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**Evaluation of a Peer-Focused Intervention to Increase Knowledge and Foster
Positive Attitudes toward Children with Tourette Syndrome**

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Abstract

This study examines the impact of a video-based intervention to increase children's knowledge and positive attitudes toward a peer with Tourette Syndrome (TS). TS, a neurological disorder characterized by verbal and motor tics, is a confusing and potentially stigmatizing disorder. Although symptoms wax and wane over the life span, TS typically begins in childhood and peaks at puberty. The available literature suggests that individuals with TS are at risk for social rejection; because TS is primarily a childhood disorder, many of the social adjustment problems experienced by individuals with the disorder have their roots in negative childhood experiences in the classroom.

An intervention was developed and evaluated using a pretest, posttest control group study. Children exposed to the intervention video showed greater changes in knowledge, positive attitudes, and behavioral intentions than a control group. Such interventions may have potential to improve social outcomes for children with differences.

Introduction

Tourette Syndrome (TS) is a brain-based, heritable disorder characterized by motor and vocal tics (Cohen & Leckman, 1994; Curtis, Robertson, & Gurling, 1992). Tourette tics can be simple, such as eye blinking or coughing, or complex, such as jumping or repeating words. TS is far more common in boys than in girls, with estimated male-to-female ratios ranging between 2:1 and 10:1 (Marcus & Kurlan, 2001). The overall prevalence rate of TS in the population has been estimated at 0.5 per 1,000 persons (Marcus & Kurlan, 2001), but research conducted in schools suggests that TS is far more prevalent than general estimates would indicate, with some studies reporting closer to 17 or 18.5 per 1,000 (Hornsey, Banerjee, Zeitlin, & Robertson, 2001; Kadesjo & Gillberg, 2000).

TS can be a confusing and potentially stigmatizing disorder, as tics can be perceived by others as bizarre, hostile, or inappropriate. The obvious physical symptoms of the disorder may decrease opportunities for social interaction due to the negative reactions of peers. Although one study (Carter, et al., 2000) found that children with TS were rated very similar to their peers on measures of social adjustment, other studies have found that peers rate children with TS negatively—withdrawn, aggressive, or undesirable as a playmate (e.g., Bawden, Stokes, Camfield, Camfield, & Salisbury, 1998; Friedrich, Morgan, & Devine, 1996; Stokes, Bawden, Camfield, Backman, & Dooley, 1991). Indeed, a study using sociometric peer ratings (Stokes, et al., 1991) found that 35% of the sample of children with TS received the lowest rating in their class on one or more measures of social adjustment. More recent work by Boudjouk, Woods, Miltenberger, & Long (2000) found that adolescents rated an individual with motor tics less favorably than a typical peer after a video exposure; females with tics were rated less socially acceptable than males. Persons with more severe tics are generally viewed as less socially

acceptable than individuals with mild tics (Woods, Fuqua, & Outman, 1999).

In general, children with developmental disabilities such as Tourette Syndrome tend to have more negative self-concepts than their typical peers (Bussing, Zima, & Perwien, 2000; Gentschel & McLaughlin, 2000; Skinner & Piek, 2001). Although empirical research is limited, it seems that social relationships may also be difficult for children with TS. Although most children with TS report having some friends (Jagger, Prusoff, Cohen, Kidd, & Carbonari, 1982; Nomura, Kita, & Segawa, 1992), many individuals with TS also report having been the target of peer victimization and rejection during childhood (Champion, Fulton, & Shady, 1988; Jagger, et al., 1982; Packer, 1997; 2005). Many students with TS describe feeling embarrassed and anxious because of poor peer acceptance and understanding, and they may withdraw from peers to prevent teasing (Prestia, 2003).

Friedrich and his colleagues (1996) examined attitudes toward children with TS using an experimental exposure to a video of a child with tics. It was found that typical peers rated a child with tics as a less desirable playmate, and pairing the video of a child with tics with information about Tourette Syndrome did not ameliorate negative attitudes. Recently, the studies of Woods (2002) and Woods and Marks (2005) have looked specifically at improving attitudes and behavioral intentions toward individuals with TS through a targeted intervention. In his work with college students, Woods (2002) found those individuals who viewed an educational video on TS had more positive attitudes toward individuals with the disorder and more positive behavioral intentions toward a hypothetical individual with TS. However, the 2005 follow-on study had contradictory results. Although individuals with TS were rated as more socially acceptable by individuals who had seen a video about TS than those who had seen a video about depression, there was no difference between the TS-information group and a control group on

either attitudes or behavioral intentions.

