table with us.*
- *The nurse came and showed us how to be consistent with feedings, scheduling, and structuring feedings.*
- *She showed us how to feed the proper amount to compensate for tube feedings.*
- *They [KidStreet professionals] really helped transition him to more oral feedings and make eating normal.*
- *The speech therapist at KidStreet taught me how to feed him.*
- *I had to change foods a little but they help me know what to feed in general.*
- *We are Asian and food is different but they helped me know what to substitute to give some vitamins.*
- *They [KidStreet professionals] think of things to help feed her when she gets an ear infection.*
- *We were afraid to let him do things at first and try certain foods. We learned more about what he is capable of and how to feed him.*
- *They [KidStreet professionals] gave me info about how to let him try the flavor of foods.*

Helping Children Learn At Home

Several parents told us they take home the strategies they learn from KidStreet therapists in order to extend their child's learning benefit beyond KidStreet. Parents use play therapies they learned from OT and PT staff as well as other interventions they observe therapists using during their child's circle time.

- *I learn about what's done in circle time so I can do it at home.*
- *I learn about how to carry out and continue OT and PT therapies at*

home.

HOW KIDSTREET HELPS PARENTS EXTEND CARE TO THE HOME

- *I can observe new skills in her and I adjust how I care for her because of the new skills.*
- *Progress reports on daily activities allow us to incorporate these activities at home.*
- *I can reinforce her learning with activities at home.*
- *I know what to play on weekends to help with OT and speech.*
- *They [KidStreet professionals] keep me updated on a weekly basis of what he's playing with -- what I should buy for him.*
- *Now I know more of what to do in the house.*
- *They [KidStreet professionals] taught me how he should sit in a "W" instead of crisscross – this is good for CF kids.*

Provide Therapy And Treatments At Home

Many times parents are required to perform treatments and therapies at home. KidStreet nurses and therapists teach parents the skills necessary to extend this care to the home.

- *OT taught me how to put pressure on his skin, but not restrain him. He likes to have pressure put on different parts of his body – it's his kind of hug.*
- *They [KidStreet professionals] taught me CPR.*
- *They [KidStreet therapists] recommended how to do his O2 therapy.*
- *They [KidStreet professionals] helped me learn how to do percussion tapping therapy.*
- *Mostly they [KidStreet professionals] taught me how to take care of her, how to do stretching and different positions.*
- *They [KidStreet professionals] provide suggestions on treatments, and ways to get him to be still during treatments when he needs to limit his movement for a while.*

Respite For Parents

Some parents said they appreciate the respite KidStreet gives them to restore their own energy or care for other siblings.

- *I am more prepared when she gets home.*
- *Her being at KidStreet gives me more time with my older daughter.*

HOW KIDSTREET HELPS PARENTS EXTEND CARE TO THE HOME

No Change	<p>A few parents felt they were already skilled in caring for their children at home and did not benefit further from anything they learned from Kid Street professionals.</p>
	<ul style="list-style-type: none">• <i>I'm not doing anything different [because of KidStreet].</i>• <i>I had to figure out things by myself. No one communicated with me after Cheryl left. I learned what to do to help him.</i>• <i>It [KidStreet] didn't change how we help her, feed her, or tend to her needs.</i>• <i>It [KidStreet] didn't help me make changes. I knew this was my problem and I have to do it</i>• <i>I mostly know what he needed at home so not too many other changes.</i>

REFERRALS BY KIDSTREET

<p>Transition to Public School</p>	<p>Several parents found the assistance that Kid Street professionals provide in linking families to the school system and ultimately helping them with the transition from Kid Street to public school particularly beneficial. It is the primary referral benefit parents mentioned.</p>
	<ul style="list-style-type: none"> • <i>They [KidStreet professionals] talked to me about school assessment – they're proactive for educational growth.</i> • <i>They [KidStreet professionals] helped us get an IEP for Kindergarten and helped with the transition.</i> • <i>They [KidStreet professionals] helped get our child into public school and helped with the transition.</i> • <i>The Kid Street social worker contacted the new school and talked to the nurse there to help inform her about our child.</i> • <i>She [KidStreet social worker] helped me do my child's IEP through Child Find.</i> • <i>They [KidStreet professionals] are helping us get ready for transition to school.</i>
<p>Necessary Medical Services</p>	<p>Nurses at Kid Street refer parents to various specialty clinics and referral services associated with Children's hospital.</p>
	<ul style="list-style-type: none"> • <i>They [KidStreet professionals] referred us to a specialty clinic at Children's Hospital.</i> • <i>They [KidStreet professionals] tried to help her get psychological counseling.</i> • <i>They [KidStreet professionals] helped us find medical services.</i> • <i>The nurse referred us to two different endocrinologists about growth hormone injections.</i> • <i>They [KidStreet professionals] helped with the paperwork and with services at Children's Hospital.</i> • <i>They [KidStreet professionals] helped us get speech therapy through Children's Hospital.</i> • <i>I got referred to different nursing staff for answers to my questions.</i>

REFERRALS BY KIDSTREET

<p>Medical Resources</p>	<p>Through Kid Street, parents are linked with resources (Kid Carts, shoes, chairs) that help their child compensate for his/her disability.</p>
	<ul style="list-style-type: none"> • <i>They referred me to AAA Medical Supply to get a ‘Kid Cart’ for him.</i> • <i>KidStreet has some resources they can pull from –they hooked our child up with a chair he can sit in that can be moved from room to room. Then they got funding to pay for it.</i> • <i>They [KidStreet professionals] helped us get shoe lifts for her feet.</i> • <i>They [KidStreet professionals] got a Gait Trainer for him to walk.</i>
<p>Transportation</p>	<p>A few parents said they benefited by the transportation referrals to Medicaid and KidsWheels made by KidStreet.</p>
	<ul style="list-style-type: none"> • <i>They [KidStreet professionals] helped find some transportation.</i> • <i>They [KidStreet professionals] told us about the Medicaid Mileage program – we get reimbursement for mileage [to medical appointments].</i> • <i>We got transportation – KidsWheels.</i>
<p>Other Referral Sources</p>	<p>One parent said that KidStreet social workers work continually to find additional services but she often falls through the eligibility cracks. Several parents were referred to Developmental Pathways. Others spoke of referrals to DDRC, IFSP, and Metro Community Services.</p>
	<ul style="list-style-type: none"> • <i>Developmental Pathways</i> • <i>DDRC – They track him there.</i> • <i>IFSP – an organization to make plans for your child.</i> • <i>They gave me referrals to other places we might go to after KidStreet.</i> • <i>North Metro Community Services. They help with developmental planning.</i> • <i>I got gift certificates to get groceries.</i> • <i>KidStreet social workers work continually to find services such as respite care, financial services and free things. But I always seem to fall through the cracks and don’t qualify.</i>

