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Lessons from the 1%: children with labels of severe disabilities and their peers as architects of inclusive education

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The 1% of US students with labels of severe disabilities including mental retardation have been historically excluded from ‘inclusive’ education, and from the important epistemological, political, pedagogical, and pragmatic currents in systemic education reform. They have been also been excluded from the design of, and participation in, the general academic curriculum. With ever increasing emphasis on academic goals, assessment and achievement standards are legally mandated to promote access to and progress in the general curriculum for ‘the 1%’. This study utilizes symbolic interaction to explore children’s construction of their own inclusive education in academic and social contexts. Symbolic Inclusion and Symbolic Exclusion are posited as constructivist definitions of inclusion, which transcend a traditional, one-dimensional measure of time spent in the presence of children who do not have disabilities. Symbolic Inclusion and inclusive pedagogical practices are found to be instinctively and effectively utilized by a child with Rett syndrome and her peers with and without disabilities, though they were given exclusionary models by paraprofessionals, and limited opportunities for interaction. Recommendations to facilitate Symbolic Inclusion are suggested based upon Disability Studies in Education frameworks.

Introduction

On the kitchen table in the fourth-grade life skills classroom, a Betta fish named Red lives with a philodendron plant in a small vase half filled with water. Today Red’s water ripples, as the fourth graders dash around the room. They are making last-minute preparations for a very special guest.

Annabelle,1 dressed in velvet and lace for the occasion, is a notorious hugger. Already today she has hugged three teachers and a researcher. Ethan, a creative writer

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and Special Olympics athlete, can weave all ten of the week’s spelling words into one stunning sentence. Katy, when asked what languages she speaks besides English, replies: ‘Magic, a little Spanish, and Sign.’ Krystal can restore order to an unruly classroom with the skill of a veteran teacher. She eliminates off-task conversations with a stern glance, straightens pictures on the wall, and paces in front of her classmates’ desks to observe their work. Sammy is a law-abiding, quietly competent child. But today he was reprimanded for running in the hall, and bursting into the classroom through the forbidden side entrance. Breathless, he asked: ‘Where’s Lynda?’

Now she is here — Lynda — their classmate who has been absent for nearly a month! Lynda has deep, brown eyes with eyelashes so long they cast shadows on her fair face. She resembles Snow White, but she is much more independent and wide awake. Lynda’s long, dark curls are tied back with a purple ribbon. It matches the two purple casts that embrace her from ankles to hips. She is enthroned on a padded wheelchair that will keep her legs thrust stiffly out in front of her for about four weeks.

Lynda’s mom lets go of the wheelchair and steps out of the way as the children surround her. They are hugging her, piling presents on her lap, signing her casts. She is smiling. With the skill of highly paid parking valets, Krystal and Sammy manoeuvre the wheelchair up close to the kitchen table. Red’s water stays smooth as glass. The chair does not bump into anything! The adults seem spellbound. Is anyone (besides the researcher) holding her breath? The label ‘medically fragile’ is appropriate here. But the children have never heard it.

Sammy holds Lynda’s hand while Krystal helps her eat a cookie. Lynda chokes on the bit of cookie, then recovers. Ten hands help Lynda open her presents. Annabelle explains the frenzy: ‘We missed her long!’ Later, when she visits her inclusive social studies class, the children will admire Lynda’s beautiful painted toenails and ask her if she liked the cookie bouquet, balloons, and cards they sent her to celebrate her surgery. Lynda will be tired from her visit, but she will continue to smile.

Lynda has just had the surgery that her physical therapist and paraeducator were talking about last month, as if Lynda were not there. But Lynda was there; and she frowned and whined when she heard:

They’ll do a hamstring release and cut her heel tendon. She’ll be in full leg casts. If they decide to correct the scoliosis at same time she’ll be in a full body cast for months. After that, with Rett’s, they usually never walk again.

(added emphasis)

Lynda’s family moved across the country to find this inclusive school for Lynda; and they are pleased with her placement. Even so, her mother wonders:

What does Lynda think? Does she just give up — ‘Well, this is the way it’s gonna be. They’re gonna talk about me like I’m just this thing for the rest of my life’. You know, I always wonder, what does she think?

Talking about Lynda this way is a form of ‘Medical Othering’, defining Lynda by her symptoms, and as if she were so diminished by her disability that she was mentally
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absent from the room. Lynda’s peers consider her symptoms to be similar to their own medical adventures, as they indicate by ‘Medical Sharing’. For example, in a presentation by Lynda’s mother about Rett Syndrome, her classmates offered: ‘I have Tourette’s syndrome.’ ‘I had a seizure.’ ‘My dog had a heart attack.’ Katy shared a trip to the hospital that ‘sucked’.

When I was like three, I taked my mother’s pills. I thought they were candy and they were blue. And I couldn’t speak. And guess what happened. I went to the hospital and I had to drink charcoal and then I spit up on my mom’s shoulder.

These examples help to illustrate the continuum of exclusive and inclusive interactions with Lynda, a child who is labelled with severe disabilities. The following research explores the wisdom and competence of Lynda and her peers, as architects of inclusive education.