The current study extends the important work of Woods and others by examining the impact of a peer-based video intervention designed specifically to increase *children's* knowledge and positive attitudes toward a peer with TS. Although symptoms wax and wane over the life span, TS typically begins in childhood and peaks at puberty; symptoms generally decline in late adolescence (Budman & Feirman, 2001). Tourette Syndrome is primarily a childhood disorder; thus, many of the social adjustment problems experienced by individuals with the disorder have their roots in childhood experiences in the classroom (Packer, 2005).

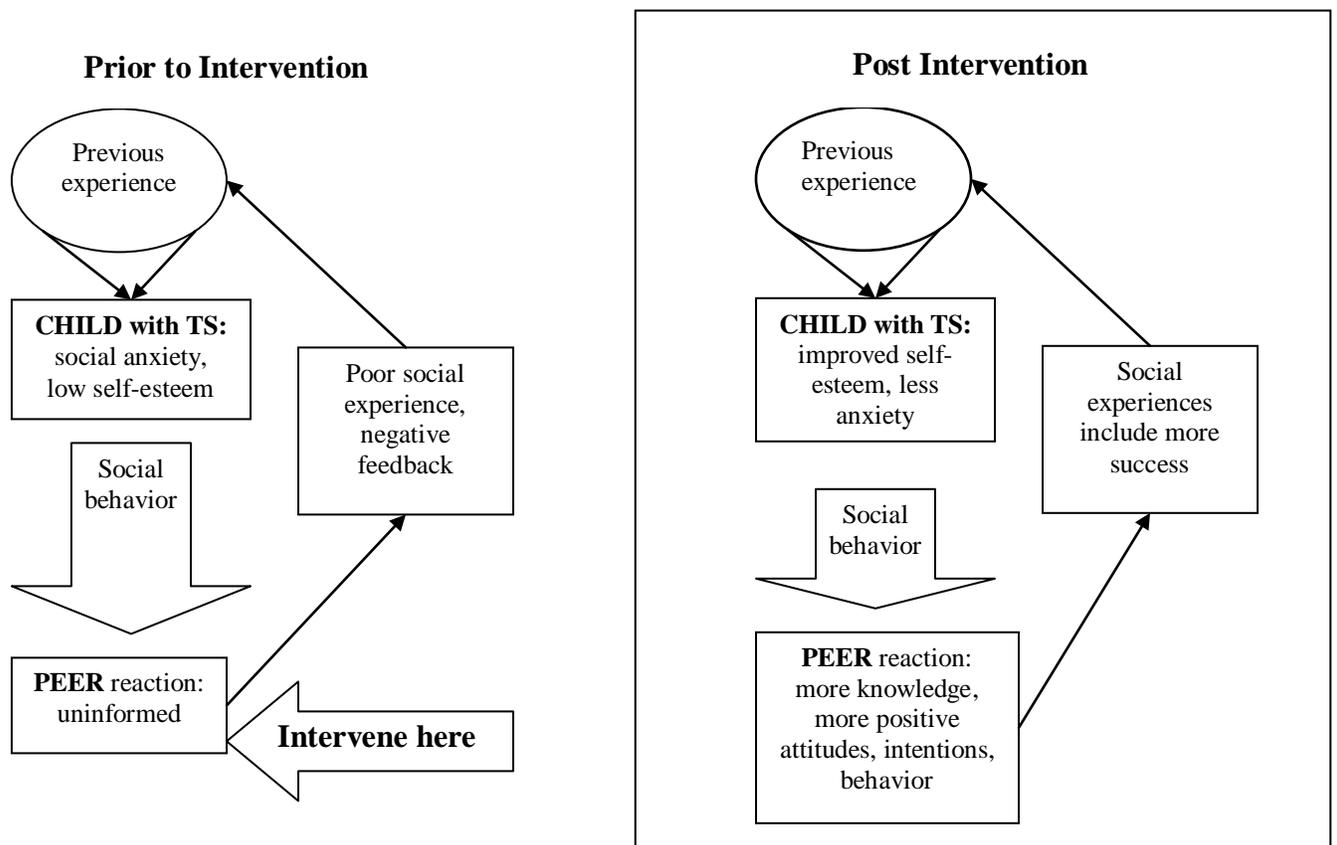
The TS community needs interventions to explain TS symptoms, and prevent and ameliorate peer rejection (Packer, 2005). To this end, a theory-based, developmentally appropriate video was created to educate children about TS, with funding from the National Institute of Mental Health. The theory basis and development of this intervention are described below.