IF NOT FOR KIDSTREET

<p>Significant Child Delays</p>	<p>When parents were asked where their child would go during the day if KidStreet were not available to them, most chose instead to talk about the delays they feared their child would realize without KidStreet. Many parents felt their child would not be walking or talking or communicating without Kid Street. One mother wondered if her daughter would even be alive without KidStreet.</p> <ul style="list-style-type: none"> • <i>My son would not be doing well without KS. He would be about two [years old] developmentally and would not be thriving.</i> • <i>I couldn't understand the importance of meds. Without KidStreet he would be sick more often.</i> • <i>I have no other children at home so he would be behind with no other kids at home [to imitate].</i> • <i>She wouldn't be eating if she hadn't gone to KidStreet.</i> • <i>He wouldn't be walking or crawling – he'd be behind physically too. He has better kid interaction too.</i> • <i>If not at KidStreet, she would probably not be as far along developmentally (18 mo now, probably 12 mo w/o).</i> • <i>He would be way behind without KidStreet. His motor skills and social skills would not be as advanced.</i> • <i>She wouldn't be as social, wouldn't be talking or walking, or as well off developmentally.</i> • <i>She would probably be halfway where she is now. The biggest improvement is socially – she's not as fearful.</i> • <i>If not for KidStreet, she'd not be walking, she'd be deteriorating and not communicating. Maybe she wouldn't even be alive.</i> • <i>I think he'd be behind without KidStreet. The constant therapy has made a difference.</i> • <i>If there were no KidStreet, physically she wouldn't be as far ahead as she is; mentally she's pretty bright.</i> • <i>Without KidStreet he wouldn't be walking. Right now he's only two months behind. He's doing really well.</i> • <i>I don't think he'd be so advanced and it would be difficult for me to help him. With so much disability he wouldn't get so much attention elsewhere.</i>
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IF NOT FOR KIDSTREET

<p>Home Or Family Daycare</p>	<p>Most parents acknowledge that if their child were not at Kid Street he/she would probably be in a home or family daycare situation. Except for one parent who felt her child did better at home because of less exposure to infection from other children, others knew their child would be less advanced staying at home.</p>
<p>Nowhere Else To Go</p>	<p>Many parents felt that there really are no other options but KidStreet.</p>
<p>Public Preschool</p>	<p>A few parents are aware of preschool programs available to their children – one at Fitzsimmons, others at Arvada West and Fletcher-Miller preschools. Other parents have not yet researched potential options but wonder if there are preschool programs available for their children. One mother tried placing her daughter in preschool but she was not able to stay due to her deficient immune system.</p>

- *If not for KidStreet, he would have gotten daycare from my mom but he wouldn't have gotten the child interaction and encouragement.*
- *Couldn't have found day care. He might have had to stay with grandma.*
- *If no KidStreet, he'd be at home all day and he'd be less advanced.*
- *He'd be at home without KidStreet.*
- *Would be at home if not at KidStreet.*
- *He would be home with me.*
- *He would be in the house.*
- *He has in home day care now and gets sick less than at KidStreet.*

- *There's nowhere else available here. I would have moved back to Massachusetts.*
- *There's no other place to go. He has Medicaid but we don't have another place to take him.*
- *It's impossible to find a place that does all that KidStreet does for him. It doesn't exist.*
- *There's nothing available until preschool. We couldn't afford it if there was something.*
- *There's nowhere to go without KidStreet.*
- *There isn't any other service available to her.*

- *Maybe there's a public school early childhood program but I don't really know about this.*
- *I would try to put her in preschool full time.*

IF NOT FOR KIDSTREET

- *I tried Arvada West last year, but her immune system is too weak.*
- *If there were no KidStreet he would go to Fletcher-Miller preschool. Or we'd move to Denver to get more services.*
- *If she weren't going to KidStreet I suppose she would get more days at preschool.*
- *She is at Fitzsimmons now two days per week. They do PT, OT, feeding*
- *If there were no KidStreet, maybe I could find a special-ed preschool. But maybe there is no such thing here.*

Parent Impacts

Some parents talked about how their lives would be impacted if their child were not enrolled in KidStreet. Some would not be able to work. Others would not be able to pursue educational goals.

- *If there were no KidStreet, we would not know what to do. We can work while they take care of her.*
- *KidStreet gives me time away from my son so I can continue my education.*
- *I'd have to study at night and pay for care. This really makes a difference in my life.*
- *I was really stressed and physically worn out without KidStreet. We've both come a long way.*
- *We would be at daycare, but I wouldn't be going to college.*
- *I would have had to quit my job.*

INFORMATION AND SUPPORT BEYOND KIDSTREET

<p>No One Else To Turn To</p>	<p>Several KidStreet moms are single parents who have no one else to turn to for support with their child. Occasionally another family member (aunt, mother, brother) provides some respite but the main responsibility lies with them. Consequently their dependency on KidStreet is significant.</p>
	<ul style="list-style-type: none"> • <i>KidStreet is my biggest support.</i> • <i>There's nobody else to turn to.</i> • <i>My husband is a long haul driver, so I can't even turn to him much.</i> • <i>My child's dad came back into the picture recently and he is somewhat supportive but not really to me.</i> • <i>There's no one else - I don't get advice from anyone but my husband.</i> • <i>We just depend on KidStreet and each other.</i> • <i>My brother occasionally [helps] but we really do it on our own.</i> • <i>No one else is available.</i> • <i>Mostly I do it by myself.</i> • <i>I am in charge of everything. I am very careful with her. I cannot leave her with others.</i> • <i>My aunt can feed him and other things but it's mostly just me.</i> • <i>Once in a while, I get a phone call from my mom.</i> • <i>No one else is there; only KidStreet and the hospital.</i>
<p>Family Members and Friends</p>	<p>Some parents receive support and advice from family or friends. A couple of parents consult with a friend or family member who also happens to be a nurse.</p>
	<ul style="list-style-type: none"> • <i>My step-mom is a nurse with the WIC program. I talk to her and go the WIC clinic to see dietician.</i> • <i>My parents support me.</i> • <i>My mom gives general advice.</i> • <i>My extended family helps.</i> • <i>I have lots of relatives who help a lot.</i> • <i>Dad and Grandpa give support - it's a very small circle.</i> • <i>I get lots of support at home.</i> • <i>Sometimes I ask for help from a friend who is a nurse.</i> • <i>Friends lend support.</i>

INFORMATION AND SUPPORT BEYOND KIDSTREET

<p>Doctor or Nurse Practitioner</p>	<p>Parents receive advice on caring for their child from the doctors (pediatricians, family practice doctors, specialists) and nurse practitioners who see their child on a regular basis.</p> <ul style="list-style-type: none"> • <i>The nurse practitioner at the Special Care Clinic at Children's hospital was very helpful.</i> • <i>I go to the doctors/nurses at Children's for medical advice.</i> • <i>Our primary care doctor that we see occasionally gives us medical advice.</i> • <i>We have several doctors - pediatrician and specialists.</i> • <i>Our child's doctor helps give us advice.</i> • <i>The doctors at hospital support us.</i>
<p>Social Worker</p>	<p>KidStreet parents sometimes realize the support of social workers.</p> <ul style="list-style-type: none"> • <i>The social worker at DHS was helpful because of the foster system.</i> • <i>The social worker at Children's and all the people at Children's [provide support].</i> • <i>The social worker at Children's referred us to KidStreet.</i> • <i>Adams County Social Services helps us also.</i> • <i>A social worker visited once a month but they don't know the evolution of these types of conditions.</i>
<p>Church</p>	<p>A few parents turn to their church or faith for support.</p> <ul style="list-style-type: none"> • <i>My church sometimes helps a little bit but they are afraid they will do the wrong thing.</i> • <i>Friends from church give us spiritual support through this.</i> • <i>[I get support] from God and my faith.</i> • <i>At our church- several members have been trained to care for our son.</i>

