Inclusion as Social Practice: Views of Children with Autism

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Abstract

This study illuminates the social realities of inclusion of 16 high functioning children with autism (HFA) in public schools in the United States. The study suggests that the practice of inclusion rests primarily on unaffected schoolmates rather than teachers, who typically are occupied monitoring academic progress and disciplinary transgressions across a range of children. Utilizing ethnographic observations and video recordings of quotidian classroom and playground activities, the analysis elucidates how classmates employ a range of positive and negative inclusion practices that either integrate or distance autistic children. Ethnographic observations of the study population indicate that the children whose diagnosis was fully disclosed enjoyed more consistent social support in the classroom and on the school playground. The study further suggests that high functioning children with autism exhibit a range of reactions to negative inclusion practices such as rejection and scorn. Such reactions include oblivion, immediate behavioral response, and emotionally charged accounts of disturbing school incidents shared after-the-fact with family members. Significantly, these observations indicate that HFA children can be cognizant of and distressed by others' derisive stances and acts, despite symptomatic difficulties in interpreting others' intentions and feelings.

Keywords: high functioning autism, autism, confidentiality, inclusion

Introduction

This study illuminates the social realities of high functioning children with autism in public schools in the United States.¹ Ethnographic observations and video recordings of quotidian classroom and playground activities indicate that inclusion practices rest primarily upon unaffected schoolmates rather than teachers, who often are occupied monitoring academic progress and disciplinary transgressions across a range of children. Classroom peers, however, may be poorly informed and, in some cases, uninformed concerning the nature of autism and strategies for handling the idiosyncrasies of children with this disorder. Children with autism are predisposed to social isolation by virtue of their disability. Autistic persons, for example, have difficulty maintaining

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social relationships, tracking a sequence of actions, developing a conversational topic, empathizing, fathoming non-literal meanings and participating in imaginative play (Baron-Cohen, 1998; Frith, 1989; Happé, 1996; Sigman & Capps, 1997; Sigman & Ruskin, 1999). Classmates' lack of understanding of this disorder, however, aggravates autistic children's drift towards marginality.

Inclusion is a federal policy that promotes the integration of children with disabilities into mainstream educational settings (Baker et al., 1994; Buysee & Bayley, 1993; Eaves & Ho, 1997; Nisbet, 1994; Siegel, 1996; Strain et al., 1979). The landmark 1975 Education for All Handicapped Act mandated 'free and appropriate public education for all students with disabilities in the least restrictive and most integrative environment possible' (Public Law 92–142, 1975). Amended as the 1997 Individuals with Disabilities Education Act (IDEA), this policy gives handicapped children, including children with autism, the right to be educated with non-handicapped peers. Contact with typical peers is thought to be crucial in assisting children with autism to develop social and communicative skills, but physical placement of children with disabilities in inclusive educational settings *alone* is not sufficient for successful socialization (Gresham, 1982; Mesaros & Donnellan, 1987; Myles et al., 1993). Rather, successful inclusion depends upon recipiently designed procedures for maximizing participation and understanding which address typical peers' lack of information as well as HFA children's social deficits.

The literature on inclusion is pedagogically oriented, delineating and evaluating academic programs for enhancing autistic children's accomplishment of curriculumgenerated tasks (Cushing et al., 1997; Dugan et al., 1995; Kamps et al., 1994, 1995; Kohler et al., 1997). Alternatively, our analysis contrasts inclusion as a legal policy and a pedagogical program with inclusion as a set of practices in which students and teachers rely upon limited or no information about the disabilities of affected children in the classroom. The methodology utilized in this study is qualitative and is rooted in the anthropological tradition of participant observation. The generalizations posited are exploratory but nonetheless resonant with intensive, sustained field observations of 16 children with autism in schools and homes. Insights rely upon field notes, ethnographically informed video and audio recording, and most importantly, familiarity with the children and the social settings in which they participate to obtain a socioculturally viable understanding of inclusion experiences. As methodology specialist H. Russell Bernard notes (1995: 141), 'participant observation gives you an intuitive understanding of what is going on in a culture and allows you to speak with confidence about the meaning of the data.'

The school settings examined in our study have not been selected for experimental interventions or training programs centering on children with special needs in general or on children with autism, more specifically. Rather, they are institutions in which inclusion is simply a *de facto* practice, and whose social contours we delineate here. We elucidate how ordinary participants in inclusion classrooms spontaneously cope with inappropriate social behaviors of high functioning autistic children.

The implementation of IDEA and other legal acts extends the range of heterogeneity among children in a classroom. Consequently, pupils may be brought into social contact for the first time with a variety of classmates who have significant physical, cognitive, and emotional impairments. Although any child may be marginalized within a peer group, children who are institutionally identified as having 'special needs' are particularly vulnerable to social distancing. As McDermott aptly notes:

People are incidentally born or early enculturated into being different. It is more important to understand how they are put into positions for being treated differently. . . . Not only are cultures occasions for disabilities, but they actively organize ways for persons to be disabled' (McDermott, 1995, pp. 336–337).

The present study examines familial, institutional, and situational dynamics that impact the social positioning of high functioning children with autism in mainstream public school settings. Classmates' lack of affiliation with disabled peers may be provoked when these children manifest unusual or unexpected behaviors. While the majority of autistic children are mentally retarded (Sigman & Capps, 1997), those in our study display intellectual capabilities in the normal to gifted range. Generally, the behavioral symptoms associated with autism are milder in these children. Symptoms such as hand-flapping, spinning, and perseveration occur less frequently. Further, these children may pass first order and even second order theory of mind/false belief tasks; thereby evidencing some ability to take the perspective of others in circumscribed contexts (Baron-Cohen et al., 1985, 1986; Happé, 1994; Perner, 1993; Sigman & Capps, 1997).

