

family

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Abstract:

This is an interview with Mark Oherberg, co-ordinator of an Inclusive Recreation Project in the USA. The organisation assists families to assist their child with disability to participate in recreation programs together with same aged peers without disability. Mark argues that recreation is a crucial way of breaking down barriers between people with and without disability, allowing children with disability to belong in the 'real world' and to be valued as 'real people'. The highlight of this article is the numerous anecdotes provided, which illustrate how the organisation successfully brainstormed innovative solutions which allowed children to find happiness and friendship in inclusive recreation programs tailored to their unique interests.

Inclusive Recreation - A PASSPORT TO REAL LIFE!

Revolutionary Common Sense from Kathie Snow

Mark Ohrenberg is a Coordinator of the Missouri Access Recreation Project at the University of Missouri/Kansas City, Institute for Human Development, Center of Excellence. As you'll discover in this interview, inclusive recreation has a profoundly positive affect on the lives of people with disabilities, their families, and their communities.

Mark, please describe your job.

The Missouri Access Recreation Project staff provides training for parents, recreation providers, and educators on how to increase access to inclusive recreation for kids with disabilities in their communities and schools. We also lead person-centered planning sessions—working with families on the interests, talents, abilities, and needs of a child—to develop strategies which will ensure positive outcomes. And a third component of our activities is providing technical assistance to a wide variety of organizations on methods to include and support children with disabilities in any type of recreational and/or extra-curricular activities in school and in the community.

A total of seven people work on the project. In addition to our professional expertise, we bring our personal experiences to the job. Two of us are individuals with disabilities—I have muscular dystrophy and use a walker. Thanks to the foresight of my parents, I was always included in school and the community when I was growing up, so I have real-life experience in inclusion! Another staff person has a physical disability, too, and she also has a child and a brother who have disabilities.

Our project was initiated through a grant from the U.S. Department of Education, and we based our model after a similar project in Michigan. The grant limits our official activities to Missouri, but we're always happy to provide information to others across the country, and we do inclusive recreation workshops at conferences outside of Missouri.

Anyone can call us for help. In addition to responding to individual inquiries, we're working on seven specific communities in Missouri to make recreation happen for every person. These locations were selected because parents, recreation providers, and/or educators showed an interest in making inclusive

recreation a reality for every member of the community.

How do the recreation projects in those seven communities operate?

In each location, a diverse network is engaged. These networks include parents; people with disabilities; community recreation providers (such as 4-H, scouts, park and recreation, boys/girls clubs, YMCAs, etc.); and educators and volunteers (who provide FFA, drama and speech clubs, band, and a variety of extracurricular activities). The goals of the networks include discussing and resolving issues; identifying and providing the training that the community needs; and helping folks become connected to one another. We do whatever the networks tell us they need; we don't tell them what they need—they tell us! And the same is true when we receive individual requests from parents, schools, or recreation providers.

Mark, how do you define inclusive recreation?

Well, we think it's a pretty simple concept. But first, let me say how we see "recreation," in general. Recreation can be anything you enjoy doing—activities that are both interesting and pleasurable. And recreation is voluntary. It's not like work or school or anything else a person is *obligated* to do. So inclusive recreational activities can be anything a person with a disability likes to do—activities which occur in the natural environments at school, in the community, or in other settings, alongside people without disabilities. In other words, it's participating in the same fun activities which are enjoyed by members in the community. Inclusive recreation allows people with/without disabilities to (1) enjoy the activity and the fellowship of others; (2) learn from one another in an informal environment; and (3) become more accepting and respectful of differences among all people. In a very important way, inclusive rec breaks down the barriers that separate people with disabilities from people without disabilities while everyone is having a great time.

Can any person with a disability, regardless of the type or significance of the disability, participate in and benefit from inclusive recreation?