INFORMATION AND SUPPORT BEYOND KIDSTREET

Other	<p>Other sources of support and information for parents include other KidStreet parents, Developmental Pathways, Denver Options, North Metro, DDRC, and the Internet.</p> <ul style="list-style-type: none">• <i>The other parents at KidStreet were very helpful and informative – gave advice and referrals.</i>• <i>Developmental Pathways keeps me informed. I got some respite care and money for it through them.</i>• <i>The social worker at Developmental Pathways tells us about other resources, e.g., they found us money to build ramp and also helped find respite care</i>• <i>I'm on the board of Jeffco First Step.</i>• <i>Someone from Denver Options comes to help me about twice per month.</i>• <i>I search the Internet to get understanding.</i>• <i>North Metro helps - they help us with funding and keeping Medicaid</i>• <i>DDRC helps us.</i>
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PARENT COMFORT IN ASKING FOR HELP

<p>Very Comfortable With KidStreet</p>	<p>Nearly every parent we talked to told us they were ultimately comfortable in communicating their child’s needs as well as their own needs to KidStreet professionals. They find staff at KidStreet to be very approachable and knowledgeable.</p> <ul style="list-style-type: none"> • <i>I have no hesitation. I ask questions and I always get answers. KidStreet is very approachable.</i> • <i>I’m very comfortable with KidStreet. I ask for second opinions and details. They let me know what other parents and kids are going through -- no communication problems.</i> • <i>I ask questions of KidStreet all the time and ask for help all the time. They also call us to offer help</i> • <i>I’m very comfortable - half the time they suggest things before I have to ask.</i> • <i>We communicate with KidStreet easily and them with us about our child's well being.</i> • <i>I haven't felt uncomfortable at all in asking for services from KidStreet. They are very approachable.</i> • <i>KidStreet is always available to answer questions. They even call home with information for us.</i> • <i>Communication with KidStreet is good both ways</i> • <i>KidStreet is very helpful and tries to help us understand and be informed on what's going on.</i> • <i>I took my child every day and every day I talked to them [KidStreet professionals].</i> • <i>I always asked questions and felt comfortable asking. No one has ever looked down on me at KidStreet.</i> • <i>When we have questions the door is always open to come in and ask.</i> • <i>When he is ill, I let them know and I am comfortable.</i>
<p>Always Been Assertive</p>	<p>Some KidStreet moms see themselves as generally assertive. They do what they have to get what they need for their child.</p> <ul style="list-style-type: none"> • <i>If I don't know, I ask. I get what I need for my child.</i> • <i>I’m comfortable asking my child's doctor questions as well.</i> • <i>I’m totally comfortable. I’ve always been this way. I’m a pretty empowered mom.</i> • <i>I learned I just need to keep pushing for what I want. I read all the research and talk to doctors about doing things my way. If I don't know</i>

| *something I look for information.*

PARENT COMFORT IN ASKING FOR HELP

- *I have no problem asking for what we need. Sometimes I just get tired from all the phone calls and paperwork.*
- *Denver Options has so many resources. They gave me a list of services. I call from the list*
- *If he needs it, IT WILL BE DONE! I ask who to talk to and bug everyone to get details.*

Hard To Ask For help

A few individuals find it hard to ask for help. One mom said she is so worn out after caring for her child that it's hard to be pro-active with the little energy she has left. Another parent was intimidated by a doctor at the Cystic Fibrosis Center. One mother does not go to anyone else but KidStreet with questions.

- *The CF doctor at the CF Center was very domineering and I couldn't ask him questions comfortably.*
- *It impacts my self-esteem to have a child like this that requires so much of my attention. There's nothing left for me. Sometimes it makes it hard to be pro-active when I don't have energy.*
- *I don't talk to anyone much. I was comfortable with the old social worker at KidStreet but when they began assuming so much, I stopped talking to her too.*
- *I wouldn't go to anyone else other than KidStreet to ask anything. I trust KidStreet like family.*

WHAT ELSE COULD KIDSTREET DO FOR KIDS AND THEIR PARENTS

Nothing	<p>Nearly all of the 25 parents we spoke to deny that there's anything else KidStreet could be doing that they're not doing already. Many took this opportunity to share their gratitude and appreciation for the services their children receive. There is great appreciation among parents for the loving and dedicated way the professional staff at KidStreet care for their children.</p> <ul style="list-style-type: none"> • <i>It's amazing – they're just fabulous at KidStreet.</i> • <i>Nothing else -- they were tremendous.</i> • <i>They are like family to us. Our child has been there longer than anyone else.</i> • <i>They helped my daughter for three years. We appreciate everything they did.</i> • <i>At this point they are doing everything they can. They have always done a great job.</i> • <i>They take care of a lot.</i> • <i>They're doing a good job already -- don't need anything else right now. They're so great there.</i> • <i>I am so glad it's there. It gives me six hours of free time to get things done.</i> • <i>I can't think of anything else. They have my praise and my thanks for sure.</i> • <i>My grandson (interview with involved grandmother) is doing very well because of them.</i> • <i>I'm thankful they have been there. If they weren't, we wouldn't be where we are today.</i> • <i>It is a good place and is a pleasure to be with the program.</i> • <i>I think it is a complete, full, rich program. They are helping him do many things. They give to education 100 percent and I think it is a very good program.</i> • <i>I hope that this program continues to help children who need care for eight hours a day. It is an opportunity to attend a place that specializes in disabled children.</i> • <i>The good thing is that when he is ill they miss me and they miss him.</i> • <i>They kept my wishes as far as her dad being in town and my preferences about who could or couldn't see her.</i> • <i>They always write what she did during the day.</i> • <i>KidStreet people have even checked on our child while she's been in hospital the past few weeks.</i>
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WHAT ELSE COULD KIDSTREET DO FOR KIDS AND THEIR PARENTS

<p>Listen To Parents</p>	<p>Two parents felt that KidStreet professional staff do not value how much they as parents know about their own child.</p> <ul style="list-style-type: none"> • <i>Maybe they could have a little more understanding about how parents know their children.</i> • <i>They question me when I keep my child home sick, but I know better than them.</i> • <i>He has so much potential -- they're not pushing him. I want him to go to YMCA.</i> • <i>I see different things at home -- he drinks water. They won't color with him.</i>
<p>Other</p>	<p>Although most parents are pleased and grateful with existing KidStreet services, when pressed to share additional services they might want, several made suggestions. They include:</p> <ul style="list-style-type: none"> ~ Continue help through kindergarten transition ~ Keep in touch after child leaves KidStreet ~ Have a parent support group ~ Organize more social events for KidStreet families ~ Improve the physical facility ~ Have a live person answer the phone at YMCA ~ Have a consistent social worker ~ Ensure all staff are familiar with all kids ~ Extend the enrollment age to seven years old ~ Help with transportation problems ~ Be more informed about community services ~ Improve communication within and without <ul style="list-style-type: none"> • <i>They could continue to help with transitioning to kindergarten.</i> • <i>I wish they would call me more often! I miss them now that we are gone! I used to keep in contact with them but I think to help transitioning to schools they keep contact to a minimum.</i> • <i>We need a parent support group, or at least a "questions frequently asked" information sheet.</i> • <i>Have more special events like the trip to Elitches so kids can feel special and parents can meet other parents.</i> • <i>Their aesthetics bothered me from the outset. They have tile floors and indoor/outdoor carpet. They need a nicer setting and more supplies</i>

| (only have one foam chair, and one Gait trainer).