Nonetheless, these high functioning children with autism act oddly at times. They avoid eye contact, for example, and tend to be reluctant to enter social gatherings. Although they speak grammatically, they do not always use language appropriately (Baron-Cohen, 1988; Bartolluci & Pierce, 1977; Cunnigham, 1968; Frith, 1989; Loveland et al., 1988; Tager-Flusberg, 1981, 1986, 1988). These pragmatic deficits are related more broadly to autistic children's difficulties in fathoming societal expectations surrounding relationships, activities and settings and in discerning their interlocutors' intentions and emotions (Baron-Cohen, 1988; Happé, 1994; Tager-Flusberg, 1989). Autistic children, for example, tend to ask inappropriate questions, such as 'How old are you?' to a stranger (Langdell, 1981), make impolite comments, ignore others' attempts to change the topic of conversation, and perseverate on idiosyncratic subjects (Baltaxe, 1977). Moreover, they often fail to understand contextual cues for conversational turn-taking (Loveland, 1993; Sigman & Capps, 1997). Manifest in varying degrees of severity across the population of children with autism, these and other atypical behaviors differentiate and marginalize autistic children from their unaffected peers.

The present study analyzes the interactional dynamics of two kinds of inclusion, which we refer to as 'negative inclusion' and 'positive inclusion'. The distinction between negative and positive inclusion is based on the *actions and stances displayed by others* towards the affected children in their class rather than on the relative success of their efforts. *Negative inclusion* is defined here as essentially entailing others' failure to *attempt* to include a child with special needs in an ongoing focal activity. Negative inclusion covers cases of neglect, in which a disabled child is left out due to oversight, as well as overt rejection. In our observations, negative inclusion of autistic children occurs especially in unmonitored encounters between these children and classmates but also can take place when the teacher is cognizant of such encounters. In contrast, *positive inclusion* is defined as others' attempts to include a disabled child in the focal activity at hand, regardless of the outcome. In cases of positive inclusion, members of the school community attempt to affiliate with autistic children. They may minimize their differences, for example, or correct atypical behaviors in a caring manner.

Experimental studies suggest that high functioning children with autism may not fully comprehend peers' negative reactions to them (Bauminger & Kasari, 2000;

Capps, Yirmiya & Sigman, 1992). In laboratory settings, for example, HFA children appear less able to recognize emotions than do typical comparison children (Capps & Rasco, 1999; Yirmiya et al., 1992). Children with autism also seem less aware of affect-loaded prosodic features. Their own speech often displays unusual intonation, pitch, loudness, stress, and rhythm (Baltaxe, 1984; Baltaxe & Simmons, 1985). In addition, they have difficulty discerning the social emotions of pride and embarrassment (Capps et al., 1992) and linking these and other emotions to interactional contexts (Jaedicke et al., 1994). Highly relevant to the present analysis, Heerey, Capps & Keltner (1999) found that children with autism were able to recognize teasing encounters yet were less aware of the situational cues that trigger teasing and the use of teasing to influence others' social behavior.

The present ethnographic study, however, reveals that high functioning children with autism display a *wide variety* of responses to peers' teasing, scorning, ignoring, or otherwise rejecting them. These responses range from oblivion and inaction, to overt efforts at showing peers that they can act just like everyone else, to emotionally charged accountings of disturbing school incidents told to parents later in the day.

The Autism Corpus

The subject pool for the present study consists of sixteen high functioning autistic (HFA) children between the ages of 8–12, all of whom were fully included in mainstream public school classrooms.² All of the children had a previously established diagnosis of autism. They were recruited in 1997-98 through referrals from clinicians associated with the psychiatric institutes and medical centers of two university hospitals as well as from private mental health practitioners. Three of the children were diagnosed with Asperger Syndrome, a disorder on the autism spectrum involving social, emotional, and motor difficulties, yet characterized by less profound language delays. To confirm each child's diagnosis, the Autism Diagnostic Interview—Revised (Le Couteur, Rutter, Lord, Rios, Robertson, et al., 1989) and Autism Behavioral Checklist (Krug, Arick, & Almond, 1978) were administered to the children's principal caregivers. As a further qualification for participation in the study, each child was administered the Wechsler Intelligence Scale (WISC-III, Wechsler 1992) to ensure Verbal, Performance, and Full Scale IQ scores of 73 or higher. The children additionally were evaluated using measures of emotion expression and recognition, empathy, and a series of increasingly complex theory of mind tasks (Baron-Cohen, 1989a, 1989b; Baron-Cohen, Leslie, & Frith, 1985; Capps, Yirmiya, & Sigman, 1992; Feshbach, 1982). Below is a table of the subjects' ages and IO scores:

The observational component of data collection involved recording the children in mainstream public schools and at home over a three-week period to ensure ethnographically informed data collection. Each child was video-recorded at school for a minimum of 10 hours while participating in both structured and unstructured activities (e.g. in the classroom during instruction, taking a test, on the playground, during lunch break). Each child also was video-recorded for a minimum of 4 hours at home before, during, and after family dinner time. In addition, audio recordings were made by parents over a 5-day period, and were completed during breakfast and school preparation activities as well as while driving or walking with their child to and from school. In total, the data corpus contains approximately 250 hours of video-recorded interactions between autistic children and family members, teachers, aides and peers, and 160 hours of audio-recordings of autistic children's interactions with family members

Name	Age	FSIQ	VIQ	PIQ
Karl	9	73	73	78
John	12	77	74	83
Don	9	81	73	93
Mary	9	81	70	98
Keith	11	83	91	78
Jason	12	87	89	89
Erin	9	88	91	85
Jonah	13	91	90	94
Anthony	9	92	90	95
Angela	11	96	92	102
Jed	8	98	106	90
Sylvester	8	106	97	116
Calvin	8	106	111	100
Adam	11	110	128	89
Mark	8	128	126	126
Connor	8	139	145	126

Table 1. HFA Subject's AGE at time of IQ testing, and IQ scores

before and after school. The corpus was transcribed using vPrism software and subsequently was coded for key analytic dimensions.

Confidentiality and Inclusion Practices

As a first step in understanding negative and positive inclusion, we consider institutional circumstances that impact inclusion practices. These circumstances include the decision to protect the confidentiality of the autistic child's diagnosis or to disclose it to school officials and the child's peers, teachers' expertise regarding the disorder, and pragmatic demands made on the teacher during school hours. Such circumstances have important consequences for the well-being of children with autism in school settings.

