

Socialization and Self-Determination in Different-Age Dyads of Students Who Are Deafblind

Susan M. Bruce, Mary C. Zatta, Mary Gavin, and Sharon Stelzer

Structured abstract: *Introduction:* Deafblindness limits access to social cues and social feedback, thus restricting the development of social skills. Many children with CHARGE syndrome, a leading cause of deafblindness, experience challenges with emotional self-regulation and anxiety that may interfere with socialization. Learning about self-determination skills such as goal setting, problem solving, and choice making, in the context of socialization instruction, may improve emotional regulation and social skills. *Methods:* This collaborative action research study employed grounded theory design, with ongoing data analysis. The primary research question was: How will interactions between adolescent students with CHARGE syndrome and younger students with mixed etiologies of deafblindness change over time, in the context of an arranged interaction space? Data sources were videotaped observations of interaction and feedback sessions, evaluation forms, and field notes. Independent qualitative analysis by two raters and member checks enhanced the trustworthiness of findings. *Results:* The younger students learned to make toy choices when presented with them by the adolescent students. Joint attention challenges occurred, as adolescent students did not understand their pals' visual latency and play skills. The adolescent students learned to interact more effectively with younger students while rehearsing self-determination skills such as goal setting and problem solving. *Discussion:* Adult support was essential to successful interactions and to adolescent students' engagement in self-reflection and self-evaluation during the feedback sessions. More research is needed on socialization and self-determination instruction of children who are deafblind, including those with CHARGE syndrome. *Implications for practitioners:* Children who are deafblind require direct instruction for social skills and opportunities to practice interactions with differently aged children. They also require opportunities to problem solve in the context of socialization opportunities. Support from familiar adults may reduce the anxiety experienced during socialization.

Deafblindness affects the development of communication and social skills (Emerson & Bishop, 2012; Janssen & Rødbroe, 2006). Children who are deafblind have fewer opportunities to interact with others due to reduced awareness of possible interactions and to the specialized skills required of communication partners (Bruce, 2005; Janssen, Riksen-Walraven, & van Dijk, 2004). Deafblindness limits access to social feedback and social cues (Correa-Torres, 2008). Reduced access to social opportunities and social feedback, coupled with the communication challenges faced by children who are deafblind, put them at risk for extremely delayed socialization.

CHARGE syndrome is a leading cause of deafblindness in the United States (National Center on Deaf-Blindness, 2015; Silberman, Bruce, & Nelson, 2004). Hartshorne and Salem-Hartshorne (2011) described children with CHARGE syndrome as “socially interested, but not always socially appropriate” (p. 208). Many face significant issues with emotional regulation and the management of emotional states (Hartshorne & Salem-Hartshorne, 2011). Gioia, Isquith, Guy, and Kenworthy (2000) reported that about half have difficulties with monitoring their own behavior, understanding the effect of their behavior

on others, and controlling impulsivity. Children with CHARGE syndrome often experience anxiety and may engage in obsessive-compulsive behaviors as coping mechanisms (Pitroff, 2011; Stratton & Hartshorne, 2011). These behavioral characteristics interfere with social opportunities and, paradoxically, could be addressed through social skill instruction.

Although the development of social skills has been extensively studied in children with other disabilities, there is very little research on children who are deafblind (Ferrell, Bruce, & Luckner, 2014). Social skills include learning to initiate interactions, responding to others, and sharing in activities (Hartshorne & Salem-Hartshorne, 2011). Social skills instruction for children who are deafblind must be considerate of the students’ communication needs, interests, preferences, and the most effective activities for teaching those social skills (Haring, Haring, Breen, Romer, & White, 1995).

Self-determination means being a causal agent in one’s own life or, simply put, having some control over one’s life (Wehmer, 2005). Wood, Fowler, Uphold, and Test (2005) cite the following components of self-determination: choice making, decision making, goal setting and attainment (including a self-evaluation component), problem solving, self-awareness, self-advocacy, self-regulation, and self-efficacy. It has been recommended that these skills be addressed within the expanded core curriculum (Agran, Hong, & Blankenship, 2007). Opportunities for supported problem solving, in the context of social skills instruction, may improve self-determination and emotional regulation.

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Table 1
Characteristics of child participants.