Development of a theory-based intervention

A number of theorists (Crick & Dodge, 1994; Harter, 1982) suggest there is a strong, reciprocal interaction between children's self-concept and their actual social behavior. Given that a child's previous social experiences comprise a "database" from which that child bases future social cognition and actions, it is likely that the child's way of thinking about his success or failure in the social sphere will strongly influence his later social behavior. For instance, if a child with TS has experienced teasing or rejection from his classmates due to his symptoms, these experiences become part of his self-concept as "not socially accepted." Consequently, the child begins to avoid new social situations or behave incompetently in other social situations (Coie, Dodge, & Kupersmidt, 1990).

Understanding social behavior as an ongoing, transactional process provides a number of intervention opportunities. Behavior change theory (Ajzen 1980) suggests that peers with more positive attitudes will behave more positively toward the child with TS. After an intervention to change attitudes, therefore, the child with TS will be able to include more positive interactions with knowledgeable peers in his social “database”. The child with TS’s self-concept and social behavior will change in turn. Therefore, a positive, self-perpetuating cycle may be set into motion by an educational classroom intervention designed to change peer knowledge and attitudes, as shown in the schematic below.

Figure 1: Schematic of rationale for peer intervention



In behavior change theory, knowledge and beliefs form the basis of attitudes, which in turn predict behavior. In order to change an attitude, interventions must target the underlying beliefs and knowledge that comprise that attitude (Fishbein & Azjen 1975; Halloran, 1975). Research has suggested that children's misinformation, fear, and feelings of dissimilarity toward individuals with disabilities may create negative attitudes (Fazavva, Philippsen, & Kumar, 2000). Increasing peer knowledge about TS, therefore, should decrease fear, and increase feelings of similarity and empathy. Changing these underlying beliefs should in turn lead to more positive attitudes.

From this, positive attitudes result in behavior change when a person feels their behavior will have a positive outcome and is well supported within their social environment (Azjen & Fishbein, 1977). To this end, the intervention video contains information that reinforces the notion of positive outcomes from prosocial behavior toward a child with TS, and normalizes these beliefs and behavioral outcomes in the social environment (Fishbein & Azjen, 1975).

Indeed, interventions to increase positive attitudes toward peers with physical disabilities have been successful (Favazza & Odom, 1997; Odom, et al., 1999). Westervelt, Brantley, and Ware (1983) found that a video presentation emphasizing similarities between children with and without disabilities, followed by a teacher-led classroom discussion, improved peer attitudes toward and acceptance of a child with physical disabilities. Similarly, Hammond (2000) reported that a motivational video intervention designed to increase participation in a peer-tutoring program for high school students with disabilities was effective in achieving its goals.

The ultimate goal of this intervention is to improve social outcomes for children with TS. This paper is the first step in exploring the effectiveness of this theory-based intervention, and the specific goal of the current evaluation was to determine the extent to which a video-based

intervention for typical children can increase knowledge and positive attitudes toward a child with TS. Specifically, it was predicted that children in the experimental group would report greater changes in knowledge, positive attitudes, and social acceptance after watching the intervention video, when compared to a control group of children who watched a video on an unrelated topic.

Method

Development of the video intervention

The content of the video intervention was developed in conjunction with a team of TS experts, the assistance of a local advocacy agency (Tourette Syndrome Association of Greater Washington), and many parents and children affected by the disorder.

The mean typical age of onset of Tourette Syndrome is age 5 and the mean age of greatest tic severity is 10 years old (Leckman et al, 1998). Therefore, the target age group for the video was set to coincide with this age range.