In the state of California, the extent to which a child's disability is disclosed to school personnel and to students depends upon the parents of the affected child and school district policy. A wide range of parental desires and school practices characterized the situations of the families in our study, as displayed in Table 2 below³:

As can be seen in Table 2, one family did not share their child's diagnosis with the school district personnel. Thus, no one in the school setting, including the regional school district inclusion specialist, the school principal, their daughter Erin's teachers, and the other students in the class, was made officially aware of her autism⁴. Rather than seeking special school services, this family felt that Erin's best interests would be served by avoiding the institutional identification of autism. In this situation, and with the family's consent, the school first learned of the child's diagnosis through the family's participation in our research project.⁵

The majority of families (14) in our study informed and worked with the district and with school personnel to enhance their child's social and academic well-being. Typically, these parents met once a year in a closed meeting with school personnel

	Disclosure to	Disclosure to	
Name	School Staff	Peers	
Erin	no	no	
Mary	yes	no	
Jed	yes	no	
Jason	yes	no	
Don	yes	no	
Jonah	yes	no	
Angela	yes	no	
Keith	yes	no	
Calvin	yes	yes*	
Anthony	yes	yes*	
Adam	yes	yes	
John	yes	yes	
Sylvester	yes	yes	
Mark	yes	yes	
Karl	yes	yes	
Connor	no info	no info	
Total 14 yes; 1 no; 1 no info		7 yes; 8 no; 1 no info	

Table 2. Degree of Disclosure of Autism

and a regional special education officer to evaluate their child's educational profile and to create an Individualized Educational Program (IEP). This program specifies the child's educational strengths and vulnerabilities, and targets instructional goals to be implemented in the classroom.

Seven of the families who informed the school district chose not to further disclose the disorder to the child's classmates. In a remarkable article on this topic, a boy diagnosed with Asperger Syndrome (AS) and his mother comment poignantly on the difficulties of deciding whether or not to reveal the condition to classmates (Lisser & Westbay, in press, p. 2):

Should his first identification to new classmates be as a kid-gloves kid? Over time this situation calcified into a kind of conviction: an ethic of privacy and the application of policy meant that, in Max's case, full inclusion came to mean full silence. Even after Mom and Dad had told Max about his AS, they kept it private from others, sharing the diagnosis only with need-to-know professionals and some fellow parents.

As part of the inclusion process, seven families either requested that the regional special education coordinator facilitate the entry of their child into the inclusion classroom or informally discussed their child's condition with his or her classmates. Schoolgenerated disclosure usually consisted of a brief, one time explanation of the autism disorder. The interface between the autistic children and their classmates characteristically was not scaffolded beyond this institutional introduction. By and large,

^{*}Classroom communication about disabilities in general.

teachers and classmates were left to their own resources to comprehend the disorder and to develop strategies to engage the affected child.

Moreover, outside the IEP proceedings, teachers and classroom paraprofessionals often were afforded little or no opportunity to enhance their abilities to educate children affected by autism and to assist others in engaging the affected child. In one school the staff voiced resentment over the impact of inclusion—time, effort, and resources devoted to the child with autism—on the academic well-being of other children in the class.

Of the seven families who chose to inform their child's peers, two families made an effort to talk about autism in relation to the child as a whole and engage the classmates in interactive discussions. One family brought in a behavioral therapist who was familiar with the child to speak at length with the child's classmates about this particular child and the nature of the disorder. The child's mother also spoke with the students and urged them to provide sustained emotional and practical support for their peer with autism. This message was fortified by repeated classroom visits by the mother as well as by the teacher's sympathetic efforts to create a classroom community.

A second family implemented an elaborate, structured effort to mentor unaffected peers in the effects of autism. The child, assisted by his mother, played a central role in introducing himself as a whole person, including his abilities and disabilities. They co-authored an interactional manual for other children in the class (Lisser & Westbay, in press). The manual begins by noting that all kids are alike and different in certain aspects, it goes on to explain how brains are similar and different, introducing the term Asperger Syndrome (AS) to describe the child's 'special brain'. In a child-friendly rhetoric, it highlights both the unusual talents and characteristic vulnerabilities associated with AS (e.g. 'I sometimes lose control when I am embarrassed or hurt or frustrated or angry') and advises how classmates might best respond ('Can you and I make an agreement? Please ask me nicely if you want me to do something or not to do something. I will try to ask you nicely if I want you to do something or not to do something'). In effect, this child and his mother created an interactive text complete with snapshots and drawings that familiarizes and personalizes the disorder.

While variables such as the range of classroom demands on teacher time and attention influence the dynamics of inclusion classrooms and while our sample size is small, videotaped data recordings suggest that disclosure of the child's diagnosis and the manner in which it was disclosed had an effect on the social experiences of the high functioning children with autism in our study. In our observations, the child (Erin) whose diagnosis was unknown to school authorities and classmates often encountered negative inclusion by peers. In the fourteen instances in which the school officials were informed, the HFA children had the benefit of occasional teacher intervention and, importantly, in six cases the assistance of a classroom aide for a portion of the school day. Within this group, the seven HFA children whose diagnosis was disclosed to peers as well as to school personnel tended to encounter a more tolerant and affirming peer atmosphere. Two of these children, whose families actively personalized the disclosure process, routinely encountered caring responses from their peers, even in situations in which their behavior violated peer expectations.

Negative Inclusion

Our analysis of the inclusion of high functioning children with autism focuses on members of the school community as agents in the integration of affected children into the social life of the school. Those in the social environs either may display a disposition to include or not to include a child with special needs in an ongoing social activity. Negative inclusion is afforded in situations where members do not make an effort to draw in such a child. We consider here two kinds of negative inclusion: 1) neglect and 2) overt rejection.