Participant	Age	Etiology	Hearing (unaided)	Vision (with best correction)
Mark	14 years	CHARGE syndrome	Severe bilateral	Normal with eyeglass correction
Maggie	18 years	CHARGE syndrome	Profound left ear, moderate right ear	20/100
Walter	17 years	CHARGE syndrome	Profound bilateral	20/40, superior field loss
Tommy	10 years	Unkown CHARGE-like characteristics	Moderate–severe bilateral	20/400
Elijah	6 years	Leber’s congenital amaurosis and cystic fibrosis	Moderate right ear, mild left ear	20/200+, superior and inferior field loss, nystagmus
Danny	8 years	CHARGE syndrome	Cochlear implant, 30-db speech threshold	20/94

Methods

Action research is a recursive, problem-solving form of research involving multiple cycles of action-instruction, reflection, and revised action-instruction (Bruce & Pine, 2010). This collaborative action research study applied grounded theory design to study socialization skills in six children who are deafblind in the context of an arranged interaction space. The Institutional Review Board of Boston College approved the study and the consent process. The primary research question was: How will interactions between adolescent students with CHARGE syndrome and younger students with mixed etiologies of deafblindness change over time, in the context of an arranged interaction space? Additional questions were: How will younger students change their interactions with objects over time? What socialization goals will adolescent students select? How will a self-evaluation procedure impact the socialization goals selected by the adolescents? and What interaction strategies will teachers and adolescents suggest?

PARTICIPANTS

The child participants were a purposeful sample of six students (three adolescent students and three elementary school-aged students), selected by their teachers because they could benefit from socialization experiences with differently aged students. All of the child participants were deafblind and ambulatory, and four had CHARGE syndrome. The three adolescent students, Mark, Maggie, and Walter, were linguistic (speaking or signing in full sentences), as was Elijah, an elementary student. Tommy and Danny (elementary students) were prelinguistic (communicating in one to two sign utterances). All names used for the child participants in this article are pseudonyms. Mark was apprehensive about interacting with younger children, while Maggie was the most comfortable (perhaps due to her child-care experiences). See Table 1 for more information on the students’ disability characteristics. Although the teachers originally grouped students based on expressive communication characteristics,

the students regrouped themselves based on preferences for a particular activity in the arranged interaction space (such as vehicles), resulting in the following dyads: Mark and Tommy, Maggie and Danny, and Walter and Elijah.

The adult participants were two teachers of children who are deafblind; one taught the adolescent students and the other taught the elementary students. Both completed university preparation in deafblindness. The teacher of the adolescent students had 27 years of experience and the elementary education teacher had 5 years of experience.

THE INTERVENTION

The intervention consisted of six monthly dyadic interaction sessions involving both the adolescent and elementary students. The teachers selected this level of frequency because it fit the demands of their classrooms. Each of the dyadic interaction sessions was followed by a feedback session with only the adolescent students.

Dyadic interaction sessions

The dyads interacted one time per month in a classroom setting that was environmentally arranged by the two teachers. The teachers selected specific toys and other objects to include in four interaction spaces within one large classroom: books; music; vehicles; and toys, stuffed animals, and a playhouse. This last area was often the site of pretend play. In addition, there was a large table and chairs where students could choose to bring toys, books, or musical instruments. The older students were instructed to offer a choice of play area to the younger students (as part of learning to defer to the preferences of younger children). The interaction ses-

sions lasted about 15 minutes due to the attention spans of the younger students. The students were to interact with each other, not just with objects or in parallel play. Teachers were located just outside the interaction space, to provide support only after the adolescent students engaged in problem solving on their own. The interaction sessions were video recorded.

Action research is a problem-solving form of research that may involve multiple action cycles. Thus, the intervention was altered in response to student performance and needs. In the first interaction session, two students exited the interaction space to seek adult input. Thus, to encourage independent problem solving by the adolescents, mats were placed on their sides to more clearly mark the interaction space. The students all had sufficient vision and ambulation to see the adults and gain assistance, but the mats discouraged one adolescent student from too easily seeking adult help and one younger student from exiting the interaction space to seek adult attention. The expectation was that the older students would first try a strategy or two before seeking adult help. An additional change was in the way the adolescent students offered choices to the elementary students. In the first two sessions, they attempted to use a menu of options expressed in line drawings. It proved to be ineffective because the younger students entered the classroom and went directly to their preferred toy area. It was very difficult for the older students to gain their attention to look at the choice sheet. In addition, some of the representations on the choice sheet were not understood by all of the younger students. The older students identified the choice sheet as a problem and decided to offer choices with

real objects starting in session three. These intervention changes represented action research cycles.

