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# Stigma and Its Management: A Pilot Study of Parental Perceptions of the Experiences of Children With Developmental Coordination Disorder

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## KEY WORDS

- ICDH-2
- impairment
- participation

The findings of a small qualitative interview study with 8 parents of 6 children with developmental coordination disorder are reported. The parents discussed the social consequences of their children's motor difficulties. The new International Classification of Functioning, Disability and Health was used as a framework for the analysis of the interview transcripts. The analysis revealed that the parents believed that their children's impairments restrict their participation in society. The interactions between impairment and participation are interpreted in the context of stigma and its management. The significance of occupational therapy interventions in the area of physical activity play to children's social life is discussed.

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The new International Classification of Functioning, Disability and Health (ICIDH-2; World Health Organization [WHO], 2001) presents a framework for organizing and describing human functioning and its restrictions. The final draft of this framework consists of two parts: (a) functioning and disability and (b) contextual factors. Each part consists of two components: Functioning and disability consists of (a) body functions and structures and (b) activities and participation, and contextual factors consist of (a) environmental factors and (b) personal factors. This framework is based on the concept that impairment, which is defined as problems in body function or structure, may affect an individual's ability to perform activities and to participate fully in life (WHO, 2001). The manner and extent of the impact on activities and participation depend on the impairment, individual characteristics, and the social context.

The sociological, analytic framework of stigma and its management (Goffman, 1963) can elucidate the interactions between impairment and participation. Goffman (1963) defined stigma as “possessing an attribute” (p. 3) that makes one different from what others expect one to be and is, therefore, “deeply discrediting” (p. 3) of the person.<sup>1</sup> The discredited attribute may be of the body; of one's character; or of one's race, ethnicity, or religion. Goffman clarified that the attribute not necessarily is discrediting in and of itself, but depends on the situation in which persons are interacting. In this article, Goffman's conceptualization of stigma situations and their management is used to demonstrate the interactions among impairment, activity, and participation in the case of children with developmental coordination disorder.

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<sup>1</sup>The uses of Goffman's (1963) *Stigma: Notes on the Management of Spoiled Identity* in this article have been partial and purposive. Therefore, this case study is not intended to give readers a comprehensive review of his framework.

Developmental coordination disorder affects about 6% of children between 5 and 11 years of age (American Psychiatric Association [APA], 1994). The symptoms of developmental coordination disorder may include marked delays in achieving milestones of motor development, dropping things, clumsiness, poor performance in sports, or poor handwriting. If any of these symptoms interferes with a child's performance of daily activities, a diagnosis is warranted (APA, 1994). Observations of school-age children with developmental coordination disorder during organized and free play show that these children spend less time in formal and informal team play than children without the disorder (Smyth & Anderson, 2000).

Physical activity play in the form of free and team play is important for children's social life (Blatchford, 1998; Humphreys & Smith, 1987; Pellegrini & Smith, 1998). In a summary of the literature on physical activity play, Pellegrini and Smith (1998) indicated that exercise play (i.e., gross locomotor movement in the context of play) seems to increase in the late preschool years and peak during primary school years. For example, Blatchford (1998) found that in Britain, 84% of the 11-year-old boys and 36% of the 11-year-old girls played soccer during break time in school. Rough-and-tumble play with peers, a form of free physical activity play, seems to peak around 8 to 10 years of age (Pellegrini & Smith, 1998).

In his longitudinal qualitative and quantitative study of British children's experiences during break time, Blatchford (1998) described how friendships develop in conjunction with physical activity play when children begin their first year in school at 7 years of age. He stated that at the beginning of the year, children play during break time with different groups of children and in various physical play activities. However, as the year progresses, the play groups become more stable in the games played and in the children who belong to the groups. Blatchford concluded that "games are a main medium through which groups come together and friendships are formed" (p. 82). Additionally, rough-and-tumble play seems to have the social function of establishing and maintaining dominance relationships among boys (Humphreys & Smith, 1987; Pellegrini, 1995; Pellegrini & Smith, 1998).

According to Goffman (1963), participation in society or social groups is possible when groups perceive individuals as possessing all the qualities required for participation. The conglomerate of these qualities creates a stereotype. The group measures every individual who wishes to belong to a social group against this stereotype. Each social situation and group has a set of required characteristics that comprise the stereotype. Individuals who do not possess all of these characteristics are said to have disqualifying

attributes. As long as these attributes are not known about or visibly evident in a social situation, individuals who possess them are said to be "discreditable persons." If these disqualifying attributes are known about or visible to others in social situations, these individuals become "discredited persons" (Goffman, 1963).