Neglect

In all of the inclusion classrooms in our study, a form of neglect occurred in which others sometimes disregarded or paid no attention to a child with special needs. Neglect stemmed in part from the partial invisibility of HFA children's social and cognitive difficulties and in part from teachers' and classmates' lack of preparedness to recognize and attend to these difficulties. That is, others' blindness to the symptoms of autism translated into situations in which a HFA child was isolated from others

Mitigated symptoms of autism among HFA children facilitate entry into mainstream classrooms precisely because high functioning children are capable in many spheres. Paradoxically, however, these children's attenuated symptom presentations mean that the children's difficulties engaging in school activities may not be immediately evident to those in their midst unless the children themselves signal for assistance. Along these lines, the children we observed often withdrew into themselves without attracting attention, as peers and teachers simply continued their involvement in individual class work, class discussion, a group project, or play yard conversation. Although social withdrawal is a hallmark of autism, others in the school setting often appeared oblivious to the detachment of HFA children, which frequently endured for extended periods of time with no social intervention.

It is important to note that withdrawal often is an attempt by the child with autism to cope with an over-stimulating environment and can serve as a means of restoring equilibrium. When the children in our study became extremely overloaded, however, they typically would display their intense internal discomfort by shutting their eyes, holding their hands over their ears, falling asleep at their desks, or exiting from the immediate social setting to a quiet area. Our concept of neglect does not apply to these types of intense withdrawal episodes, as others typically did take notice of such behavior.

Instead, others' neglect transpired in milder situations involving withdrawal that displayed the following three properties:

- 1) the HFA children indexed their social detachment through sustained eye gaze avoidance, body orientation turned away from focus of interest, lack of verbal responsiveness, and the like;
- peers and/or teachers did not evidence awareness of the HFA children's detachment, despite the fact that the indexes of detachment occurred frequently and over prolonged intervals; and
- 3) the HFA children were capable of participating more fully in response to social intervention, as evidenced by their sociability following overtures by family members, teachers and peers who had been educated to notice these behavioral indexes.

Some HFA children whose families notified the school district of their child's condition were assisted by a classroom aide throughout four hours of the school day. These

aides are not required to receive special training in working with autistic children. Typically, they floated among several children in the class who required help. Nonetheless, they periodically were able to redirect the HFA child's attention to teachers' instructions and/or an academic task at hand, for part of the day.

On the play yard and for the rest of the academic day, however, these HFA children were left to their own resources and to the sensibilities of their teachers and fellow students. In situations in which an aide is absent, in which a teacher's attention is directed elsewhere, or in which classmates seated nearby are occupied with their own tasks, the HFA child may be corporeally present but mentally elsewhere.

As an example, consider what transpired during our observations of one of the HFA children in our study, Don, during an art appreciation class with no aide present. The teacher and Don's classmates focused their primary attention on analyzing an art slide projected on a screen in front of the room. They appeared seemingly unaware that Don's body and eye gaze remained oriented in a completely different direction from the projected image throughout much of the lesson and that he remained silent and unresponsive. The children seated at the same table did not nudge him; the art teacher, who was busy responding to the other students' lively comments on perspective and balance in Monet's painting, did not realize that Don had drifted nor, moreover, that this class activity presented a challenge to Don, given that one of the central deficits of autism is precisely a difficulty linking parts into a coherent whole (Frith, 1989; Happé, 2000).⁸

The school day of Erin, the child whose diagnosis of autism had been unknown to the school district, also was marked by long stretches in which she was silent and apart. In Erin's classroom there was no aide. Although Erin's teacher made sure that each student answered at least one question posed during a lesson, she did not seem to realize that Erin always answered certain types of questions (e.g. 'What color is Ireland on the map?') then drifted off for others (e.g. 'Why did immigrants leave their countries to come to America?'). During one social studies discussion we video recorded. Erin went to the pencil sharpener and sharpened one pencil after another for an extended period of time during question period. At Erin's table and throughout the room, classmates were intermittently engaged in sotto voce chatting and making faces to one another, but Erin was never involved in these exchanges. At lunch time, classmates lined the picnic table benches bantering and laughing, while Erin often sat with her body and eye gaze oriented away from those seated at the lunch table. The combination of Erin's presence as an incognito autistic, leaving her teacher and her classmates in the dark about her capabilities, and Erin's kinesic signals of remoteness created conditions of default neglect which exacerbated her status as a social isolate.

Rejection and Scorn

Beyond spates of passive neglect, certain HFA children were at times explicitly rejected, and their odd behaviors openly scorned by their classmates. While censure is an integral component of childhood socialization, and therefore is critical to a HFA child's socialization into conventional expectations, censure was voiced in an unsympathetic, sometimes derisive, manner in the cases discussed here. Although Erin was not the only child in our study to be spurned by peers, she was, unlike the other HFA children, subject to such negative remarks both in the classroom (in proximity of the teacher) as well as during unmonitored play yard encounters. In our view, classmates'

lack of informed understanding about Erin's disorder led them to be bewildered, disturbed, and frustrated by her unusual behavior, and sometimes to reject her in strong terms.

During a computer lesson, Erin was ousted from her computer station by a classmate, Joanie. Erin initially sat behind Joanie, gazing at the computer screen over Joanie's shoulder, while Joanie operated the computer game. Suddenly, Joanie commanded Erin to move away, and pointed over her shoulder to another part of the room¹¹:

```
→ Joanie: [Uh (pause) G- go over there
(pause) OK?
[((looking at screen. pointing over her shoulder with her index finger))
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Erin, however, continued to stare at the computer screen and softly commented on the game Joanie was playing. When the teacher approached, Joanie twisted around to face the teacher with her back to Erin and, pouting, asked the teacher to move Erin elsewhere, referring to Erin in the third person:

```
Teacher: Joanie and Erin, you're sharing?