WHAT ELSE COULD KIDSTREET DO FOR KIDS AND THEIR PARENTS

- *I would like to have more space for the nurses to work in and more lockers for kids to keep clothes and food.*
- *The only thing I don't like about KidStreet is that I always need to leave a message. When your child is somewhere else you want to talk to the person caring for him live. It would be nice if someone could pick up the phone (YMCA)*
- *It would be helpful to have had a consistent social worker. Maybe my child could have received mental health counseling if so.*
- *Staff should all be familiar with all kids so if a staff member leaves, other's can still be comfortable caring for any child.*
- *I wish there was a program beyond the age of four. I don't trust the public school. I wish he could stay until age six or seven.*
- *Nothing, other than extending the age kids are accepted there. I know their goal is to get kids transitioned into school, but I would prefer to leave my child there since she is extremely medically involved.*
- *Get transportation problems straightened out for us.*
- *With some of the transportation companies I have had trouble. They would arrive late and not let me know.*
- *Be more informed about community services so appropriate referrals can be made.*
- *Communication is really a primary thing. Let parents know what is going on – it has an effect on child.*
- *I would like to see them communicate with each other better. Nurses and therapists are not coordinated internally. I get mixed messages because they don't communicate with each other.*

ACUITY SCORES – Documented Improvement

Acuity Scores Defined

Every morning and afternoon KidStreet nurses conduct physical assessments on each child. Their assessment is based on the nursing standards of care at The Children’s Hospital in Denver and reflects the child’s medical status compared to his/her baseline and established pediatric norms. Upon completing the assessment, nurses distill their findings into one number called an acuity score. Nurses use acuity scores to determine when a child may need more acute care or observation, or possible outside medical intervention. The score is also helpful for discerning the sometimes-indiscernible improvements children make over time.

In an effort to objectively document the improvement parents see in their children, acuity scores were accumulated over the first twelve months of a child’s enrollment with Kid Street (for a few children we have less than 12 months data, for some we have more). The twelve-month enrollment period could have occurred during any consecutive twelve-month period between January 1, 2001 and May 15, 2003. Data was available for children of 18 of the 25 parents interviewed in this study.

The higher the acuity score the sicker or more compromised the child. The scale ranges from 1.0 to 3.5 and is recorded in increments of 0.5. Acuity scores for most KidStreet children range from 2.0 to 3.0. Each child, depending on the complexity and severity of his/her disabilities, has a baseline score that indicates a stable condition for that child. The most severely compromised children have the highest baselines. As children improve over time their acuity scores level off or fall below their baseline more frequently.

How Acuity Scores Were Plotted For This Study

For the 18 children included in this component of the study, all acuity scores recorded in their first twelve months of enrollment were plotted on a twelve-month timeline. Their individual baseline provided the zero point for acuity score deviance. The number of times per month acuity scores were higher than the child’s baseline was plotted above the baseline; the number of times scores went lower than the baseline was plotted below the line. These deviations above and below individual child baselines were plotted using Excel vertical bar graphs.

To more easily discern trends in acuity data over time, quarterly net acuity values (accumulated scores above the baseline minus accumulated scores below the baseline) were plotted using Excel line graphs. The line graphs revealed five different trends in acuity score improvement over time: (1) **Most Improvement**; (2) **Substantial Improvement**; (3) **Moderate Improvement**; (4) **Stable Acuity**; and (5) **Erratic Acuity**. Acuity trend graphs for the 18 children included in this component of the study are grouped by these five categories and displayed on the following pages. Only their discrete study numbers identify individual children on the graphs.

Acuity Score Trends

The overall trend depicted by the quarterly graphs is one in which acuity scores spike above the child’s individual baseline several times in the first quarter of enrollment then, either level off (scores at or near baseline) over time, or start appearing below the child’s baseline as more improvement occurs. This trend indicates that most children enter KidStreet in a compromised condition, but, over time with the intense vigilance, treatment and therapies provided by KidStreet, kids improve as reflected in their acuity scores.

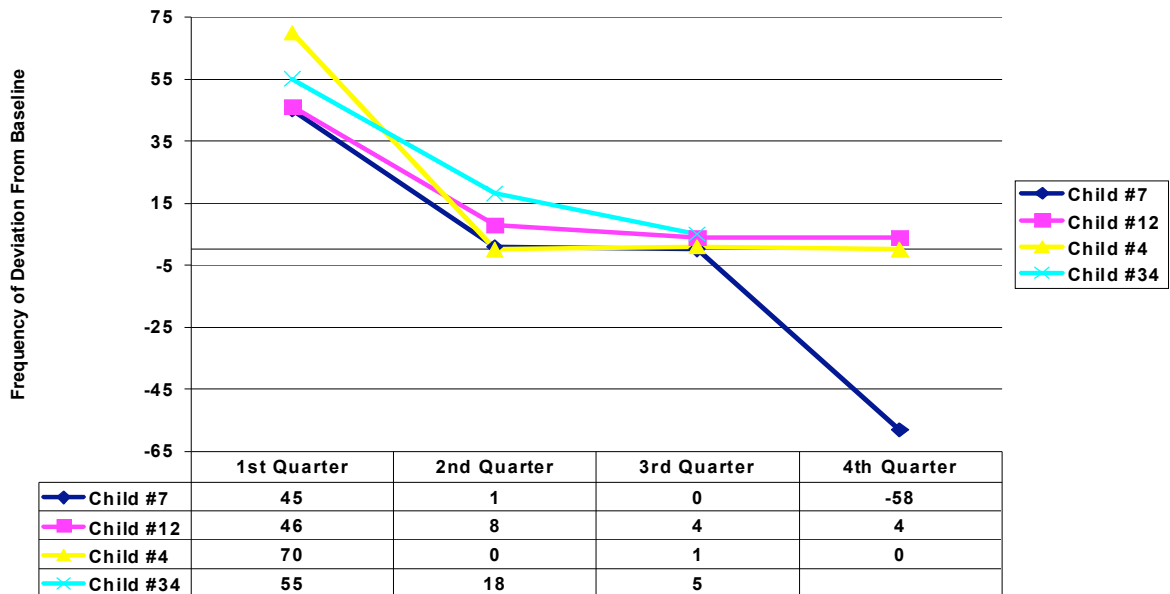
Children with the widest deviations between above baseline scores and below baseline scores over time are included in the (1) **Most Improvement** grouping. Those with slightly less dramatic improvement are included in the (2) **Substantial Improvement** grouping and those with even less overall improvement in the (3) **Moderate Improvement** grouping. Children whose scores rarely varied from the baseline are depicted in the (4) **Stable Acuity** grouping. The acuity scores of two children do not seem to follow any trend, therefore are labeled (5) **Erratic Acuity**.