Feedback sessions

Within one week of each interaction session, the three adolescent students gathered to view the video of the most recent dyadic interaction session. After viewing the video, the adolescent students engaged in a conversation with the teachers and peers about how the interactions went, what worked well, what did not, and what they could improve. Finally, they set a socialization goal for the next interaction session. These feedback sessions were video recorded. The socialization goals were reviewed with the adolescent students prior to the next interaction session.

Two written evaluation sheets were completed during each adolescent feedback session. The student's self-evaluation sheet addressed the question: How did I do? At the top of the sheet, the adolescent student recorded the socialization goal established for the session just reviewed on video. Each student then participated in self-evaluation, using this criterion: I did it myself, I needed help, or I could not do it. The teachers gave feedback about the student's self-evaluation. On the reverse side of this self-evaluation sheet, each adolescent student recorded his or her goal for the next interaction session. The teachers also completed an evaluation sheet on the adolescent students' performance on three interaction dimensions: greeting (at the beginning of the session); conversation (taking turns and sharing topics); and closing the interaction. These three interaction dimensions also shaped conversations about the video-recorded interactions.

DATA SOURCES

Three types of data sources were used in this study: observations, written documents, and field notes. Observations of the dyadic interaction sessions and the adolescent student feedback sessions were video recorded. The written documents were the adolescent students' self-evaluation forms and the teachers' evaluation forms. Field notes were primarily used to record contextual characteristics, such as changes in toys or procedures.

DATA ANALYSIS

This study applied elements of grounded theory design. Perhaps the most foundational principle that distinguishes grounded theory design from case study design is that data analysis occurs as data is collected (McHatton, 2009). This is highly compatible with the philosophy of action research because of its problem-solving orientation. Grounded theory analysis focused primarily on open coding to identify and name concepts and themes (Charmaz, 2006) in explaining the dyadic interactions and the adolescent students' self-evaluation. In this study, ongoing analysis of data occurred as the teachers and researchers observed the interactions and reviewed the videotaped observations and the written documents. This review influenced how adults set up the interaction space and how they facilitated interactions.

Analysis of observation videos

The observation videos (of the interaction and feedback sessions) were independently viewed and coded by the first and second authors (after being viewed by the teachers). Each video was viewed three times, and notes and suggested themes were

organized by research questions. The dates of filming and information about context (such as in which interaction area the play occurred) were noted. After viewing the videos and taking notes independently, the two raters' analyses were merged into a new document. The two raters then met to reach consensus on the identified themes and to rename some of the merged themes.

Analysis of written documents

The first author analyzed each student's evaluation forms for changes over time. The teachers' evaluation forms were also analyzed for changes in ratings over time for each student. A member check was conducted by asking one teacher to review these analyses. Both teachers also reviewed these evaluation forms as part of ongoing analysis.

Analysis of field notes

The first author coded the field notes, which were read in their entirety for the first reading. During the second reading, each comment was coded according to the research question it related to (such as RQ1 = related to research question one). A second document was then electronically created with each research question used as a heading. The comments were organized under each of the research questions. This second document was then reviewed and coded for themes that fit each research question. Member checks were conducted by asking each teacher to review the final written analysis and give feedback.

Results

Results are organized under the following headings: interactions with objects and

toys, dyadic interactions, adolescent students' self-evaluation and socialization skills, and interaction strategies.

INTERACTIONS WITH OBJECTS AND TOYS

There were three primary influences on interactions with objects and toys: the younger child's preferences, whether or not the younger child entered the interaction space with a toy in hand, and the older student's interest in the toy. Although the category of toys and other objects that interested each student tended to remain constant, their selections varied. Tommy was primarily interested in the musical instruments, although he engaged in some writing activities in the final two interaction sessions. Danny was interested in stuffed animals and musical instruments. Elijah was interested in a variety of toys, including cars and trucks, musical instruments, and pretend play. Elijah was the only younger child interested in the pretend play area, which featured a large dollhouse with furniture and characters. Elijah was also the only younger student who took toys from one area and integrated them into play schemas in another area (such as enacting play schemas with stuffed toys in the pretend area).