→ Joanie: ((turns to teacher with back towards Erin, makes pained face))
[Can she go over there, because last time I had to share with her.
[((Erin continues to stare at computer screen))]
```

The teacher initially refused Joanie's request, and Joanie frowned in response. Rather than mediating and scaffolding a direct interaction between the two girls, however, the teacher continued Joanie's practice of using the third person pronoun to refer to Erin:

```
Teacher: ((looks behind her then back to Joanie))

→ [Oh well actually this was her computer first so:—
[((points with thumb and index finger pinched together to computer))

→ Joanie: ((makes a face, frowns, turns head away from teacher & Erin))

Teacher: This has always been her computer so:—
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In this exchange, the teacher left her utterance unfinished, leaving it up to Joanie to discern the appropriate next move. Instead of resolving to collaborate with Erin, however, Joanie requested that she herself be moved to another computer, and contorted her mouth into an exaggerated scowl. In other words, Joanie was willing to relinquish her particular position at the computer but not to be Erin's computer partner:

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Teacher: [((disapproving face))

→ Joanie: [So what computer can I play on
[((twists face in scowl, bites lower lip))
[((Erin steadfastly stares at computer screen))
```

In the aftermath of this exchange, the teacher allowed Joanie to remain seated at the computer, instead directing another child to vacate his seat and moving Erin to this child's computer station. In this manner, through both words and actions, the teacher reinforced Joanie's negative stance towards and rejection of Erin.

In another incident during lunchtime recess on the playground, classmates scorned Erin as an oddity. At first, Erin was seated alone on a bench, watching the boys play kickball from the sidelines. Suddenly, she began jiggling her legs, and then also flapping her hands in the air, while simultaneously bobbing her head and making loud, rhythmic vocalizations. Several children approached the bench, observing and commenting on Erin's behavior, as indicated by classmates Jenny and Gary's comments below:

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→ Jenny: [What's your ↑problem↓

[((sits down some distance from Erin))

[((Another girl (Katie) approaches, looking at Erin

Erin: ((ceases repetitive movements and vocalizations but holds teeth clenched,

turns to look towards Jenny and Gary))

→ Gary: [What the [heck is ↑she doing

[((leans towards Jenny))

Jenny: [((looks towards Gary, half-smiling, shrugs shoulders))

Erin momentarily stopped but then resumed her jiggling motions. She began vocalizing loudly as two other classmates, Katie and Alison, sat down on the bench facing Jenny, with their backs turned towards Erin. At this juncture, Erin attempted to secure Alison's attention by gazing towards Alison, calling out Alison's name, emphatically rapping her knuckles on the bench, then leaning over Alison's shoulder:

```
    → Erin: [Alison! ALISON!
    → [((looks towards Alison))
    → ((pause))
    → [Watch this!
    → [((raps knuckles on bench))
    → [Watch this.
    - ((scoots down bench and leans over Alison's shoulder))
```

After the girls ignored her, Erin made one more attempt to garner Alison's attention:

```
→ Erin: [Alison!
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→ [((breathy voice, presses palm forcefully on bench))

((pause))

 \rightarrow Erin: [Watch.

→ [((breathy voice, moves back to end of bench))

→ Watch this!

Alison pointedly did not respond, shielding her view of Erin with her hand. Eventually, however, she turned to face Erin. Once Alison's attention was secured, Erin smiled. She next reproduced her jiggling motions and vocalizations as a performance for her newly acquired audience then halted suddenly, her hands in midair, staring at her classmates with a rigid grin. Rather than validating Erin's performance, the children dismissed it. The girls immediately turned away from Erin, and Gary invited the group into a choral disapproval of Erin by posing the question, 'What the *heck* did she just do?' Erin once again was invisibilized through means of third person reference, and was given the cold shoulder through a combination of verbal and physical rejection. Following this exchange, Erin ran off in the direction of the open yard.

Reactions of HFA Children to Isolation, Rejection and Scorn

The functional gaps in sociability associated with autism suggest that HFA children may experience acts of isolation, rejection and scorn directed towards them differently than do non-affected children. As noted, children with autism have a diminished capacity to recognize conventional vocal, facial, and gestural cues associated with others' expressed emotions and social goals (Capps, Yirmiya & Sigman, 1992; Heerey, Capps & Keltner, 1999; Hobson 1986a, 1986b; Jaedicke et al., 1994). Nonetheless, our study yields a more complex picture of HFA children's awareness of expressed negative emotion. The children we observed varied in their demonstrated reactions to negative emotions directed towards them. On the one hand, the children may appear impervious to social isolation, rejection, and scorn. Yet, on the other hand, they may

immediately display appropriate behavioral responses, such as ceasing the offending behavior or re-framing and normalizing the offending behavior as an entertaining performance. Further, at a later point in time, they are able to narrate and reflect upon negative social encounters with their family.

On some occasions, the children appeared to be *oblivious* to negative remarks. Throughout the entire interchange in which Joanie rejected Erin as her computer partner, Erin displayed no overt response. Instead, even when the teacher and Joanie discussed the matter of sharing the computer, Erin sat motionless, with her gaze fixed upon the computer screen.

Does Erin's behavior in this situation mean that she is impervious to the act of rejection by a classmate? The incident provoked by Erin's jiggling on the play yard bench evidences that she indeed is sensitive to peers' negative assessments of her. In this specific instance, Erin displayed two interactionally relevant responses: First, Erin temporarily *ceased* jiggling and vocalizing immediately following Jenny's exclamation, 'What's your problem'. A bit later, while classmates were huddled with their backs to Erin, she tried to secure their attention and once it was secured, she re-enacted the jiggling and vocalizing as a *performance*. All the while, Erin smiled, as if taking on the role of a class clown entertaining the other children. Erin's performance can be interpreted as an attempt to normalize her symptom displays, as she demonstrates that she can control when they begin and end. Relatedly, this can be understood as an attempt on Erin's part to turn a negative inclusion experience into a positive one.

Further evidence that HFA children can be aware of others' negative reactions towards them comes from recorded communication between the children and their parents after school and during dinnertime in which they recount the day's events, including troublesome incidents at school. Some of the HFA children offered detailed accounts, while others needed to be cajoled into telling what transpired. On several occasions, we witnessed a HFA child, Jason Chang, being bullied by a classmate, Jeremy Murray. These incidents became topics of family conversations. In the following dinnertime exchange, Jason's parents used Chinese and English to probe whether or not their HFA son had been bullied by Jeremy Murray at school. Like many children, Jason at first was reluctant to disclose the incident when his mother tried to probe in a concerned manner:

Mother: Jeremy Murray jin tian you mei you ni jian hua.