Most Improvement

In the first line graph the acuity trends of four children are depicted. Child #7 represents the most radical improvement in scores over time. During the first quarter of enrollment this child’s net acuity scores were above his/her baseline 70 times and by the fourth quarter of enrollment plunged below the baseline a total of 58 times.

The acuity scores of the other three children depicted on this graph follow similar but not as dramatic improvements over time. All represent acuity scores above their baselines numerous times in the first quarter and then a leveling over time.

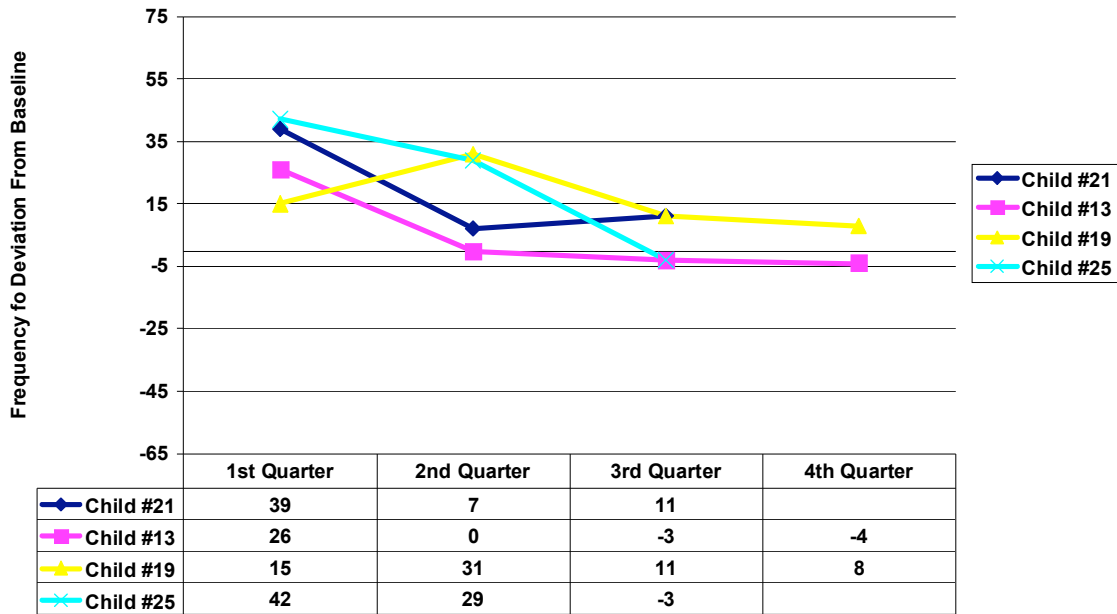
Most Improvement In Acuity Scores Over Time



Substantial Improvement

Four of the 18 children showed substantial improvement in their acuity scores over time with scores above their baseline 15 to 42 times in the first quarter and 0 to 31 times in the second quarter before eventually leveling off. Child #19 shows the most fluctuation with a dip in the first quarter and a spike in the second quarter before showing declining frequency above the baseline in the 3rd and 4th quarter quarters. Due to the complexity of some of these children’s cases, a crisis or surgery that might occur after enrollment into KidStreet can easily send the child back to first quarter type scores.

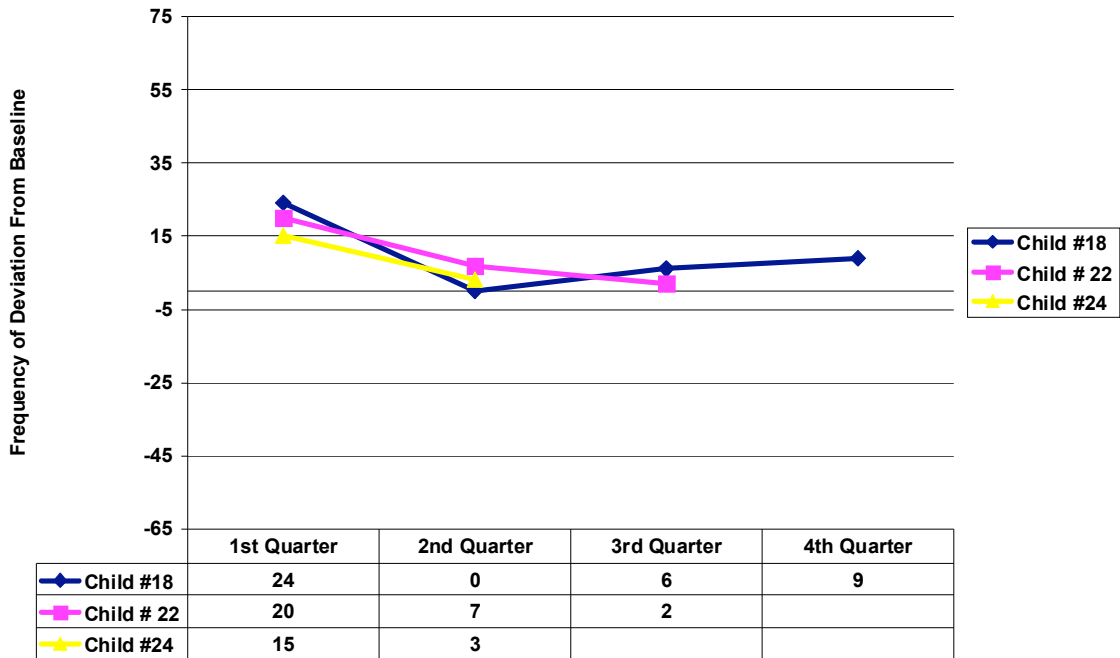
Substantial Improvement In Acuity Over time



