

Jacob's Circle of Friends

By Nancy Hartshorne, Parent of Jacob and former Director of the Michigan Deafblind Project

Key Words: Family, blind, visually impaired, deafblind, building relationships

Abstract: One parent shares how her son's Circle of Friends has worked for them in creating community that not only supports Jacob, who is deafblind in having a rich and fulfilling life but has had reciprocal impact on those within his circle.

Editor's Note: Nancy Hartshorne, PhD, is a school psychologist and consultant. Nancy previously directed a federally funded grant to serve children and youth who are deafblind in the state of Michigan. She has chaired the Professional Advisory Board for the CHARGE Syndrome Foundation, Inc. She is coauthor of numerous book chapters and journal articles pertaining to development in children with CHARGE syndrome and inclusion strategies and tools. She is an advocate for quality education in the least restrictive environment for her son as well as for all children.

A Circle of Friends is a circle of support, which forms around a person with a disability. It is meant to be a support to the person's inclusion into the school, community, and workplace, and thus, is considered an "inclusion tool". The person with the disability invites who he or she wishes to be involved in the circle, based upon who they feel supports them in their lives. For a person with limited communication skills, those closest to the person (parents, for example) would decide who would be invited. Circles of Friends often start by using a person-centered-planning process, MAPS, Personal Futures Planning, or PATH. Then the action plan is carried out by the members of the circle.

Circles of friends may or may not involve professionals, depending upon whether the person feels these folks are part of her/his support network. This person included her developmental disabilities case-workers in her circle. Community Mental Health, the agency responsible for services to the DD population in Michigan, also supplied the circle facilitators. The MAPS process is facilitated by two people: a verbal facilitator and a graphic facilitator who records the ideas of the others through the use of words and imaginative graphics depicting the ideas so that everyone can access them.

Jacob's (my son's) circle of friends includes his school friends, for the most part, although the deafblind consultant attends and helps facilitate (she has provided deafblind simulations, helped the kids come up with name signs for Jacob, etc.) and the general education teacher has been attending this year.

Jacob's circle has about 18 student members, about half boys/half girls. They have identified themselves over the years as the kids who really seem to connect with and care about Jacob in his inclusive setting (he is in sixth grade, this year). Although Jacob doesn't give these kids much social feedback, they really care about him, and have hung in there for a while. Most of them are charter members, since first grade. Each meeting we spend some time planning, snacking, interacting, and having fun. Until now, the circle has focused on social interaction with Jacob. This year we are focusing more on transition to the middle school than anything (there is only one middle school in town.) The kids have decided to go to all of the sixth grades in the city (six schools) to speak about Jacob and his circle of friends. Then when Jacob starts middle school inclusion, there will be (hopefully) much less "pointing at the freak" than there would be otherwise, because of understanding having been facilitated. Activities we have undertaken in the past couple of years have included the following:

- **Halloween party:** the kids each bring a snack, decoration, and game that Jacob can access (usually they make something really neat), and something for the haunted house. (I don't have to bring anything!) They come in costume and have a great time. This year, after the deafblind simulation, they decided to do the haunted house in the dark, to see what it would be like for a person who is blind. :)
- **Birthday Party:** each year in the same place, the local pool. They tried the gymnastic center one year, but Jacob hated it, and they learned that because swimming is his favorite activity, and because it is his birthday, the pool is a better place. Last year for his birthday they made him a quilt with all of their pictures (faces) scanned onto it. They decorated it with tactile paint, etc. We keep it on his bed, so he can see all of them. It is really beautiful. I will be bringing it to Indianapolis for my presentation on Circles, and all can see it.
- **Canoeing in the summer**—Jacob loves this; he sits in the middle at the bottom with another student sitting behind him, and trails his fingers in the water. I didn't even have to be in his canoe, which made it much more fun for me!
- **School talent show.** One year the circle did a “men in black” number, really cute, all dressed up in ties and sunglasses, and Jacob was “the alien”, because he was still using a wheelchair. They made him (with him) a papier mache alien head to fit over his wheelchair, and we rigged up a jellybean switch for him to operate the lights in the eyes. It was a cool dance. Last year they did a number from Tarzan, Trashing the Camp. They dressed up as gorillas, and danced. Jacob and a few others stood in the back and were percussion, hitting pie plates with wooden spoons during the number.