The video had three goals, based on behavior change theory

and best practice suggestions from the literature (Bauer & Shea, 1984; Matthews & Barabas, 1985; Westervelt, Brantley, & Ware, 1983). First, accurate, developmentally appropriate information about TS is provided to prevent misunderstanding and misattributions for the atypical behaviors. Similarities between individuals with and without TS are highlighted, and

Content of *You've Got a Friend* video

- What is TS?
 - Includes an explanation that TS is a genetic disorder, which is something a person is born with.
- What does TS look like?
 - An overview of tics with animated examples of common vocal and motor tics.
- What does TS feel like?
 - Explains that tics can't be helped. They're something a person with TS has to do – as difficult to stop as holding in a sneeze, or blinking.
- What is TS like on the inside?
 - Simple explanation of comorbid problems that people can't see, like Obsessive Compulsive Disorder and attention problems.
- What's so funny?
 - Explains that kids with TS may be embarrassed by their tics. Teasing doesn't help and is hurtful.

empathy about the impact of TS on a child's life is encouraged. The number and type of tics symptomatic of mild to moderate TS are demonstrated by the actors, based on substantive feedback that previous videos focused too much on the extreme, severe (and less common) cases of TS. Box 1 outlines the content of this 10-minute video, entitled *You've Got a Friend* (Danya International, 1999).

Study Design and Participants

The study was conducted in elementary school classrooms in six different schools in the Washington, DC metropolitan area; 4 were public and 2 private. One hundred seventy nine (179) children provided data. Of this sample, there were 91 boys and 88 girls. The sample was mostly Caucasian (113 subjects or 65%), with 13 African American participants (8%), 9 Asians (5%), 1 American Indian, and 16 Hispanics (9%). Twenty-two children reported "other" as their ethnicity (13%). Children ranged in age from 7 to 15, with a mean age of 9.5 years.

After collecting the pretest data, all participants were given an identification number and, using a random numbers table, assigned to participate in either the experimental or control group. The experimental group (n = 91) consisted of 46 boys and 51 girls; the mean age was 9.1, and 70% was Caucasian. The control group (n = 45) consisted of 20 boys and 25 girls; the mean age was 9.5, and 37% was Caucasian.

Procedure

An experimenter visited each school to conduct the study. Prior to her arrival, teachers were given an outline of the procedure and a parental informed consent form to send home with the children. Signed consent was obtained from parents, and signed assent was obtained from children prior to participation in the study. Children without parental consent or unwilling to give

assent participated in an alternative activity in a different room during the intervention.

Two visits were made to each classroom. On the first visit, children completed the measures in a group setting. These pretest measures were completed before group assignment because of logistical considerations, as teachers reported that it was simply easier to keep the class together in one room for this phase of the evaluation. The experimenter distributed packets of questionnaires and read each question out loud as children recorded their answers in pencil on the appropriate form. The teacher and two research assistants walked around the room to ensure that children were doing the work on their own and to answer any questions that arose.

On the second visit one week later, children within the classrooms were randomly assigned to control and experimental groups, and then sent to separate rooms, by group, for the remainder of the intervention.

Children in the experimental group were given an introduction to the video from the facilitator's guide, shown the *You've Got a Friend* video, and given the opportunity to ask questions in a group format at the conclusion of the video. Following the presentation, they completed the posttest, which was identical to the pretest. Children in the control group viewed a segment of an unrelated video of equal length —*Brainstorm: The Truth About Your Brain on Drugs* (Children's Television Workshop, 1992), an age- and developmentally- appropriate video designed to educate children about the effects of drugs on the brain. They then completed the same posttest as the experimental group. The intervention and data collection for both groups lasted approximately 45 minutes.

Measures

Children completed three dependent measures on knowledge about TS, attitudes toward

children with disabilities, and behavioral intentions toward a hypothetical child with a difference.

The knowledge questionnaire. An eight-item knowledge questionnaire about Tourette Syndrome was developed to reflect the content of the *You've Got a Friend* video. Prior to the study, this measure was pretested with a gender and racially diverse group of 38 children in the target age group (8 to 11 years old) to make wording adjustments and ensure there was neither a ceiling effect (where almost every child got all the answers right), nor a basement effect (where almost every child got every answer wrong).

The final knowledge questionnaire contained four multiple-choice questions, e.g., “For someone with TS, what is a tic?,” and four true-false questions, e.g., “You can always tell from looking at someone if he or she has TS.” Answers on the knowledge questionnaire are scored as correct or incorrect, and then summed for a total score. Scores ranged from 0 to 8 and a high score indicated more knowledge.