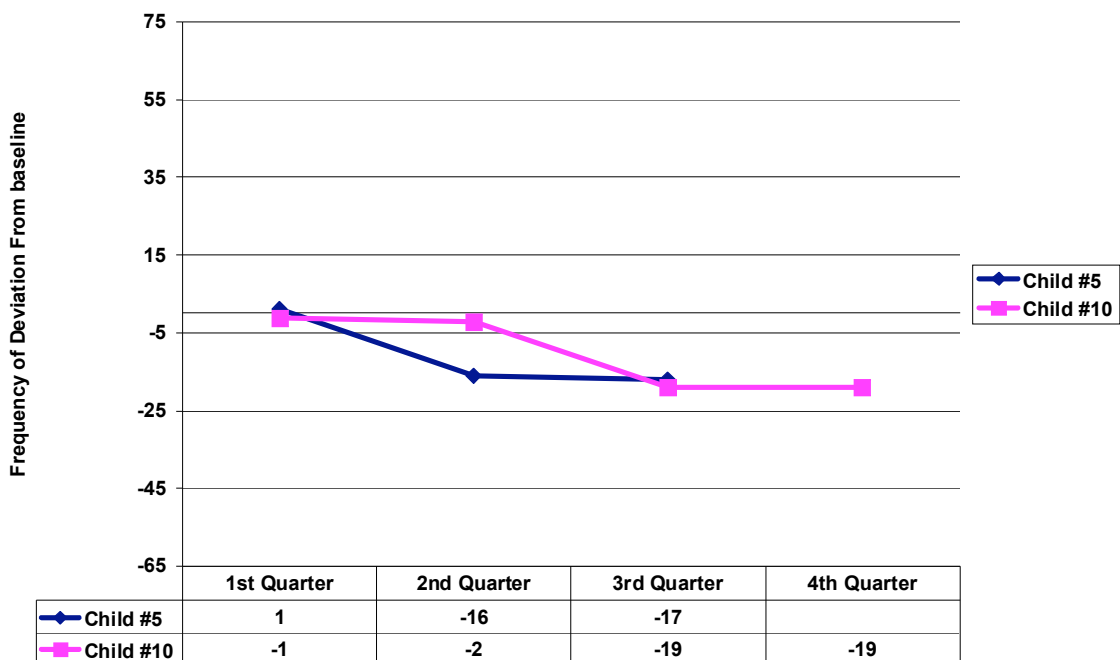
Moderate Improvement

The five children who experienced moderate improvement in their acuity scores over time are depicted in the two graphs on the next page. The two groups are split because of their distinctly different trends. The top graph on the next page includes three children whose first quarter net scores land above their baselines 15 to 24 times before declining with time. The bottom graph shows two children who, unlike other children, started their enrollment at KidStreet with first quarter net scores close to their baseline before their net scores started to dip below their baselines over time.

Moderate Improvement In Acuity Over Time



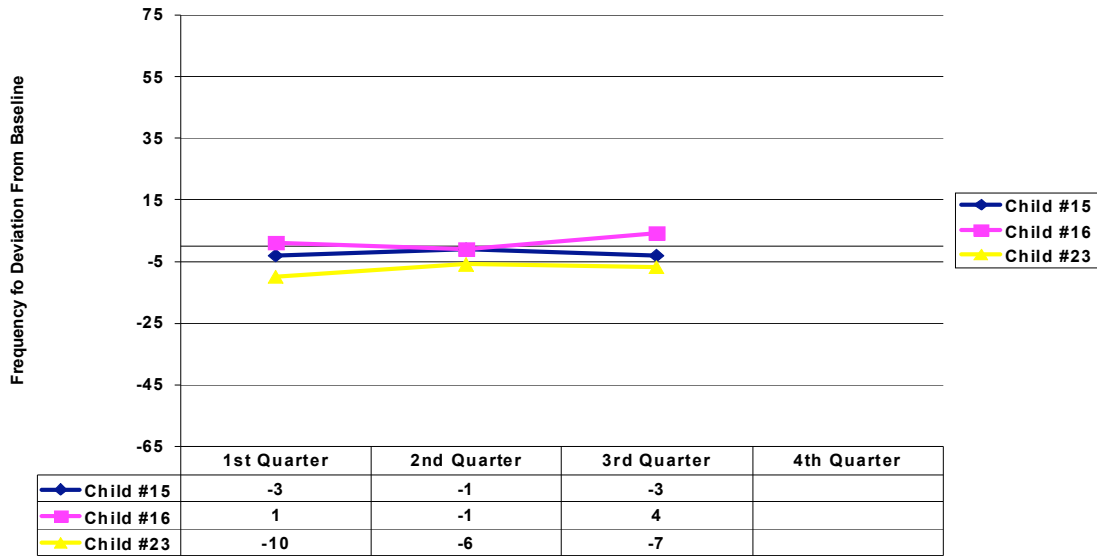
Moderate Improvement In Acuity Over Time



Stable Acuity

Acuity scores for three children seemed to hang close to their baselines over time indicating fairly stable conditions.

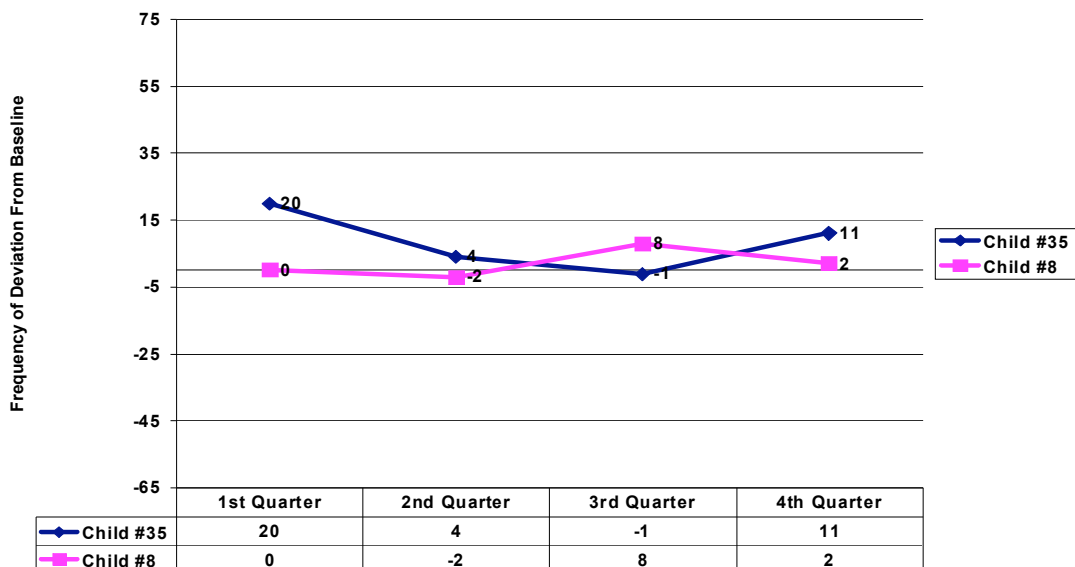
Stable Acuity Over Time



Erratic Acuity

Acuity score trends of two children did not fit any of the other four trend groupings because of the fluctuation of scores over time. It is known, however, that child #8 had a major surgery during the third quarter of enrollment, probably accounting for the deviance above the baseline during that time.

Erratic Acuity Over Time



OT, PT SPEECH – Documented Improvement

In an effort to substantiate the remarkable progress that parents told us they saw in their children as a result of their enrollment in KidStreet, pre and post standardized test scores for PT, OT, and speech were reviewed. KidStreet therapists use four different batteries of standardized assessment tests to measure skills in speech, sensory neurology, and developmental motor areas as outlined in the table below.