Did Jeremy Murray talk to you today?

(1.0 sec pause)

Jason: Huh?

(2.0 sec pause)

Mother: Jeremy Murray

(1.0 sec pause)

Zai shue shao you mei you gen ni jian hua?

Did he talk to you at school today?

(2.0 sec pause)

Jason: He talked to me but

Mei you yi yi de hua

→ It was nothing worth mentioning

(1.0 sec pause)

Mother: Mei you yi yi de hua

It was nothing worth mentioning

Father: [((Unintelligible in Chinese))?

((What did he say?))

Mother: [She me jiao mei you yi yi de hua

Inclusion: Autism 411

What does 'not worth mentioning' mean?

(1.0 sec pause) (Unintelligible)

→ Jason: **I don't know**

(4.0 sec pause)

Mother: Ta ge ni jian shen me?

What did he say to you?

'I don't know'

After minimizing what transpired, Jason began to recount a disturbing school encounter with Jeremy Murray:

 \rightarrow Jason: I: (.) Actually (6.0) actually

(2.0) he pick on me—he picked on me today.

Jason's mother tried to elicit the cause of Jeremy Murray's offense, but Jason seemed bewildered:

Mother: Really? °Why°? Jason: I don't know

 $[\ldots]$

Mother: Ta zhen me

How did he (2.0 sec pause)

How did he pick on you, what did you do↓

(3.0 sec pause)

→ Jason: [I didn't do anything.
 Mother: [(Why he pick on you?)
 → Jason: He just bothers me a lot.

Mother: He bother you a lot? Jason: ((nods his head))

Mother: °Oh°

Like what?

Jason: Like what

When Jason's father asked Jason how he handled being bullied, Jason reported that he had greeted Jeremy ('hello'):

Father: [So how you handled it? Mother: Like what Jason? Father: How do you handle it?

(1.0 sec pause)

→ Jason: I say 'hello'

But this strategy, which had worked on a previous occasion, did not help him on this occasion:

→ Jason: ((animated)) When I say 'hello' to him

He says 'AAAAH' He gets scared.

Father: Pretend
Mother: [uh hmm
Father: [uh hmm

(2.0 sec pause)

Mother: [It's OK, it's alright Jason

Jason: [But I

Then he walked away, So I wanted to do that

→ But it wo- (.) it worked in the first place but now it didn't.

Jason's mother then suggested a future strategy for dealing with Jeremy Murray, namely to ignore him, and Jason agreed:

Mother: But Jason it's not worth it to-

(2.0 sec pause) to get ups- upset

or pay attention on him

Jason: °uh hmm°

Mother: Just ignore him OK?

→ Jason: I just pretend that Jeremy Murray wasn't here.

Mother: Uh hmm.

(1.0 sec pause) That's a smart way

Jason: [OK Father: [°hmm°

→ Jason: I wonder why Jeremy Murray do this to me

→ Mother: °I don't know°

This narrative interaction suggests that HFA children are aware of and are distressed by specific acts of rejection and scorn directed towards them. The final turns of this exchange indicate as well that the distress experienced by a particular negative school encounter can not be tidily put to rest by parents but may remain unsettled in a child's mind.

In summary, all the HFA children in our study were at times neglected, rejected, and scorned in the school setting, but those children whose diagnosis was held confidential tended to have more of these experiences. In addition, despite their symptomatic difficulties in interpreting others' intentions and feelings, our observations indicate that HFA children can be cognizant of and distressed by others' derisive stances and acts.

Positive Inclusion

Positive inclusion refers to social interactions in which others attempt to include a child with disabilities as a participant in a focal activity and/or as a member of a social group. In this study, positive inclusion transpired when members of the school community displayed positive affect towards HFA children. Classmates, for example, would demonstrate or explain what to do, patiently correct the HFA child when he or she acted inappropriately, acknowledge yet minimalize certain symptom displays, give the child credit for good ideas, and/or befriend him or her.

Among the children in the study, Mark and John, the two HFA children whose families fully and elaborately disclosed their condition, generally were immersed in a positive inclusion environment.

Significantly, the boys' Full scale IQ scores differed by 50 points: John's Full scale IQ score was 77 while Mark's was 127. In addition, Mark's and John's schools differed radically in their socio-economic and ethnic make-up. Mark's school is located in an affluent and predominantly Caucasian American neighborhood. John's school is situated in a low-income area, populated predominantly by Asian American (70%) and Latino families (20%). Yet, the classroom atmosphere in both schools had much in common: The children usually were supportive of their fellow students with autism. John's classmates, for example, frequently acknowledged and adopted John's suggestions. In the interaction below, John's teacher and classmates support his idea for miming a Christmas carol during a rehearsal for the school's Christmas show:

 \rightarrow John: I got an idea,

Teacher:

we can, uh, get a, get like these little uh,

uh, like, many thingies, >you know like books,< and then start like singing,

thingies

>you know like< Oh::: Yeah::::!

→ Students: ((chorus of voices indicate approval))

At times a student would fail to acknowledge John's suggestions. In these situations, the classroom aide and/or other children would intervene. In a group project that we recorded, John repeatedly suggested stabilizing a straw tower by running a straw up the middle of the tower, with additional straws running to the four corners of the tower:

- → John: **Do the bottom like that, look.**
- → Let's put one in the middle,
- → We need something to make it stronger.
- → We put one in the middle.
 Connect those thing that it's holding on the bottom.
 And then connect all of these four corners to this one pole.

Eventually, Kevin accepted John's proposal with modifications:

→ Kevin: No not all four corners, just the bottom and a couple on top.

Afterwards, Kevin claimed sole credit for their successful efforts:

→ Kevin: Hey, look what I did eh, it works. It stuck.