Attitudes toward children with disabilities. The Chedoke-McMaster Attitudes Toward Children With Handicaps questionnaire [CATCH] (Rosenbaum, Armstrong, & King, 1986), a 36-item self-report measure, was used in the study. The CATCH questionnaire has been used in numerous studies measuring attitudes toward a diverse range of disabilities (e.g., Rosenbaum, et al., 1986; Demellweek, Humphris, Hare, & Brown, 1997). Reliability is reported at .90, with test-retest reliability of .70, and adequate validity (Rosenbaum, et al., 1986). Possible scores on the measure range from 0 to 36, with a high score indicating more positive attitudes. For the current study, the wording of the CATCH questions was modified by substituting the word “disabled” or “children with disabilities” for all occurrences of “handicapped” or “handicapped children.” This adaptation was implemented due to concerns expressed by the participating schools about the negative connotation of the term “handicapped.” Permission to change the

wording of the scale was obtained from the authors of the measure prior to the study.

Some examples of the CATCH questions include: “I would talk to a disabled child I didn’t know,” “I would be happy to have a child with a disability for a special friend,” and “I would feel good doing a school project with a disabled child.” Children rate their agreement to these CATCH questions on a 5-point Likert scale, ranging from strong agreement to strong disagreement with each question.

The Foley Scale (1979) is a 5-point Likert scale self-report instrument that was used to measure children’s behavioral intentions toward an individual with a disability. Internal consistency is high at a coefficient alpha of .92. and convergent validity with other scales that measure behavioral intentions has been reported (Wisley & Morgan, 1981). This 12-question scale describes academic, social, and general activities, and asks if the respondent would like to participate in that activity with the target child. Responses range from “would really like to do that” to “would really not like to do that.” Each response is anchored to a smiley face illustrating that response. To define the target child for the scale at pretest and for the control group, children were read a brief description of a hypothetical child with Tourette Syndrome and asked to complete the measure thinking about this target child. For the experimental group at posttest, the children were asked to think about one of the key characters in the video as the target child as they completed the scale. Scores on the Foley Scale range from 10 (most negative) to 50 (most positive).

Results

Between-group analyses were conducted to determine if there were significant between-group differences at the time of the pretest (Time 1) on any of the dependent variables.

Independent sample t-tests indicated no differences on pretest scores existed between the

experimental and control groups before viewing the video, indicating that random assignment was effective.

Change scores were then computed for all three dependent measures by subtracting the pretest score from the posttest score. Between-group Mann-Whitney tests were then used to explore group differences in these change scores. These analyses indicated there were no significant group differences in knowledge change by gender ($Z = -.48$, $p = .63$) or race/ethnicity ($Z = -.45$, $p = .65$). In addition, there were no significant group differences in attitude change by gender ($Z = -.55$, $p = .58$) or race/ethnicity ($Z = -.1.663$, $p = .096$), nor a change in behavioral intentions by gender ($Z = -.43$, $p = .66$) or race/ethnicity ($Z = -.20$, $p = .84$). These results suggest that the groups were approximately equivalent for comparison purposes.

Independent sample t-tests were then run on the change scores, using group assignment (experimental or control) as the independent variable. These t-tests indicated a significant increase in knowledge in the experimental group, when compared with the control group [$t(129) = 8.44$, $p = .001$], a significant increase in positive attitudes [$t(134) = 3.82$, $p = .001$], and a significant increase in behavioral intentions [$t(79) = 2.57$, $p = .01$]. Table 1 presents the pretest and posttest means on all three measures by group, along with the change scores.