On a day in which the younger child brought in a toy, it shaped the interaction, because the younger child tended to stick with that toy. For example, in session one Tommy brought in a guitar and in session four Danny brought in a toy frog. It then became difficult for the adolescent students to attract the children's attention to another object. Occasionally, these toys were very attractive to the adolescent student (because they did not have toys in their classroom) and this interest distracted them from the interactions.

DYADIC INTERACTIONS

Analysis of the video-recorded observations of the interaction sessions and field notes resulted in the identification of the following themes: joint attention, choices and preferences, and facilitating engagement.

Joint attention

Problems with joint attention were apparent, especially in the early interaction sessions. In the first session, Mark offered Tommy a choice by using a visual menu sheet while signing all the options, without establishing eye contact with Tommy or observing whether Tommy looked at the choice sheet. Similarly, Maggie repeated the choice options three times to her pal without gaining his visual attention to the choice sheet. By interaction session four, Mark had learned to use the strategy of saying Tommy's name to gain his attention. Following repeated demonstration by their teachers, all three of the adolescent students and one younger student, Elijah, learned to tap their pal's shoulder to gain their attention.

During the third secondary feedback session, the adolescent students decided that interacting while sitting might support joint attention. The younger students reduced their wandering and increased their attention to a specific toy once the older students implemented sitting in interaction session four. Once seated, Mark was able to orient his body toward his younger pal to further enhance visual attention.

In observing interaction session five, we noticed that Mark did not wait long enough for Tommy to direct his visual attention because Mark did not know

about Tommy's visual latency. If he had just waited another two to three seconds, he would have observed a response to his efforts. When told about the need to wait, Mark was able to generate a strategy of counting to 10 after making a bid for Tommy's attention. He applied this strategy independently in the final interaction session.

Over the sessions we saw an increase in both younger and older students watching each other. This allowed them to glean strategies from each other and, as sessions progressed, older students were more likely to use a strategy that one of their older peers had just attempted. For example, in interaction session six, Maggie imitated Mark's efforts to incorporate writing activities with her younger pal.

Choices and preferences

One of the instructional aims of the intervention was for older students to offer options and then respect the play choices of younger students. Initially, options were presented on a choice sheet of line drawings, but they were later offered through actual objects. Across sessions, adolescent students became more responsive to younger students' toy selections. After the younger child made a choice of toy, Mark and Maggie followed their lead and joined in play. Walter would join in briefly, but then expected to negotiate play activities. His decision was acceptable, given that Elijah was linguistic and could negotiate.

In addition to offering choices of familiar toys, the adolescent students tested out new toys with their younger pals, which occurred most often starting in interaction session five when they were sitting around the table. The older students

would show the younger students new toys and observe their responses. They were able to report the category of toys most preferred by their younger pals. For example, Mark reported that Tommy especially liked musical instruments. Maggie noticed that her pal Danny liked auditory input (but not limited to musical instruments), so she systematically selected toys with auditory output, such as a truck that played a song. Tommy especially became more responsive to the offerings of his pal, Mark. Tommy entered the room for the final interaction session carrying his iPad, and Tommy's teacher demonstrated how to support its use. This was sufficient for Mark to later initiate the use of the iPad with Tommy in that session.

Facilitating engagement

The adolescent students worked to improve engagement in a variety of ways. Maggie and Mark became more careful about their greetings. Mark went to the door to greet Tommy starting in interaction session two. This behavior kept Tommy from starting out the session by wandering. All three adolescent students continued to need some prompting for greetings or closings. Across the sessions, the younger students learned to rely on their adolescent interaction partner rather than to seek out adult support.

Two of the younger pals, Danny and Tommy, engaged in self-stimulatory behaviors. Their older pals demonstrated awareness that self-stimulatory behaviors with objects can interfere with engagement. They attempted to correct these behaviors without adult prompting or support by gaining the attention of the younger child or by offering a

different toy or object. Maggie even placed toys on top of the object of self-stimulation and then attempted to gently remove the object she identified as being problematic.