When classmate Sammy asked who had the good idea, Kevin again claimed authorship:

Sammy: Whose idea was it?

→ Kevin: **Mine**

But Sammy and John's aide publicly announced John's authorship:

→ Sammy: Are you sure-

→ Aide: I thought it was John's idea.

Kevin: No, he just said 'Connect it so it can be stronger'.

[But I (xxx)

The aide, along with a second classmate, both doubted Kevin, while Sammy chided him for being 'jealous':

 \rightarrow Aide: {We::Il. \uparrow ((pause))

 \rightarrow Jeffrey: It was (his) idea.

Aide: Uh s long as you guys work together, that's all.

 \rightarrow Sammy: **He's jealous.**

A similar atmosphere prevailed in Mark's school. Mark's teacher and classmates were compassionate, even when annoyed by his occasional disruptive behavior. In the exchange that follows, Mark's teacher and the other children at his table sympatheti-

cally yet firmly reproached Mark for making noises into the microphone and disrupting a reading-skills game. Initially, Mark's teacher reprimands him. When Mark persists in blowing into the microphone, the children collaboratively manage to halt his disruptive behavior and draw him into the card game:

Mark: ((leans in closer to the microphone and begins singing the theme song to Star Wars and imitating Darth Vader's loud breathing))

→ James: Mark, Mark, shhhh.

→ Kathy: Mark, MARK, MARK↑ [MARK, MARK.

→ ((puts hand on Mark's shoulder))

→ James: [Mark, please.

→ ((puts hand on Mark's head))

Mark: Just doing Darth Vader imitations to that thing.

→ Kathy: Yeah, but it interferes with the sound.

→ James: ((to Kathy)) [Uh, is it his turn

[((pointing at Mark))

Kathy: Yeah.

→ James: ((turns to Mark)) Mark, your turn. Mark: ((picks up and reads a card)) Foil.

Peer interactions such as the above suggest that positive inclusion is enhanced through the disposition of enlightened classmates as well as teachers and aides. In contrast, in other classrooms that we observed, positive inclusion was accomplished through interventions by aides, if they were provided in the classroom. In these situations, HFA children sometimes actively elicited help from aides; at other times, distracted HFA children's attention was redirected by these paraprofessionals. For HFA children without aides, opportunities for positive inclusion were restricted by the extensive work load of the teacher, who simply could not monitor the HFA child at the same time as meeting the instructional needs of the class as a whole.

In summary, in the inclusion classrooms we observed, positive inclusion initiatives by peers were more prominent in schools where family and staff worked together to create a class-wide dialogue about autism, as compared with schools in which the disorder was minimally or never acknowledged. Classmates unaquainted with autism, however, *did* scaffold HFA children's inclusion in two important social contexts: 1) when a HFA child was a *member of a sports team during structured play activities* and 2) when another marginalized classmate *befriended* a HFA child.

In sports activities, Erin's team mates paid attention to her abilities and disabilities. Given that her prowess was needed to win a game, classmates urged and cheered her to the finish line during relay races. Softball team mates also instructed her how to hit the ball:

```
→ Ricki: Erin (.) Swing [like that okay? [((swings bat horizontally))
```

Erin: ((approaches, reaching for bat))

→ Ricki: [Not like this]

((swings bat angled more vertically))

→ [Straight like that okay?
 → [((swings bat horizontally))
 ((hands Erin the bat,))

Erin's classmates applauded her when she managed a hit, even though she reached first base too late and was declared 'out'.

A second circumstance evidencing classmates' supportive stance towards a HFA child was *friendship*. In certain inclusion classrooms, another marginalized child in

the class—e.g. the only African American child in the class, a Russian immigrant, a child with undiagnosed learning problems, a newly arrived child—sought out the HFA child as a companion. These children were affectionate, even when the HFA child was uncomprehending of their affect. In one playground interaction, Karl (a HFA child) was spinning around in circles, when his African American friend, Eddie, ran up and hugged him. As they wandered the yard together, with Eddie's arm slung around Karl's shoulder, Karl asked Eddie why he always wanted to play with him:

```
Eddie:
          [Whadya doin'?
          [(running up to Karl, hugging his arm))
          ((Eddie puts arm on Karl's shoulder, walks alongside him))
          [Whad'ya doin'?
          [((strokes back of Karl's head while walking with him))
 Karl:
          Battle (Fight)
          (pause)
          (I'm just uh- Let's see)
          We should find the (true) submarine.
 Eddie:
 Karl:
          ((stops, pivots to face opposite direction, disengaging from Eddie's arm))
          [Why do you always play with me]
Karl:
          [((looking down, walking, while Eddie puts arm back around Karl's
          shoulders))
          (pause)
Eddie:
          (W-) You're my friend!
 Karl:
          [Oh look! There's Kenneth!
          [((smiles, points and looks to Kenneth then to Eddie))
          ((Karl and Eddie run off in the direction of Kenneth))
```

Such exchanges indicate that certain peers may be less fazed by the occasional oddities of HFA children and that, with their help, HFA children are able to experience friendship.

Conclusion

Although the sample size is small, our ethnographic observations and recordings of the everyday experiences of HFA children in mainstream classrooms suggest that positive inclusion may vary in relation to disclosure practices. Positive inclusion experiences appear to be facilitated by peer awareness of the capabilities and impairments of HFA children. Among the families who fully disclosed the child's condition, positive inclusion was enhanced when the child, the parent, or a clinician who knew the child engaged the child's classmates in a discussion about autism and introduced the HFA child as a whole person, complete with likes, dislikes, strengths, and weaknesses.

While not a specific focus of our study, we were intrigued regarding whether there might be a relation between the HFA children's IQ levels and positive or negative inclusion in their classrooms. Children in our study who routinely experienced positive inclusion varied greatly in their IQ scores, ranging from 73 to 139. This variability suggests that peer awareness of the autism diagnosis, more than the HFA children's IQ scores, impacts the success, or lack of thereof, of the inclusion process for high functioning children with autism. This possibility is an important area for further investigation.

