e-newsletter



SPECIAL NEEDS RESOURCE PROJECT

Things to Think About!



By Brandan Atkin

***Editor's Note:** SNRP periodically accepts articles for publication from outside sources.

Bec Oakley is an SNRP Recommended Blogger. She writes about Autism, Parenting and Support on her Blog, Snagglebox. You can check out her blog here: http://www.snagglebox.com

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How To Offer Services That Special Needs Families Can Actually Use

By Bec Oakley (used with permission)

As I chatted over coffee with a couple of friends, both occupational therapists, they lamented the imminent closure of a program they'd worked hard to get up and running. "The after-school social skills group is being shut down. They've redirected the funding into other services because almost nobody showed up! I don't understand, parents say they don't get enough help but when it's offered to them they don't come. What's going wrong?"

Yup.

It's a conversation I've had many times before, with speech therapists, psychologists, early intervention providers. All with similar frustrations - they put time and effort into creating services that they really believe in, only to find the initial rush of parent enthusiasm dries up a few weeks later. But amongst all their good intentions, they've overlooked one incredibly important fact...

People won't use a service when the benefit is outweighed by the cost.

When it comes to special needs, that cost is not just financial. It's time and energy. And it's this part of the equation that's most often forgotten when designing services, where all of the focus goes into what will be provided rather than how. *If we build it, they will come.*

The social skills program ran on a weekday from 5-6pm. Parents had to stay, but siblings weren't allowed to. The centre was in the middle of town, with parking in a lot across a busy three-lane street. It doesn't matter how awesome that program was - it required babysitting, expensive parking, crossing a busy street with little kids, battling rush hour traffic in the middle of the city and starting dinner late for a tired and hungry family. That's waaaaaaaay too much cost.

The resources within special needs families are often spread incredibly thin without a lot to spare. So if you're offering a service that you want these families to utilize, either the cost for them needs to be low or the benefit needs to be big - so big that the drain on their valuable resources will be worth it.

So no matter what kind of service you provide - respite, playgroups, physical therapy, early intervention, support groups, workshops, seminars - it needs to help families without making their lives harder, by taking into account the costs as well as the benefits.a

COSTS

Even a free service can be too expensive for families that have overwhelming demands on their emotional, physical and mental resources. A user-friendly service is one that delivers benefits without adding to those demands...

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Make it easy to get involved

A registration or application process that's long and complex is discouraging, demanding and puts time-poor families at a disadvantage. Make it simple to sign up, and be contactable by email or outside of regular business hours.

Make it easy to get there

Be aware that getting out of the house with kids can often require a monumental effort, especially when everyone's tired or there's extra equipment to bring along. Offer services in the home or provide onsite babysitting, with caregivers who understand the kids' needs. Run flexible schedules that aren't based around 9-5 days. Offer courses online or on weekends, when parents have extra support available at home. Have accessible, free parking that's close to the building.

Make it easy to be there

Being tired, stressed and busy makes people reach the point of sensory and information overload more easily, so pay attention to stuff like lighting and acoustics. Keep sessions short and group sizes small. If you're giving a presentation, use visuals and email information to participants beforehand so they can get a head start. Don't make parents uncomfortable by putting them on the spot or forcing them to share personal experiences with people they barely know.

Keep financial costs reasonable

Offer free services where possible or at least offer a payment plan. Parents are usually required to provide for 'additional needs' themselves, and stuff like diagnosis, specialist appointments, therapies, equipment and time off work can really add up. I'm not kidding when I say even a few extra bucks in parking might be the deciding factor.

Accommodate everybody

Families of kids with special needs are just that, families. They come in all shapes and sizes. There may be siblings, grandparents, single parents, step-parents... all of them need the services that you're providing. So make provisions for parents who need to bring their other children along. Be flexible with shared care arrangements. Don't forget that there may be other family members with special needs too, including parents, so don't make it challenging for them to participate.

Be mindful of language

When you've been working in a field for a long time it's easy to forget that much of the terminology you use might be unfamiliar to other people. This can be especially confusing for new parents, who might be reluctant to admit that they're not up to speed yet. Also be aware that individual special needs communities may have preferred ways of referring to themselves or their disability, and there may be sensitive topics that trigger strong emotions for some families.

BENEFITS

Make it relevant

Forget what the experts and research committees have decided is important - ask the families what they need, and how best you can deliver that to them. What do they want to learn? How do they want to learn it? What are their priorities? What kinds of support do they need most? What's a good time for them to come? What makes a comfortable environment for them? Your support services are limited and valuable, so make them count.

Socializing is a mixed bag

The social aspect of using your service might be a benefit to some families and a cost to others. Chatting with people and meeting other parents in a session or waiting room can sometimes be too much to face, especially if you haven't showered in days (or cut your hair or slept) and feel like complete crap. Conversely, going to a workshop might be the only chance that parents have had to get out of the house on their own all week, and they need to socialize... maybe even more than they need the information you're providing. So offer flexible arrangements, with socializing opportunities that are optional or run on a stand-alone basis.

Offer different levels of service

Parents of newly diagnosed kids don't have the same needs as those who are further down the track. Often the diagnosis might be all they want to talk about, just at a time when more experienced parents have moved on to other topics. They need a space where they can feel supported to share their feelings, to not feel embarrassed that they don't know the right words to use and don't have all the answers just yet. More experienced parents on the other hand might need to tackle topics at a more advanced or in-depth level.

Be patient

It takes time for families to adjust to a special needs diagnosis and all that it entails. The benefits of your service might be clear to you, but they might not yet understand what it's for or why it will help, or might have set different priorities for what their kids need at the moment. They might simply be overwhelmed by choices and decisions, and need time to figure out whether they can benefit from the service that you're offering.

The bottom line

When designing services for special needs families, most of the focus is on what the help looks like rather than how it is delivered... but no matter how awesome a service might be, it will have zero benefit if nobody can use it.

Understanding and reducing the cost of these services for families will go a long way towards providing much-needed assistance in a way that's accessible to everybody.