Absolutely! Unlike success in other arenas, such as work or school, success in inclusive recreation isn't necessarily dependent on a person's skills, talents, or abilities. *Instead, success is measured by a person's enjoyment!* And while our project officially focuses on children in school (grades K-12), the outcomes have an effect on the community as a whole and on people with disabilities of all ages. There's a ripple effect. For example, when a particular community activity has successfully included one or more students with disabilities, the way is paved for others with disabilities to participate. A wide variety of opportunities are opened up, and it's wonderful to see!

What happens when a person calls your office for individual assistance?

First, we ask what the person with a disability wants to do—including what his hopes and dreams are. Then we investigate if and where the desired activities are happening in the person's community: at the YMCA, on a campus, through park and rec, and so forth. Next, we get into the specifics. If, for example, the person's interest is swimming, we ask the individual and/or the family what the ideal swimming environment looks like. What would enable the person to be successful? Which would be better: a small swim class or a large one? Would a male or female teacher be better? What kinds of supports and accommodations will be needed? In order to make this work, we'll bring the swim instructor to the meetings so he/she can learn how to be supportive and instrumental in helping the person succeed.

Here's a real life example. "John" is an eleven-year-old who has autism. His parents knew if there were too many kids in the pool, John would get distracted. We found a small swim class at the park and rec center. But the supervisor was concerned about the cost of providing a support person for John. So we brainstormed who else could provide support. During the person-centered planning process, we discovered that John's older brother has a good friend—Richard—who also has a brother with autism! Obviously, Richard was familiar with and comfortable around people with autism. And to top it off, he was trained as a lifeguard! So Richard accompanied John to the swim classes as a friend, at no cost to the park and rec facility. It was a very successful experience for everyone.

It's important to understand that "learning how to swim" can mean learning how to float, how to kick your feet, how to dog paddle, or anything else. In all situations, the child with a disability and his family define what the activity really means. It's critical that this definition be shared with the recreation instructor. In John's case, he didn't want to be a world class swimmer; he just wanted to have fun and learn the basics, and that's what happened.

"Suzanne" asked us to do planning around recreation with her daughter, "Emily," a twelve-year-old who has autism. Emily and her younger sister, "Tammy" (who does not have a disability), both enjoy music. With no difficulty, Tammy had joined the church youth choir. But this wasn't seen as an option for Emily. Tammy had bugged her mom about why her sister wasn't in the choir; she didn't see why she and Emily shouldn't be in the choir together. But Suzanne didn't see this as a possibility. In the first place, she wasn't really aware that Emily was interested in music, and second, she didn't see how a child who doesn't speak could participate in vocal music. When we did planning around this issue, Suzanne discovered the depth of Emily's interest in music, and we provided ideas on how to work with the choir director who, it turned out, was very open to the idea.

Emily's participation and success isn't due to her extraordinary skill at singing. In fact, Emily doesn't speak or sing, but she hums and dances to the music, and her efforts add a valuable new dimension to the choir. Emily is seen as a real contributor and the other kids see her as a friend. This has been a very successful endeavor for everyone!

How do you work with public schools?

Oh, I'll tell you another real life success story that will answer your question. "Becky" is a fourteen-year-old girl who uses a manual wheelchair and has a visual disability. She was totally included in regular ed classes at school. One of the activities in PE was softball, but no one was sure how Becky would be able to successfully participate. So we worked with Becky and her parents, classmates, and PE teacher. There were several issues, and all were resolved through creative brainstorming.

Becky had difficulty seeing a ball coming her way. So the other kids came up with the idea to create a stand for the ball, by taping one traffic cone on top of another. When it was Becky's turn at bat, the pitcher placed the ball on top of the stand instead of pitching it. This allowed Becky to successfully bat the ball. Well, very quickly, some of the other kids (who don't have disabilities) realized they could hit the ball better this way, too, so the students decided *anyone* could use the stand, not just Becky!

Another issue was how Becky could get to first base since she can't push herself in her chair. The adults were stumped, but Becky's classmates thought a pinch runner would be a good solution. As the discussion went on, the kids argued about what type of runner should do this. Would it be fair if the fastest runner was chosen? But if the slowest runner were picked, how many times would Becky actually get on base? The solution was the one that simply made the most sense: Becky's personal attendant would push her, which would enable Becky to be in control. Once she was on base, Becky could tell him whether to stay or go when another batter hit the ball.