The discredited and discreditable statuses are Goffman's (1963) distinctions that allow for analysis of stigma situational conditions (see Table 1). It is important to note that a person may be discredited in one social situation but not in another. For example, individuals must be a certain height to join professional basketball teams. That is, in such social situations, individuals who are "too short for basketball" are discredited; however, the attribute of being "too short for basketball" is not discrediting in other social situations, such as dodgeball or soccer.

Individuals who possess disqualifying attributes that are visible and, therefore, known about become discredited persons in many situations, regardless of their actual ability to participate fully in social situations. The exclusion of persons with physical disabilities from educational settings and work situations regardless of their ability to participate in and perform all required activities is well recorded in the literature (e.g., Frank, 2000).

When individuals possess disqualifying attributes that are nonvisible, their ability to manage the flow of information about these attributes is crucial for their social participation (Goffman, 1963). One form of managing stigma refers to the process of hiding an attribute when it disqualifies the individual from participating in a social group and revealing it when the attribute is necessary for group participation. Failing to hide the attribute makes it known to the social group, and the social situations become similar to those when the attribute is visible. Successful management of nonvisible disqualifying attributes means that the attributes remain unknown to the social group. In such situations, participation is contingent on individuals' ability to control the flow

**Table 1. A Summary of Goffman's Analytic Conceptualization of Stigma and Its Management**

| Attributes of the Situational Condition | The Situational Condition   |  |
|---|---|--|
|   | The Discredited Person  | The Discreditable Person   |
| Visibility of stigmatizing attribute    | Known and/or visible  | Potentially knowable or visible  |
| Stigma management technique             | Tension management of unease in social contacts   | Information control of personal biography                                  |
| Participation                           | Restrictions in terms of acceptance and accessibility in physical and social environments | Contingencies: Potential for stigma in the physical and social environment |

*Note.* Adapted from *Aspects of Stigma: Goffman's Stigma—Understanding the Experience of Impairment, Disability and Handicap*, presented by J. V. Cook, 1998, at the 12th International Congress of the World Federation of Occupational Therapists.

of information about their disqualifying attributes. For example, persons with mental illness tend to hide their illness when applying for a job; however, they need to declare its existence if they wish to participate in a support group for persons with mental illness who hold a job.

The management of stigma is hard work because persons with nonvisible disqualifying attributes tend to monitor carefully the activities in which they participate so that their disqualifying attributes will not become evident (Goffman, 1963). In the case of developmental coordination disorder, the disqualifying attribute of poor motor coordination needs to be managed in order for the children to be accepted by their peers. A small qualitative study of parental perceptions of the social lives of their children with developmental coordination disorder is presented here. Findings demonstrate how children manage their disqualifying attribute and the consequences of these management strategies for the children's social participation.

## Method

A qualitative interview research design was used in this pilot study (Kvale, 1996; Marshall & Rossman, 1995). Six families with children with motor coordination problems were recruited from an occupational therapy clinic that specializes in teaching children with motor difficulties to perform activities and occupations of their own choice successfully. At the time of this research, the children were no longer clients of the clinic. The pilot project was approved by a university Research Ethics Board, and the approved letters of information and consent forms were sent to potential participants. Only those parents who signed the forms were included in the study. To protect the participants' confidentiality, all names have been replaced with pseudonyms.

Five of the 6 families were dual-parent families. The single-parent family consisted of a mother and two children. The number of children in the families ranged from two to four. Five families lived in an urban area, and 1 lived in a rural area. In two cases, both parents participated in the interview. Five of the 6 children with developmental coordination disorder were boys, ranging in age from 9 to 11 years of age; the girl was 10 years of age. Parents of 5 of the children reported that the children had other comorbid conditions. All 6 children had been given the diagnosis of developmental coordination disorder by a pediatrician. The children whose parents participated in this study were not evaluated by the researchers for the overall presentation of their motor coordination difficulties. Therefore, the findings reflect parental perceptions of when and where the children's motor coordination difficulties become a discrediting attribute.

Each family was interviewed once for 1 hr to 1.5 hr by the first author. Five interviews took place at the participants' homes, and one occurred in a small interview room at the work setting of one of the authors. The first interview question was a "grand tour" inquiry about the family story (Spradley, 1979). The subsequent "mini tour" questions (Spradley, 1979) covered the following issues: (a) the social life of the children, with a particular focus on peer relationships; (b) the children's experiences at school; and (c) family life and daily routines. The focus in this article is on the children's social life.