Table 1

Means and Standard Deviations for the Dependent Variables at Time 1 and Time 2 and the Change Scores

	N	Mean T1 (SD)	Mean T2 (SD)	Change	(SD)
TS Knowledge					
Control	44	4.1 (2.4)	4.7 (2.1)	.52	(1.2)
Experimental	93	4.6 (2.2)	7.4 (1.0)	2.86	(2.0)
Attitudes Toward Disabilities					
Control	45	25.3 (4.7)	24.6 (5.7)	-.96	(3.42)
Experimental	93	25.4 (5.1)	26.6 (5.1)	1.2	(2.9)
Behavioral Intentions					
Control	18	41.9 (6.3)	41.2 (7.9)	-.56	(7.8)
Experimental	64	43.6 (9.3)	47.5 (8.9)	4.3	(6.8)

Discussion

The research question guiding the current study asked if an informational, peer-focused intervention on the topic of TS could change knowledge, attitudes, and behavioral intentions toward children with TS in a group of typical children. To examine this question, children were randomly assigned to watch either the intervention video about Tourette Syndrome in children—designed with a social cognitive and behavior change theory base, and input from the target audience and experts in the field—or an unrelated video of equal duration. It was found that the change in knowledge, positive attitudes, and behavior intentions or social acceptance was significantly greater in those children exposed to the educational video than the control group.

There are limitations to these data. Behavior was not measured directly in this study, and we were not able to follow up with the classrooms to determine if knowledge and attitudes were maintained over time. Theory suggests that knowledge, attitudes and intentions predict behavior (Ajzen 1980), and so future research should include classroom observations to explore if peers act in more socially accepting ways after an intervention such as this. In addition, follow-up studies would help us determine if these changes persist over time after the intervention, and if they result in improved psychosocial outcomes for the child with TS. Another possible limitation of this study is that the attitude measure was generic, asking about a child with a disability, rather than a child with TS. This concern is mitigated somewhat by the fact that the knowledge and behavioral intentions measures were TS-specific; nonetheless, future research should consider examining attitudes toward individuals with TS using a more precise measure.

Because peer rejection and victimization in elementary school predict negative outcomes, including social anxiety and loneliness (Crick, 1993), externalizing problem behaviors in adolescence (Coie, Terry, Lenox, & Lochman, 1995; Laird, Jordan, Dodge, Pettit, & Bates,

2001; Miller-Johnson, Coie, Maumary-Gremaud, & Bierman, 2002; Lopez & DuBois, 2005), and mental health problems in adulthood (Bagwell, Newcomb, & Bukowski, 1998; Hawker & Boulton, 2000; Roff, 1990), early and effective intervention is important. Peer interactions are a key force throughout development, providing a forum for the creation of self-concept, self-worth, social skills, support networks, and feedback (Greener & Crick, 1999). Therefore, improving the peer group's reaction to a child with a chronic illness or disorder can directly improve the social and academic adjustment of the child with a difference (Goodell, 1984; Varni, Katz, Colegrove, & Dolgin, 1993).

Indeed, the available research suggests that peer-targeted interventions designed to educate children about an illness or disorder being faced by a classmate can have a great deal of value in the adjustment of the affected child (e.g., Ibrahim & Herr, 1982; Kottke, Mellor, & Schmidt, 1987; Mathews, White, & Mrdjenovich-Hanks, 1990; Frederickson & Turner, 2003; Peavey & Leff, 2002). A literature review (Bauman, Drotar, Leventhal, Perrin, & Pless, 1997) identified 15 studies reporting the evaluations of psychosocial interventions for children with chronic health problems, with 11 showing beneficial impact on at least one psychosocial outcome. In fact, chronically ill children who report high levels of social support from their peers also show lower rates of both internalizing and externalizing disorders (Wallander & Varni, 1989) and better social adjustment (Katz, Varni, Rubenstein, Blew, & Hubert, 1992) than their counterparts with less peer acceptance.

Typical children can benefit from such interventions as well. Structured exposure to individuals with differences early in life can lead to more positive attitudes, and greater acceptance, in adulthood (Voeltz, 1982).

By increasing other children's knowledge and attitudes about the illness or disorder

facing their classmate, fear and feelings of dissimilarity that prompt social ostracism can be decreased. The result will be less teasing, increased social acceptance, and a more supportive classroom environment in general. The implications of this evaluation are encouraging for teachers, parents, school psychologists, and other advocates who work to promote inclusion of children with differences, and a spirit of diversity overall, in their school communities. Video interventions are often readily available, require no special training to implement, and are cost efficient. The significant change in knowledge, attitudes, and behavioral intentions reported in this study suggest that even a brief intervention can have positive impact on the social environment of a child with TS. Although more research is needed, the intervention model evaluated in this study could be used to prevent and ameliorate social rejection for the many children who differ from their peers because of illness or disability.

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