Becky played in the outfield, but she wasn't able to easily retrieve the ball, nor could she throw it very far. So the solution was for another teammate to get the ball when it came toward Becky, give the ball to Becky, and Becky would throw it toward the infield. Everyone could figure out which base Becky was aiming for. So this rule was created: if the runner was halfway to the base when Becky threw the ball in that direction, the runner was safe. But if the runner wasn't halfway, he was out. The kids drew lines in the dirt to show the halfway point.

Before putting these accommodations in place, the class of boys and girls had many practice sessions to figure it all out and make sure their new rules would

work. And one of the coolest outcomes was that the next summer, Becky participated in a park and rec softball league, using the same strategies! At first, the park and rec coaches weren't too sure about all this. But Becky was surrounded by more than twenty advocates from her PE class who said, "If we did it in PE class, we can do it in park and rec softball!" The coaches and the umpires needed a little education on these new rules, and the kids did a marvelous teaching job—they were the real experts here! They met resistance from adults by saying, "Becky enjoys softball and it's not fair to exclude her!" It's easy to see how inclusive rec in school can lead to inclusive rec in the community, and the reverse can also be a reality!

Why is inclusive recreation important?

First, it increases a person's social interactions, allowing him to feel more comfortable in a variety of situations, and it enhances his social and communication abilities. There's no better place for these to occur than through informal, unstructured events. You're there to have fun, people are just people, and pretensions and official structures disappear.

People learn problem-solving skills in inclusive recreation. Let's say a child uses a walker. On a playground, he is able to climb up the ladder to the slide. But how is his walker going to get from the base of the ladder to the end of the slide? His playmates learn how to provide natural supports: a friend learns to automatically take the walker to the bottom of the slide when "Tommy" is on the slide. These types of learning opportunities will help Tommy and his friends for the rest of their lives!

Inclusive recreation also helps others see individuals with disabilities as real people! Kids and adults with and without disabilities learn to work as a team, and real friendships develop. A lot of parents tell us their kids don't have friends. Well, one of the best ways to make friends is through fun! Recreation is the most open and least structured of all activities in a person's life!

But there's more. Recreation builds stronger families. Parents frequently worry most about education and health issues, which are very important, but kids and parents have to have fun, individually and as a family. When this happens, moms and dads don't spend so much time thinking about disability issues. Family recreation strengthens core family values.

Some people think inclusive rec means everyone should be on a team, but inclusion can mean many things. Being involved as a spectator or as a helper is also very valuable. In high school, I was the basketball manager. Speed and coordination issues prevented me from actually being a player on the team. As the basketball manager, I kept all the statistics—which are a big deal in sports—

and I took care of the equipment. So even though I didn't *play* basketball, I was an integral part of our team's success. Inclusive rec is all about how you can contribute.

In thinking about adults with disabilities, people may believe that taking all the residents of a group home to a baseball game as a group is inclusive recreation. But it's not. For example, all of the fifteen residents might not enjoy baseball. What would it be like to hate baseball and be forced to go to a game? And the residents may not all want to be together, period, since they're together all the time anyway! Unfortunately, group home operators often do what's easiest for *staff*, instead of what's best for people with disabilities. If you're stuck in a group home or in sheltered/segregated work or a day program, inclusive recreation helps you make new friends.

Back to my own experience, riding the team bus to games enabled me to be with my peers: talking, cutting up on the bus, and doing all the things that typically happen to young people who don't have disabilities. I made so many friends. In the locker room, all the jocks snapped each other with towels and I got snapped, too! That's part of being on a team—I *belonged!* And belonging is a very important part of inclusive recreation.

My teammates quickly learned what I could do and what I couldn't. So when I needed some help, they were right there for me. It was so natural. If we had not been teammates, however, these friendships and natural supports probably would not have occurred. People can't learn about one another—and can't become friends—*unless they're together.*

Little kids who don't play team sports need the same type of recreational activities that kids without disabilities enjoy: things like visiting the neighborhood playground or participating in classes like baby swim, pre-ballet, karate, etc. And, of course, an inclusive setting is the best way to go.