All interviews were audiotaped and transcribed verbatim by a professional transcriber. The transcripts were checked for accuracy by the interviewer. The transcripts were fully coded, using the grounded theory approach to analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The initial step of open coding, when the data are fractured and labeled with concepts, revealed that the parents' main concerns revolved around their children's social life. The axial coding, when each coding category is analyzed internally for processes and consequences, revealed that parents related their children's motor difficulties and interests to their social experiences. Finally, organizing the categories into a coherent and meaningful whole was done with the aid of Goffman's (1963) framework of stigma and the ICDH-2 (WHO, 2001).

## Findings and Analysis

During the interviews, the parents talked extensively about their children's social life. The findings are presented in two analytical themes: stigma situations and shaping participation.

### *Sigma Situations*

Persons with an attribute that may discredit them in interaction with others face potential stigma situations. That is, stigmatization—the nonacceptance of the person—can occur if the context of the interaction leads to discovery of the discredited attribute. The disqualifying attributes of children with developmental coordination disorder—their motor coordination difficulties—is not a discrediting attribute in every social situation: Parents who mentioned that their children had fine motor difficulties did not describe related stigma situations. Stigma situations occur in those social circumstances when the motor difficulties interfere with participation and lead to nonacceptance or rejection. In the following quote, Jennifer, mother of an 11-year-old boy with developmental coordination disorder, described a festive school activity in which her son's motor difficulties became evident:

May Fair is sort of a celebration of spring, and Michael's class...had to dance around the May pole. It's like a form of folk dancing, and everyone holds [a ribbon attached to the top of] a tall pole....And what happens is...that they weave around each other [and] create a pattern on the pole. And, and it's gorgeous, but if you screw up where you are in the...pattern, the whole group wants to kill you, and it's obvious you've screwed up the pattern....[During one song] the boys were still, and the girls were weaving in and out, but the other song required him to go in and out of each others' skipping while the music is going with the thing [ribbon] in their hand, which is difficult for Michael. He couldn't even skip, he was just running, trying to keep up, the other children were skipping. And at the end of it...Mike and Tanya were the two that were twisted. Michael would not budge....Tanya was yelling and screaming at him that he had to move....Finally, Tanya bit the bullet and went around, and it was done. The applause came.

By participating in this activity, Michael's inability to skip at 11 years of age became evident. Additionally, his inability to coordinate himself relative to the others in the group interfered with the group's successful execution of the weave. According to Jennifer, it was evident to her and the other parents that Michael was the cause of the unsuccessful execution of the weave. She also described how the audience was very tense and hesitant with the applause. In this stigma situation, Michael was not rejected for the same reason that he participated: It was a school activity in which all the children had to participate. Therefore, Michael could not choose to avoid participation as a way of managing his stigma.

Donna described the refusal of peers to include her 10-year-old daughter with developmental coordination disorder in their physical activities:

Well, at school I think they sort of almost treat her like a younger sibling. You know, they don't treat her as an equal...as their social equal or their intellectual equal or any way of an equal. The kids in her class, it is just kind of, well Nancy is different. They like her, and some of the children are really very nice and kind to her and that they will try to help her out with things and stuff like that, but they treat her more like a younger child than a child their own age. And, they don't include her in things, like if they are doing skipping and things like that. They just say, "Well, you won't be able to do it." They won't even let her try. She gets excluded from a lot.

Here, Donna reported that her daughter's motor difficulties are known to her peer group and that they exclude her from activities that they believe she would not be able to perform. Similarly, Jane, the mother of a 10-year-old boy with developmental coordination disorder, said that classmates will exclude her son when they engage in sports. She added,

"He doesn't fit in, and he doesn't feel that he fits in. So he ostracizes himself. And then quite often, they [classmates] will, if they are in the sports."

In terms of stigma management in these cases, these children had difficulties hiding their stigmatizing attribute of motor difficulties. In the first case with the May pole, the stigma situation was related to a school activity in which the child did not have the leeway to exercise a stigma management technique. Embarrassment to the child and his family were the consequence of this stigma situation. In the second case, the peer group was aware of the girl's motor difficulties and excluded her from activities that they thought she could not perform competently. Exclusion from physical activity play was the result of the stigmatizing attribute of motor difficulties becoming known to the peer group. In the last case, the mother suggested that her son's exclusion from physical activity play is the result of both the child's and the peer group's attitudes and behaviors.