The quality of the interactions changed across the sessions. Parallel play was reduced and was most likely to occur when an older student lost interest in the object selected by the younger pal. We also observed more frequent positive affect among the students and a reduction in Mark's anxiety. Interactive play increased, and there were a few instances of adolescent pals initiating contact with a younger student who was not their chosen pal.

ADOLESCENT STUDENTS' SELF-EVALUATIONS AND SOCIALIZATION GOALS

Adolescent students evaluated their performance on the goals they chose for the dyadic interaction session. While initially Maggie overrated her performance, she became more accurate over time. Mark was verbally quite negative about his performance, and he tended to underrate himself on the self-evaluation form, but he became more accurate over time. He required adults to recognize and reinforce his efforts. Walter was quite accurate in his self-assessment. Sometimes self-evaluation could be observed outside the feedback sessions. For example, at the end of interaction session three, the teacher of the adolescent students announced the session was finished. As she neared Mark, he remarked, "Nothing worked." She responded, "Yes, I can kind of see that. Nothing worked. You tried hard, though; I saw that, Mark."

Teachers rated the adolescent students in three areas: greeting, conversation,

and closing. Maggie required the most prompting for the initial greeting and was strongest on closing, with a final unprompted closing for the last session. Mark was strongest in initial greetings and required prompting for conversation and closing. Walter was strongest in conversation, and required some support for initial and closing greetings. Walter's partner, Elijah, was the only younger pal who had language, so this promoted conversation even though their expressive forms were different.

The socialization goals of the older students (selected during the feedback sessions) can be categorized as: offering choices and attention strategies. Examples of the first category include: "to take turns deciding what to play with" (Walter, feedback session one), "give Danny two choices" (Maggie, feedback session one), and "play with cars with Elijah" (Walter, feedback session two). Examples of attention strategies include: "write dot-to-dot letters and count to 10" to allow Tommy time to look (Mark, feedback session five).

Across the feedback sessions, all of Walter's strategies focused on either what to play with or learning to defer to the selections of his younger pal. Maggie shifted from thinking about how to offer choices of toys to thinking about her body position (and the helpfulness of sitting while interacting). Like Maggie, Mark began by thinking about how to offer toy choices, but later moved to thinking more about how to enhance interactions. He asserted the need for additional support from staff members in the later sessions and also added the activity of writing at the table, which was suggested by a teacher.

INTERACTION STRATEGIES

Interaction strategies emerged in primarily four ways: adolescent students generated their own strategies during the dyadic interaction sessions; an adolescent student imitated another adolescent student during the dyadic interactions; the strategy was named as part of the socialization goal; or teachers suggested strategies during the feedback sessions. Imitation of a peer's strategy occurred soon after the strategy was observed. If it was successful, the adolescent was likely to repeat that strategy in a subsequent session. Specific interaction strategies have been discussed earlier. These strategies can be categorized as: attention strategies (such as sitting down, tapping or saying the younger pal's name, or using a pause); communication strategies (such as entry and exit greetings and using the partner's primary expressive form of communication); choice strategies (choice sheet, choices of actual objects, choices of sitting or standing); and invitations to play with specific toys (with adolescent students presenting actual toys and demonstrating their use). In all but one session, teachers reviewed the socialization goals prior to the interaction sessions, which may have helped the adolescent students to use strategies.

Discussion

Both the dyadic interaction sessions and the feedback sessions were essential components of this study. Younger students were exposed to a variety of play experiences and learned to accept the adolescents as support providers. The interaction sessions presented adolescent

students with the opportunity to solve problems on their own before seeking adult support. The secondary feedback sessions provided the adolescent students with an opportunity to view their own interactions and to reflect on their performance. Initially, they were likely to make simple commentary on who was in the video scene and then turn to see if that person was in the room. They very seldom commented on the performance of their peers even though they viewed the videos together. Teacher support was essential to their ability to reflect about their performance.

The self-evaluation process that occurred during the secondary feedback sessions provided teachers with a window into how the adolescent students viewed their own performance. It created the opportunity to support students to more accurately assess their own performances. The evaluation process could be improved by having the adults and the students complete and compare the same form (as opposed to the two different evaluation sheets used in this study).