Some parents don't think their children *need* recreation, but it's important to recognize how the positive impact of inclusive recreation can influence children's lives over the long haul. Parents need to be thinking long into the future. Many are focused primarily on educational and disability issues, but there's more to life than that!

Here's an example. When we met with "Ron" and "Pam," we learned they had never had a birthday party for four-year-old "Julie," who has autism. They just didn't think it was important—they didn't know if Julie could even understand what a birthday party meant. But after we did some planning with them, they decided to make birthday parties and other social events part of their goals for

Julie. And they were in tears, because they had not seen the importance of birthday parties for Julie. Once Ron and Pam saw Julie as “a daughter,” instead of a “daughter with a disability,” they were able to understand how important birthday parties are for all children. They said, “We wish we could do everything all over again and give our daughter those other birthday parties!” And there’s no reason why they shouldn’t—it’s never too late!

It’s important to remember that recreation isn’t just sports. It can be *any* social activity: birthday parties, sleepovers, a reading group, or anything else! Recreation is whatever a person enjoys doing that’s fun and relaxing. So much of our days are spent doing what we’re told to do—in jobs and schools, for example. Recreation is a time when a person can say, “Hey! Here’s what I enjoy doing. This is what I want to do for fun!”

Inclusive recreation creates stronger communities. It’s a way for people with disabilities to have their needs met and have fun at the same time, using the natural supports and generic services in their communities. Children and adults with disabilities who are involved in inclusive rec activities are seen as participating, contributing members of their cities and towns.

In one of our Recreation Project communities, we’re working with a mom who has a child with a disability and she is also a city council member. She’s really working hard with the park and rec department on making playgrounds accessible. We’ve learned that positive, proactive advocacy and inclusive recreation go hand-in-hand.

What’s your opinion about “special” (segregated) sports and recreation?

Personally, I don’t support Special Olympics, special scout troops, or any other activities that are not inclusive. As a person with a disability, *I’m not special! I don’t want to be special!* I’m simply a citizen of my community. I *hate* that word “special!”

When we segregate people in basketball, track, and other activities in Special Olympics and similar programs, no one outside of those activities ever gets to learn who the individuals really are and what real talents they have to offer. I see absolutely no advantage of special, segregated sports. They are such superficial, unnatural environments. At some point, a person has to deal with the real world, which consists of diversity of all people. How do special programs teach that?

Our project is not saying Special Olympics is bad, but we want people to have choices so they can make the final decision. It should be the *person’s* choice about what works best. I know that some people really like Special Olympics (SO). They feel SO or other segregated programs meet the needs of the family or the person with a disability. But I believe they feel this way because they don’t

have experience in inclusive environments. It's important for people to explore the many options available outside of special, segregated sports. Any recreational experience can be done in an inclusive environment! It's not always easy to accomplish, *but it can be done*. And when we're successful, the person with the disability, the family, and the community *all* benefit from the experience!

The whole segregation thing really bothers me. I once worked in a segregated school. It was a very interesting and sad experience. There were two questions which many students regularly asked. The first was, "What do I do if someone pushes me?" Being in a segregated environment—a place where few educators held high expectations for their students—had prevented them from learning some basic social skills. They didn't have a clue what to do if someone pushed or hit them. They didn't know whether to run, hit back, do nothing, call the police, or what! The second question was, "What should I do when someone calls me names?" They were referring to what I call the "H-word" or the "R-word." Again, they didn't know what to do. Being in segregated settings does not equip people to live in the real world. Inclusive recreation can be a solution.

Let me tell you about another family. "Jenny" has autism and her parents had signed her up for Special Olympics basketball. Jenny's parents attended one of our inclusive rec awareness trainings, and a couple of weeks later, we received an Email from the mom ("Mary") asking, "You mean this could really happen for my daughter?" We said, "Yes!" and gave her some more information. A couple of weeks later, she wrote again, telling us she signed Jenny up for a park and rec league, but that before the first game, no one—including Mary, her husband, or the coach—knew how Jenny could participate or contribute.