STANDARDIZED TEST	BATTERY OF TESTS	WHAT IT MEASURES
ROSETTI	Interaction Attachment Skills	A criterion referenced instrument designed to assess preverbal and verbal areas of communication and interaction and will reflect the child's mastery of skills in each of the areas assessed at three month intervals
	Pragmatics	
	Gesture	
	Play	
	Language Comprehension	
	Language Expression	
FRESNO	Eating and Drinking	A comprehensive measure of functional ability as well as disability -- but not of impairment – designed to augment the standardized clinical assessment of motor, sensory, communication, cognition and socialization domains
	Grooming	
	Dressing	
	Mobility	
	Locomotion	
	Use of Arms and Hands	
PDMS	Grasping	A nationally standardized assessment that provides separate and comprehensive gross and fine motor scores
	Visual Motor	
CELF	Receptive Language	A practical and efficient clinical tool for identifying, diagnosing and performing follow-up evaluations of language deficits in preschool children
	Expressive Language	

Therapists periodically conduct pre and post tests on children they work with -- ideally no more than 12 months apart -- to look for improvement over time. They choose the most appropriate standardized test (Rosetti, FRESNO, PDMS, CELF) based on the child's age and the particular function or functions they are trying to assess.

All standardized tests were developed based on typical child development whereas KidStreet kids reflect development accompanied by physical and neuro-motor deficits. Additionally the range of disabilities is large among KidStreet kids. Deficits are so large in some children that no available assessment test is able to detect their progress.

Because the standardized tests for measuring language and sensory neurological advancement were developed based on typical children, there are no guidelines for appropriate scores for children with disabilities. In addition, children with disabilities do not form a homogeneous group with similar developmental milestones. What might be a small achievement for a child with cystic fibrosis, for example, might be a large achievement for a child with spina bifida.

Rosetti, FRESNO, PDMS:

The Rosetti is designed to assess preverbal and verbal areas of communication and interaction and reflects the child's mastery of skills in each of these areas. The FRESNO is a multi-faceted, performance-based system that measures motor, sensory, communication, cognition and socialization. PDMS identifies a child's strengths and weaknesses in gross and fine motor skills. Children for whom testing is appropriate receive a 'Pre' test shortly after enrollment in KidStreet and a 'Post' test anywhere from nine to sixteen months later.

Net scores were calculated (post-test score minus pre-test score) for the Rosetti, FRESNO, or PDMS tests and a range of improvement was established for each. Scores for each of the three test types were then categorized in one of four categories -- '**Small**' improvement, '**Good**' improvement, '**Remarkable**' or '**No**' improvement -- based on the established ranges. Ranges were devised by KidStreet therapists based on their own empirical evidence in conducting numerous tests with developmentally delayed children. '**Remarkable**' improvement is characterized by changes that are greater than would be made by a typical child in the same time period. A designation of '**Good**' improvement reflects change consistent with what a typical child might make over the same time period and a designation of '**Small**,' indicates fewer changes than a typical child would make over the same time period. '**No**' improvement means no detectable improvement using the standardized tests.

To facilitate ease of interpretation of scores across children and tests, visual symbols were used to designate the four levels of improvement. '**Remarkable**' improvement is represented by a ●; '**Good**' improvement is represented by a ⊙; '**Small**' improvement is represented by a ⊕; and '**No**' improvement is represented by a ○.

As depicted on the graphs on the following two pages, some children have made large improvements in some areas and small improvements or no improvement in others. It is also important to note that improvement magnitudes have not been adjusted for different disabilities. For certain children, in fact, a '**Small**' improvement may actually be a '**Remarkable**' improvement for someone with his/her disability. The notable finding, however, is the number of children who demonstrate any improvement. More notable is the number of children who demonstrate several areas of improvement – many good and remarkable.

CELF Preschool:

The CELF Preschool test was standardized for ages three to seven. It measures language form and content: word meanings, word and sentence structure and auditory memory or recall of the spoken word. Children are given a percentile score at each measurement. A table is included in the upcoming pages that documents the percentile gains in language made by three preschool age children. One child scored improved language skills in all six areas tested; the other two children showed improvement in five of the six areas.

PT,OT and Speech Assessment Results Among KidStreet Children

Improvement Over a 12-month Period During 2001 – 2003

- =REMARKABLE IMPROVEMENT: changes greater than the typical child would have experienced over the same time period
- ⊙=GOOD IMPROVEMENT: changes consistent with what a typical child would have experienced over the same time period
- ⊙=SMALL IMPROVEMENT: fewer changes than what the typical child would have experienced over the same time period
- =NO IMPROVEMENT: no change

Child	ROSETTI						FRESNO				
	Rosetti Infant Toddler Language Scale						Functional Recovery Evaluation of Se Neurologic Outcomes				
	Interaction attachment skills	Pragmatics	Gesture	Play	Language Comprehension	Language Expression	Eating Drinking	Grooming	Dressing	Mobility	Locomoti
5	●	⊙	⊙	⊙	⊙	⊙					
7	⊙	⊙	○	⊙	⊙	⊙					
9											
10**	⊙	○	⊙	○	○		○	⊙	○	○	○
12*	⊙	⊙	●	●	⊙	⊙	●	⊙	○	●	●
15								○	○	○	
16**	○	○		○	⊙	○		⊙	○	●	●
18	○	○		○	○						

** measured at 15 months post test

* measured at 18 months post test

Rosetti: 3 to 5 months = small improvement; 6 to 12 months = good improvement; >12 months = remarkable improvement

FRESNO: <10 points = small improvement; 10 to 19 points = good improvement; >20 points = remarkable improvement
PDMS: 1 to 5 months = small improvement; 6 to 10 months = good improvement; >10 months = remarkable improvement

PT, OT and Speech Assessment Results Among KidStreet Children

Improvement Over a 12-month Period During 2001 –2003

- =REMARKABLE IMPROVEMENT: changes greater than the typical child would have experienced over the same time period
- ⊙=GOOD IMPROVEMENT: changes consistent with what a typical child would have experienced over the same time period
- ⊙=SMALL IMPROVEMENT: fewer changes than what the typical child would have experienced over the same time period
- =NO IMPROVEMENT: no change

Child	ROSETTI						FRESNO						PDMS	
	Rosetti Infant Toddler Language Scale						Functional Recovery Evaluation of Sensory Neurologic Outcomes						Peabody Developmental Motor Scales	
	Interaction attachment skills	Pragmatics	Gestures	Play	Language Comprehension	Language Expression	Eating Drinking	Grooming	Dressing	Mobility	Locomotion	Use of Arms and Hands	Grasping	Visual Motor
20	⊙	⊙										⊙	⊙	⊙
23	●	⊙	○	●	●	⊙								
26													●	●
36	○	○	○	⊙		⊙		⊙	⊙			⊙	⊙	⊙

Rosetti: 3 to 5 months = small improvement; 6 to 12 months = good improvement; >12 months = remarkable improvement

FRESNO: <10 points = small improvement; 10 to 19 points = good improvement; >20 points = remarkable improvement
PDMS: 1 to 5 months = small improvement; 6 to 10 months = good improvement; >10 months = remarkable improvement