### *Shaping Participation: Avoiding Stigma Situations*

Other parents' reports of their children's social life described situations in which the children did not participate in activities in which they could not perform competently. Although, these children avoided stigma situations as described previously, it was not clear that their choice always constituted clear examples of stigma management techniques.

Mary described her 9-year-old son with developmental coordination disorder in one social situation as being "literally on the periphery" of physical activity games:

He is in cubs. At the beginning of the year, he didn't participate in anything, and they do a lot of not competitive games, but physical games, and he just would not. We would go and pick him up, and he would be standing at the wall, smiling, laughing, running along the side where his friends are.

In this case, the child, Johnny, found a way to be part of the group without participating in the physical aspect of the game and making his motor difficulties interfere with the group activity.

The success of this stigma management strategy may be attributed to both Johnny and his peers. Stigma is a situational attribute, that is, persons are stigmatized when their discrediting attribute is visible or known about *and* the group members reject them. Johnny's peer group was different from those of other children in this study. In the following quote, Mary described that Johnny's peers made sure that he could play tag again and that Nick, a peer, used his own strength and wishes to construct a playful experience:

He's [Johnny] got one friend at school who wants him to play tag. This little kid, Nick, is a soccer player, and he runs like the wind, but he likes to be "It." Johnny will cry and cry and cry [because he could not run fast enough, and he was It most of the time]. At some point this fall, the teacher had to ban all the boys in the class from playing tag partly because Johnny was crying so much. She just got fed up and said no one was playing tag, but this little Nick latched on to Johnny....So whenever Johnny was It, he would run slowly past Johnny so that Johnny could catch Nick and then Nick would be It, and then everybody is happy again. But she banned them at one point for 2 weeks. None of them could play. And then she told me that after a few days, some of them came back and asked her if they could play, and she said okay, and then a few more and then a few more, and then they came to her and said, "Can Johnny play again?" She said he hasn't asked. So they went and got Johnny, and they asked him. They told him to go and ask her, and she said okay, but no more crying. [Johnny said,] "Okay." Now he does play tag, occasionally. He still prefers his tractors.

Mary described a social environment that is accepting of Johnny and his motor difficulties. In the second quote, Nick was the enabler of smooth and competent games of tag that everyone enjoyed. However, when these special enabling conditions did not exist, as described in the first quote, when Johnny did not participate in the physical aspect of the game, his behavior did not seem to create a stigma situation.

In spite of this accepting and supportive social environment, Mary said that Johnny "does play tag, *occasionally* [italics added]," indicating that Johnny's choices are comparable with his motor abilities. Other parents discussed their children's interests when describing their social lives. For example, Barbara said the following about her 9-year-old son with developmental coordination disorder:

He never wanted to play baseball. Like, when kids would get together just for fun and play baseball, he would avoid that. He hates baseball and gym. Phys. ed. stuff. He was so hesitant on climbers that [that] was one of the goals that [the occupational therapist] worked with him on. He really wanted to be able to do the fire pole because he really felt that all his friends did the fire pole and everybody...I don't know if they teased him that he couldn't...or if he just never went near it because he knew he wouldn't, you know. But, he's not a sports person at all.

Here, Barbara indicated that not only does her son not like sports activities, but he also avoids participating, even if the purpose of the game is fun. When she talked about her son's possible motivation for asking to learn to do the fire pole in occupational therapy, she described a possible situation in which her son had to decide how to manage his motor difficulties. She suggested that he may have failed to hide it

and was laughed at (i.e., a stigma situation) or that he may have avoided it because he knew he could not do it (i.e., a stigma management technique).

In the following quote, Heather, a single mother of a 12-year-old boy with developmental coordination disorder, suggested that her son had no interest in physical activities:

So, Alex is the one friend that will come over quite frequently, and he'll have sleepovers with and because Alex has sort of his unusual interests too, they will spend a lot of time just walking around together talking, and you think, "What are you doing?" You know, but, [it's] unusual for little boys. You know, they don't play ball, they walk around or they spend time in their room, and they come out with these amazing drawings, or one day they made this fish out of cards that was huge and very complicated.

In this case, Heather described her son as having unusual interests that make him different from her own perceptions of what boys of her son's age usually do (i.e., fulfill the stereotypical image). Heather did not describe any stigma situations or indicate that her son's choices may be related to his awareness of his motor difficulties. However, his interests and choices protected him from getting into situations that may reveal his disqualifying attribute of motor difficulties, as Heather said, "Socially, he has always been a recluse, really. He's never had a lot of friends."