I called Mary and asked, "Have you told the coach about your daughter—who she is and how she succeeds in other areas?" When Mary said she hadn't done this, I recommended she share information about Jenny with Jenny's coach and the coach of the other team prior to the first game. Mary did this and then she let us know things were going well. But after a couple of games, the coach wasn't going to let Jenny play because the games were becoming too competitive and everyone was afraid Jenny would get hurt. Mary talked to the coach about the benefits of Jenny's participation, and even though there were concerns about the roughness of the game, *the benefits outweighed the risks*.

Later, we did a person-centered plan on Jenny's behalf. Jenny asked her mom what the meeting was about and Mary told her we would be discussing more inclusive recreational opportunities. Jenny responded, "Oh, good! You mean I don't have to be in Special Olympics anymore? Cause I really don't like that team. I like being with my friends [people her own age] better than the Special Olympics team." Her parents were shocked—this was a real eye-opener!

A parent once said to me, “You know, Mark, we have special education, special programs, special this and that, but when our kids get out of high school, there’s no special shopping mall, no special grocery stores to go to! Kids with disabilities need to learn how to communicate and be successful in the real world, and this happens in inclusive recreation.”

If an expert in inclusive rec isn’t available, what can people do to make inclusive rec a reality?

Parents are the key players in this. It takes collaboration and open communication between parents and recreation providers and/or educators. Having a “can-do” attitude is critical. If a child wants to play T-ball, sign your child up just like you would enroll a child who doesn’t have a disability. Then figure out what it will take for him to participate and discuss this with the coach. Parents should *never* call and say, “My child has a disability. Will you let him participate?”

Many recreation providers have told us they *want* to include people with disabilities, but they don’t know where folks with disabilities *are*—they never see them! So parents and people with disabilities need to initiate the contact and then educate recreation providers on how to make it happen. And that positive, can-do attitude will pave the way to success!

Initially, parents may have to deal with negative attitudes of people who don’t see how inclusive rec could work. So it’s really important to hold on to that positive attitude. Most of the time, recreation providers simply don’t know what to do. But if we *believe* it will happen, we’ll figure out *how* to make it happen.

Typically, organizations have mission statements along the lines of, “To serve everyone in the community.” But many don’t really include *all people*. So we need to question them and *ask* if they’re successfully fulfilling their mission statements when they don’t include people with disabilities. Then we need to educate them on why inclusive recreation is important and *show them how to do it*. Recreation providers who successfully include children and adults with disabilities have achieved success by (1) focusing on the individual needs of participants with disabilities and (2) letting go of perceptions that a game or activity has to be done a certain way.

We also need to think creatively and investigate a variety of solutions. For example, many schools have accessible buses that can be used during the summer by park and rec organizations. And how can assistive technology (AT) make things happen? AT devices are amazing! With adaptive fishing gear, a

person with a disability can enjoy fishing!

It's time for people with disabilities to join the mainstream of society in all areas, and we know that inclusive recreation can open that door. There are many, many different strategies we can use, but if a positive attitude isn't there, it probably won't happen. Attitude is everything! And here's one more little bit of wisdom that's priceless. It's a quote from Plato, and it keeps me focused: "I can learn more about a person in an hour of play than in a lifetime of conversation."

*"Recreation is not to kill time, but to make life;
not to keep a person occupied, but to keep him refreshed;
not to offer an escape from life, but to provide a discovery of
life."*

Anonymous (contributed by Mark Ohrenberg)

"As long as you're going to be thinking anyway, think big."

Donald Trump

For more information, contact Mark Ohrenberg at 1-816-235-1767, toll-free 1-877-838-3408 Email: ohrenbergm@umkc.edu or www.moaccessrec.com.

Discover more about community inclusion in Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities, available at www.disabilityisnatural.com or toll-free 1-866-948-2222.

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