A striking finding in the analysis of negative and positive inclusion is that the *student* atmosphere varied dramatically across the schools we observed. Specifically, the range of classmates who were agents of positive inclusion (e.g. offering assistance and friendship) expanded in relation to the manner in which the child was introduced to other children in the class. As noted earlier, Erin spent most of her school day co-present but socially disengaged from her classmates. Even under the watchful gaze of the teacher, other students rarely elicited (nor were encouraged by the teacher to elicit) Erin's involvement in a group activity. Outside the context of being a class team member, Erin tended to be ignored or rejected by her classmates. In contrast, HFA children whose condition was explained to classmates had positive social interactions with a wider range of classmates. Some of these children had special friends who themselves were marginalized from the hub of popular student life. In classrooms where the child's situation was a topic of extensive class-wide discussion, classmates worked collectively to incorporate the HFA child into academic or recreational activities.

While no inclusion classroom is immune to negative inclusion practices such as neglect, rejection, and scorn, the cloak of confidentiality fans the possibility of their occurrence. A HFA child, for example, is more likely to be neglected by busy classmates and teachers who have not been primed to notice the child's social withdrawal nor to understand when and how to intervene. Further, when symptom displays are noticeable, such as when a HFA child jiggles, flaps hands, spins in circles, and/or vocalizes, the bewilderment of classmates can metamorphose into explicit derision of the child.

Although children with autism sometimes appear impervious to rejection and scorn, they can be hurt by these experiences and/or become anxious to revise their public self-image. Notably these findings echo Bullock's (1988) observations of the active strategies employed by children with mental retardation to prove themselves as competent members in inclusion settings. When Erin's classmates catch her jiggling on the play yard, she tries to show them that she is only clowning around. When a boy in Jason's class jeers at him, Jason recounts the incident to his parents at dinnertime, bemoaning his inability to handle such recurrent encounters. As they mature, many children with autism voice frustration at their lack of fit in peer environments (Attwood 1998; Frith, 1989; Sigman & Capps, 1997).

Thinking, feeling, and acting in the world outside the parameters of ordinary expectations, children with autism perceive sounds, textures, tastes, odors, colors, and visual details with a vividness rarely experienced by their unaffected peers (Grandin, 1995). It is unrealistic to expect that children without autism, rooted in biology and culture, can shed their self-consciousness and conventionality to imagine the world through autistic eyes. Yet, giving autism a greater dialogic space in the school curriculum may enhance the perspective-taking skills and nurture the creative potentialities of all children in inclusion classrooms.

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Notes

- 1. This analysis is part of a larger study 'Socializing Autistic Children into the Rules of School and Family Life,' directed by Elinor Ochs and funded by the Spencer Foundation for Educational and Related Research (2000–2003). The data were collected during a Spencer-funded project 'Autistic Children's Narrative Interactions at School and Home,' co-directed by Elinor Ochs and Lisa Capps (1997–2000). The narrative project included research teams at University of California, Los Angeles and University of California, Berkeley. The bulk of ethnographic data collection and transcription was undertaken by the UCLA research group, while Autism Diagnostic Interviews and Autism Behavior Checklists with parents, as well as autistic children's intelligence tests, theory of mind and empathy tasks were administered by the UCB group. We gratefully acknowledge their contribution.
 - 2. Three of the children were assisted by aides.
 - 3. The inclusion history of one child was not known.
 - 4. The names of all individuals have been changed.
- 5. Although Erin's diagnosis was disclosed to school officials and the teacher, neither initiated further disclosure practices in the classroom nor sought to obtain further information about autism from the research team.
- 6. This meaning of neglect is found in The Oxford English Dictionary as 'the fact of disregarding, slighting or paying no attention to, a person etc.' (Waite & Weiner, 1995).
- 7. Bullock (1988) makes this point for the population of children with mental retardation observed in his study.
- 8. Frith (1989) refers to this deficit as a lack of the drive for central coherence. In puzzle tasks, for example, children with autism display difficulty in piecing together parts of a body to compose the figure of a girl or a horse.

- 9. Audio and video recordings of Erin at home attest to the fact that she chatters at length with her sister and parents in the mornings getting ready for school, in the afternoons after getting home from school, and during family dinnertime. This prolix behavior contrasts sharply with the mute persona that Erin displays during school hours.
- 10. Autistic children generally benefit from explicit and detailed instructions about how to conduct themselves in social situations (Attwood, 1998).
 - 11. Transcription Conventions
 - . The period indicates a falling, or final, intonation contour, not necessarily the end of a sentence.
 - ? The question mark indicates rising intonation, not necessarily a question.
 - , The comma indicates 'continuing' intonation, not necessarily a clause boundary.
 - ::: Colons indicate stretching of the preceding sound, proportional to the number of colons.
 - A hyphen after a word or a part of a word indicates a cut-off or self interruption. word Underlining indicates some form of stress or emphasis on the underlined item.

WOrd Upper case indicates loudness.

- ° ° The degree signs indicate the segments of talk which are markedly quiet or soft.
- > < The combination of 'more than' and 'less than' symbols indicates that the talk between them is compressed or rushed.
 - <> In the reverse order, they indicate that a stretch of talk is markedly slowered.
 - = Equal sign indicate no break or delay between the words thereby connected.
 - (()) Double parentheses enclose descriptions of conduct.
- (word) When all or part of an utterance is in parentheses, this indicates uncertainty on the transcriber's part.
 - () Empty parentheses indicate that something is being said, but no hearing can be achieved.
 - (1.2) Numbers in parentheses indicate silence in tenths of a second.
- (.) A dot in parentheses indicated a 'micropause', hearable but not readily measurable; ordinarily less than 2/10 of a second.
- [Separate left square brackets, one above the other on two successive lines with utterances by different speakers indicates a point of overlap onset.
 - hhh letter 'h' indicates hearable aspiration.
- 12. Related to their diminished ability in understanding entities as parts of a larger structure, children with autism experience difficulty organizing events and psychological states as elements that form a temporally and causally coherent narrative (Baron-Cohen et al., 1986; Tager-Flusberg, 1995).