The circle is facilitated each year by a volunteer special education student teacher from our university. This has worked out great, as I still have input, but much less work. She brings the snacks, supplies, etc., and I just reimburse her. Ideally, the circle would be facilitated during school by a teacher, and could include the whole class that Jacob is in. This is a different model, but would lend itself to more ideas being generated for inclusion in school lessons.

The circle evolves in membership, and will continue to. Some drop out, but most stay the same. As they move away to college, etc., we hope more people will identify themselves as they get to know Jacob. We hope the circle continues throughout his life span, although this is difficult, as kids get busier with sports, adults get busy with studies, jobs, families. It will change, but hopefully, will always be there to fall back on in a time of crisis, even if through an email listserv!! My ultimate goal is that Jacob will have a circle of support in place to take over decision making for him in case something happens to Tim and me. He would have a guardian, of course, but also a “steering committee”, with his best interests, dreams, and wishes at heart! One little girl was running for student council president, and on her poster, she wrote: “Activities I am involved in: 1. Jacob's Circle of Friends, 2. Junior Choir, 3. Girl Scouts” (In that order --- I was thrilled by this!!!)

This year, our focus is fund-raising. The kids (hopefully about 8 of them) are going to try to raise enough money to support their attending the CHARGE conference. I have invited them to help me present on Circles of Friends. I have had them do this in several forums before, and they do a GREAT job! I hope they can raise enough funds, because I really want all of you to meet these great kids. And their parents always extol the virtues of the circle, how valuable it has been to their character building, sensitivities to differences, compassion, and ability to think and plan for things. It also becomes a general circle of social support to all of them, less and less for Jacob, and more and more for the group as a

whole—they ALL support each other!

In a recent video interview, one charter circle member was asked why she thought the circle was important. I kind of held my breath, wondering what she would say. She blew me away. She said, “The circle is important because we help make sure that Jacob participates and is included in everything. That’s important, because if he wasn’t included in everything, he’d just be with teachers all day, and who would want to just be with teachers all day? That’s no fun!” I loved that response, because it shows that she sees Jacob as a KID, first!

Lastly, these kids are the kids who will grow up to be leaders, workers, legislators, educators, etc. in our and other communities. They will use this experience to further the lives of people with disabilities in whatever career they pursue. They will grow up to be Jacob’s employers, support persons, and friends to others with disabilities.

And Jacob will have a group of people committed to ensuring he has a rich life. Not just an integrated life, not just a life free of pain, abuse, neglect, segregation, but an “enviable” life.

An Effective Complement: Advocacy and Forgiveness

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a publication for families and others interested in Down Syndrome and developmental disabilities.

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Abstract: One parent shares her perspective on maintaining a healthy balance between being an effective advocate for your child with disabilities and practicing the fine art of forgiveness. The author provides a wonderful guide for parents to use in making forgiveness part of their advocacy tool kit.

Key Words: family, parent perspective, parent advocacy strategies

Author’s Note: This October 12, 2005 blog is admittedly written from the slant of the parent. However, all the concepts are true from the perspective of a teacher or support person.

Living the life of a disability advocate can make the world seem like a very adversarial place. Of course, a lot of it depends on your experience. Most of the time, parents of children in early intervention services feel nurtured by their early childhood specialists. Everyone is concerned about the development and health of your baby and looks for the typical milestones along with you. Parents feel supported as specialists suggest strategies to keep the baby from sliding out of the high chair, to finally get up on all fours to crawl, or to sign their first word, “more,” which everyone regrets later. I hear many parents describe Early Intervention services as a type of cocoon, protecting them from what lies just around the corner: school-aged services.

Over the years, I’ve had to advocate staunchly for my son. I remember walking into a “brainstorming meeting” to find it was a full-blown IEP review with no notice. Seventeen (17) people sat around a table smiling pleasantly at me, reassuring me there was nothing to worry about. He was only five at the time. In those early years I was devastated after every meeting. I felt exhausted—like one of the