Later in the interview, Heather described how her son could not master riding his bicycles and lost interest in them until the opportunity to master that activity in the safe environment of the occupational therapy clinic occurred. Once he mastered that activity, his interest in riding his bicycles increased, and he rides to visit friends whom he did not seek before.

## Discussion

Physical activity play is important for children's social life in terms of acquiring and maintaining friends and belonging to peer groups (Blatchford, 1998). Such activities may be difficult for children with motor coordination problems to master, and this difficulty appears to reduce their participation in activities (Smyth & Anderson, 2000). The findings from this small qualitative study demonstrate that parent perceptions of their children's social life concur with the research findings. Additionally, they indicate that their children's social life may be influenced by the children's interests and their motor coordination difficulties.

In terms of stigma management, parents reported that the children seem to suffer the social consequences of stigma that Goffman (1963) described. As he stated, "The central feature of the stigmatized individual's situation in life...is a question of what is often...called acceptance"

(p. 8). Acceptance by others is what the individual with a discrediting attribute strives for, but acceptance often is withheld when the attribute is visible or known about. Thus, the individual faces two possibilities: situations where he or she must manage stigmatization or situations which are to be avoided in order to avoid stigmatization. When the children's motor difficulties are known, they often are excluded from (stigmatized) or they avoid participating in (a form of stigma management) physical activity play. Because physical activity play is an important facet of social life and friendship in middle childhood (Blatchford, 1998), the social life of children with developmental coordination disorder is limited. For example, Donna, whose daughter was excluded by her peer group, said that her daughter played with younger children. And Mary, who described her son as being on the periphery of the game, said that her son's social group has been growing as his motor skill has improved.

In terms of the ICIDH-2 (WHO, 2001), parental descriptions indicate that children's impaired performance of physical activities in the context of play in middle childhood may lead to participation restriction. These restrictions are the results of interactions among impaired function (the impaired motor performance), the physical features of the environment (physical activity play), and the social and attitudinal world (the way social groups and friendship evolve in middle childhood). Parents identified accepting peer groups (i.e., social environment) and skill enhancement as factors that mitigated the restrictions on participation.

Perhaps the most significant findings of this study related to the occupational therapy interventions. In the clinic, the children set their own goals. That is, they chose the occupation or the activity that they wanted to work on in therapy. It seems that the children selected physical activities or occupations, such as throwing a ball, going down the fire pole, or riding bicycles. That is, children with developmental coordination disorder who had the opportunity to master the performance of a desired activity or occupation in a safe environment took advantage of this opportunity.

Some parents described the consequences of mastering such new activities and occupations. Mary indicated that her son's improved motor skill actually increased the size of his social group. Heather stated that her son became more adventurous in going to visit friends who live further away from his home as a consequence of his acquired ability to ride his bicycles. Although Heather did not relate the bicycle riding to changes in her son's social life, she talked about it in terms of an increased repertoire of activities and occupations (i.e., visiting friends). These findings indicate an important direction for future research in the area of the effectiveness of occupational therapy interventions, that is,

looking at whether and how interventions are effective in the natural environment of the therapy recipients and, in particular, increasing their social inclusion in peer groups.

## Conclusion

In this article, portions of Goffman's (1963) framework of stigma were used to elucidate the social processes leading from impairment to participation in the case of children with developmental coordination disorder. In particular, the use of his conceptual model to analyze the findings of this study contributes to our understanding of children's behavior as these children deal with their negatively valued difference from other children. The consequences of stigmatization and stigma management techniques adopted by children with a disability need to be incorporated into our theories and conceptual models of practice. Although the findings of this study are tentative, they illustrate the potential for occupational therapy interventions to enhance the social life of children and the significance of using activities that are relevant to the children's lives. ▲

## Acknowledgment

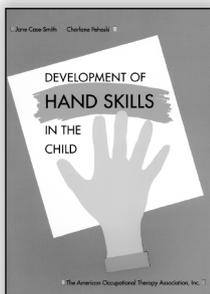
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## Build Children's Hand Skills



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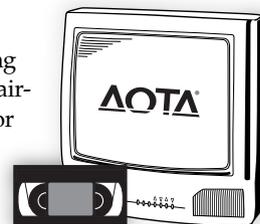
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