Speech Assessment Results Among KidStreet Preschool Children

Improvement During 2001 –2003

Child	Time Period Between Pre and Post Test	CELF: Clinical Evaluation of Language Fundamentals					
		Receptive Language			Expressive Language		
		Linguistic Concepts	Basic Concepts	Sentence Structure	Recalling Sentences in Context	Formulating Labels	Word Structure
3	16 months	↑ 13 percentile points	↑ 38 percentile points	↑ 16 percentile points	↑ 18 percentile points	↑ 47 percentile points	↑ 25 percentile points
6	12 months	↑ 9 percentile points	↑ 9 percentile points	↑ 26 percentile points	0 percentile points	↑ 9 percentile points	↑ 38 percentile points

9	9 months	↑ 58 percentile points	↑ 1 percentile points	↑ 9 percentile points	↑ 16 percentile points	0 percentile points	↑ 14 percentile points
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Interpretation

A complication in interpreting standardized test scores for children with deficits involves the notion of attribution. It is difficult to ascertain how much of a child's improvement can be attributed to KidStreet therapeutic intervention and how much is merely 'normal' childhood development. KidStreet therapists were asked to estimate the percent improvement they would attribute to therapeutic interventions based on their familiarity with the child and typical child development. Therapists interact with children on a frequent basis and understand the multiple variables that contribute to a child's advancement in language and sensory motor skills. Therapists were therefore asked to estimate the proportion of improvement they would attribute to KidStreet intervention for each of the children with reportable scores and to justify their reasoning. Representative comments follow:

- *I believe most of this child's (#10) progress is due to therapy because the child demonstrates little intrinsic interest in environmental exploration. Without stimulation, this child would have passively watched others do activities.*
- *I would estimate that at least half of this child's (#12) progress is due to occupational therapy because s/he has difficulty starting unfamiliar activities. Once shown, this child practices well on their own.*
- *I can say with confidence that all progress in eating is due to therapy. Kids with G-tubes and problems eating rarely get better without help.*
- *Nearly all of this child's gains are due to therapy intervention. Prior to admission, his home care therapists report that s/he (#20) spent all day laying on the floor at home with no environmental stimulation.*
- *Most of this child's (#16) progress is due to therapy because this child needs a high amount of repetition to learn even simple skills. Mom and dad have four other children and no time to spend.*
- *The majority of gains are attributed to therapy because every time the child (#26) and mom come in to meet with her therapists the mom admits she had no idea her child could do the things she does at KidStreet. There is no carryover at home.*
- *About half the gains are due to therapy. This child (15) is very intelligent but comes from a dysfunctional home with no carryover. This child would develop fine motor skills in any appropriate environment with toys and peers to imitate.*
- *Therapy is only responsible for half the gains due to severe neuromuscular involvement and complete lack of motivation despite adequate intelligence.*
- *Due to the nature of this child's disability, quantitative measurements do not indicate the change in quality of abilities. Parents and staff perceive good improvement for this child (#13).*
- *Due to poor carryover at home, I estimate 80 percent is KidStreet influence.*
- *Due to his/her (#10) need to be stimulated and encouraged, KidStreet intervention is probably responsible for at least 75 percent of his/her improvement.*

SUMMARY

Kids flourish at KidStreet. Parents rave about their progress and standardized test scores support parent observations. KidStreet provides children a complement of services that cannot be found anywhere else – at least not all in one package or all in one place.

At KidStreet, kids have the daily structure and routine they need to support developmental growth while their complex medical needs are monitored and addressed. Speech, physical and occupational therapies are integrated into daily routines. Despite disabilities, children learn to play with each other, communicate their needs, feed themselves, express themselves and interact with their environment. KidStreet children learn strategies for approaching life that allow them to be kids and do the things other kids do.

KidStreet parents claim their children do things at KidStreet they wouldn't do if they were at home deprived of the stimulation they get from multiple KidStreet therapies and especially from their interaction with other kids. Some parents see their child weaned off the feeding tube while at KidStreet. Others delight in being able to communicate with their child for the first time – either verbally or through sign language. Some notice an increased sense of confidence in their children, taking the initiative more, or as one parent put it, 'doing more on purpose than by accident.' Kids learn to walk at KidStreet or ride a bike when, for some, it was doubtful they ever would. Many parents believe their child has had fewer illnesses and actually avoided hospitalizations as a result of their enrollment at KidStreet.

Developmental test scores on KidStreet children validate the success stories parents relate. When KidStreet kids are tested for speech and sensory- motor functions using a battery of standardized tests their scores almost always show improvement. Despite the fact that KidStreet children do not usually fit the same scale used for typical kids, they progress nevertheless -- sometimes in remarkable increments. Although it is difficult to know how much of a child's improvement can be attributed to KidStreet interventions, therapists and parents alike credit KidStreet with much of it. Kids with G-Tubes and eating problems rarely get better without professional intervention. Many parents admit that it is impossible for them alone to conduct all the feedings and therapies that would benefit their child. Many of these children benefit most from the stimulating and therapeutic environment of KidStreet – an impossibility for parents to accomplish single-handedly.

Acuity data on KidStreet children shows that children enrolled in KidStreet have more good days than bad days over the course of their enrollment because KidStreet nurses monitor and address their complex medical needs daily. Most kids spend several days during their first two or three months at KidStreet with acuity scores higher (sicker) than their ultimate baseline score but over time kids stabilize as acuity scores hover around their baseline day after day. Scores for some kids eventually start appearing below the baseline on a regular basis indicating improvement beyond the stable state. Parents say: 'He's in the hospital less because nurses are so vigilant about his care;' or 'They find illnesses before I'm even aware.'

Parents themselves are positively impacted by KidStreet. They feel better informed about their child's condition and therefore better able to participate in his or her care. Not only do they learn how to identify signs of impending illness and provide treatments, but they also learn how to better parent their child, play with him/her, and understand when to let go of being overly concerned. Parents develop confidence in their own ability to care for their children at home through the encouragement and support they receive. One of the most notable benefits of KidStreet is that it allows parents of special needs children to work, go to school, or spend time with other siblings.

Besides the comprehensive services KidStreet staff provide on site, they also link parents to outside agencies for education, medical resources, transportation and social services. Parents find the assistance that KidStreet

professionals provide in linking families to the school system invaluable. Most families have no one else to turn to for support and guidance. They depend on KidStreet heavily, if not exclusively.

If it were not for KidStreet most parents believe their children would be significantly delayed. 'She wouldn't be eating.' 'He wouldn't be walking or crawling.' 'He would be way behind in his motor skills.' 'She would be halfway where she is now.' Without KidStreet most children would be in a home situation cared for by a family member who loves them but does not have the multiple skills it takes to support their ultimate developmental growth – something it takes a whole team of professional to do.

Through KidStreet, kids and their parents have the opportunity to maximize the quality of their lives. Children whose parents never expected them to walk or talk or feed themselves defy the expectations through KidStreet. Their parents call KidStreet a 'real blessing,' or say 'it's had a profound effect,' or 'it's so amazing to watch the turnaround.' They could not imagine life without it.