The effect of deafblindness and the specific etiology of CHARGE syndrome were evident in this study. Children who are deafblind have more limited access to social cues that support interactions. Deafblindness presented barriers to establishing joint attention and to seeing or hearing the reactions of the interaction partner. Four of the six students in this study had CHARGE syndrome, an etiology that is associated with anxiety, challenges in self-monitoring, and understanding one's effect on others (Gioia et al., 2000; Pitroff, 2011; Sratton & Hartshorne, 2011). The adolescent students in this study needed adults to pose questions

and to encourage them to observe the effect of their actions on the younger students. They also needed adults to help them recognize when they were effective in their interactions.

This study addressed the following self-determination components cited by Wood et al. (2005): choice-making, decision-making, goal setting and attainment (as part of the self-evaluation component), problem solving, and self-efficacy. Although it was not an intended aim of the study, Mark engaged in self-advocacy when he asserted his need for specific adult supports. This was an important step for him in managing his own anxiety. Through this study, the adolescents learned to use their own decision-making skills instead of immediately seeking out the support of adults. This change in behavior represented an important step in becoming a causal agent within social situations.

This study also addressed the socialization components of initiating, responding to others, and sharing, as recommended by Hartshorne and Salem-Hartshorne (2011). Difficulties in initiation stemmed from interaction partners having different expressive communication forms and a need to learn more about how to gain the attention of others. The primary barriers in responding resulted from unclear bids for attention and a partner who was not responsive at that moment. Learning to share involved supporting adolescent students to either defer to the choices of their younger pal or, in Walter's case, to take turns deciding on the object of play.

STUDY LIMITATIONS

The primary study limitations are the small purposeful sample, the infrequency

of the interaction sessions, and the length of the intervention. An additional limitation is that the students in this study all attended the same school and had varying levels of familiarity with each other. It is not our intention to claim that the results of our study will generalize to other dyads of students who are deafblind or to all individuals with CHARGE syndrome, but to elucidate the characteristics of their interactions and the strategies that supported effective interactions.

IMPLICATIONS FOR RESEARCH

There is very little research on the socialization of children who are deafblind and no other known study on socialization among differently aged students. There is also little research specifically on the socialization of students with CHARGE syndrome. More studies are needed to document strategies that support successful interactions over a longer period of time. Action research is particularly suitable to this work because it allows researchers to alter the intervention (in subsequent action research cycles) in response to student learning.

IMPLICATIONS FOR TEACHING

Students who are deafblind need support to interact with same- and differently aged peers. They require direct instruction about how to communicate with other children, including information about joint attention and the need to pause due to visual latency. They also need opportunities in the school and home to resolve issues that may arise when socializing. The anxiety that results from this demand may be reduced when a familiar adult is nearby to provide support as

needed. This support should be reduced as the child becomes more successful.

Conclusion

The younger students engaged with a variety of objects while learning that adolescents could offer legitimate choices and respond to their preferences. Dyadic interactions occurred within a predictably arranged physical space and in the presence of their teachers as strategies to support students in feeling emotionally safe. The adolescent students gained socialization and self-determination skills, including self-efficacy. In addition, they practiced observation skills when viewing themselves on video. Through guided teaching of observation skills, the adolescent students were able to engage in empathetic practices, such as observing how younger students felt about activities and choices. The feedback sessions, including the review of interaction videos, provided the adolescent students with opportunities to engage in self-evaluation. Teacher feedback was essential in identifying new interaction strategies and in accurate self-evaluation. Through gaining experience in interactions with younger children, self-observation, self-assessment, and teacher support, these adolescent students were able to improve their interactions with the younger students.

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Susan M. Bruce, Ph.D., professor and chair, Department of Teacher Education, Special Education, Curriculum & Instruction, Boston College, 140 Commonwealth Avenue, Chestnut Hill, MA 01721; e-mail: <susan.bruce@bc.edu>. **Mary Gavin, M.Ed.**, teacher, Natick Public Schools, Bennet Hemmenway Elementary, 22 East Evergreen Road, Natick, MA 01760; e-mail: <mgavin@natickps.org>. **Mary C. Zatta, Ph.D.**, director of professional development, Perkins School for the Blind, 175 North Beacon Street, Watertown, MA 02472; e-mail: <mary.zatta@perkins.org>. **Sharon Stelzer, M.Ed.**, teacher, Perkins School for the Blind; e-mail: <sharon.stelzer@perkins.org>.

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