Background

Inclusive education in the USA is subject to confusion and debate among various discourses and disciplines. Seemingly irresolvable tensions exist between equity and excellence, civil rights ideals and pragmatic practises, and standards-based education reform and the call for collaborative, multicultural learning communities (Artiles, 2003; Biklen, 2007; Kavale, 2002; Skrtic, 1991). In the language of US public education policy, ‘inclusion’ refers to the physical location in which a child with disability labels receives special education and related services, or a percentage of the school day spent with non-disabled peers. Since the enactment of Public Law 94-142 (1975), the US federal government has required public school students with all types of disabilities to be educated in the least restrictive environment — ‘to the maximum extent possible … with children who do not have disabilities’ (20 U.S.C., § 1412 [5] [B]). But the 1% of students with labels of severe disabilities (i.e., with special education labels such as mental retardation and multiple disabilities) are still isolated in special education classrooms.

Over 50% of students with labels of mental retardation, and 45% with labels of multiple disabilities, spend at least 80% of their school day in segregated classrooms (National Center for Education Statistics, 2005). Inclusive education policy and practice informed by disability studies explores the lived experience of such marginalized minorities, who still receive a separate, unequal education.

While the academic, standards-based education movement was under construction in the 1980s, special educators were developing a ‘functional’ curriculum for children with labels of severe disabilities. A functional curriculum teaches access skills (communication and mobility) and life skills (daily living competencies), which neither promote nor require an understanding of general academic content (Browder et al., 2006). Galvanizing the paradigm of standards-based education reform, the No Child Left Behind Act of 2001 (2001) held schools accountable for challenging standards of student achievement in reading and math, to be measured with rigorous, state-created, standardized tests. For students with labels of severe disabilities, states
were allowed to develop alternative achievement standards. These standards were required to promote access to, and progress in the general curriculum, and reflect the highest possible achievement.

With the emphasis shifting to academic goals, for which the assessment of functional skills is not required by NCLB, 21st-century US educators struggle with new questions about inclusion. Can the omission of academic content for a designated group of students ever be justified? What is the proper balance between functional and academic curriculum content? To what extent are current state standards relevant to maximizing students’ adult potential (Browder et al., 2006; Wehmeyer, 2006)?

If these questions were asked for all children, the answers could contribute significantly to systemic education reform. But they can more easily slip into the negative context of ‘problems’ associated with educating the 1%. Since the law does not specifically define the context where these students will access the general curriculum, the answers to these questions may result in expanded opportunities for inclusion, or strengthen the historic trend toward separate and unequal placements (Spooner et al., 2006).

**Decisions about them are made without them**

The voices of children with labels of severe disabilities are missing from the important epistemological, political, pedagogical, and pragmatic currents that will shape their future. They have been historically excluded from all aspects of the design, research, development, adoption, and validation of the general curriculum (Hitchcock & Stahl, 2008). Even within the field of inclusive education research, their voices have been virtually silenced (Snelgrove, 2005). In the rare instances where children with labels of severe disabilities achieve access to the general curriculum, mere access does not promote authentic participation (Wehmeyer, 2006). They continue to experience ‘educational segregation, inappropriate curriculum, lack of supports and services, and social rejection’ (Kluth et al., 2007, p. 43).

For children who use alternative and augmentative communication, opportunities for rich literary experiences are rare goals, seldom achieved (Koppenhaver, 2000). Even when children with disabilities are given access to literature, they find a significant lack of children’s books that have integral characters with disabilities (Blaska, 2004).

There is a need for educators, policy makers, and researchers to hear from, as well as about, children with labels of severe disabilities. What are the meanings and interactions of social and academic inclusion as they are constructed and experienced by children? What is the nature of the power, or lack of it, which children exert on their own learning environments? The purpose of this study was to explore children’s construction of their own inclusive schooling. The research question was: What is the lived experience of a child labelled with severe disabilities, and her peers with and without disabilities, in an ‘inclusive’ school environment?
Methods

This study utilized symbolic interaction (Blumer, 1969) to explore children’s constructions of inclusive education. Data were reported in the form of a case study (Miles & Huberman, 1994). Symbolic interaction operates on the premise that we shape our behaviour by the stimuli and objects we ‘take into account’ (Sandstrom et al., 2003, p. 11), and how we define them. Symbolic interactionist research is considered ‘from the position of the actor’ (Blumer, 1969, p. 73), as individuals develop awareness of their own being by attending to and interacting with selected aspects of the environment (Mead, 1934). Symbols have meaning because group members use them in a consistent way. They make it possible to transfer mental states from one person to another. Our symbolic involvement in society is essential for the realization of human potential (Blumer, 1969; Sandstrom et al., 2003). This assertion is compatible with the social model of disability (Oliver, 1996), which views disability as a socially constructed phenomenon.

While symbolic interaction acknowledges the influence of habit, and of social forces and constraints beyond individual control, symbolic interaction also grants us individual freedom and flexibility in our choice of actions. This flexibility gives us the power to give new meanings to things, and thereby reconstruct or transform society (Blumer, 1969; Sandstrom et al., 2003).

Constructivist sampling

My sampling frame required the participation of a child with a label of severe disabilities, who was placed with non-disabled peers in both academic and social situations at school. The search for this relatively rare situation led me to a rural intermediate school with 474 students, serving grades four and five. The site served as a constructivist sample (Harris, 2003), wherein inclusion of students with disabilities in general education was described and understood as a defining philosophy and practice by educators and administrators.

This study explored the lived experience of Lynda, a 12-year-old girl with Rett syndrome, in situations that presented the possibility of interaction with non-disabled peers. Lynda was included with general education peers in fifth-grade homeroom, science, physical education, music, art, lunch, and social studies. She and her peers with disabilities spent the remaining, approximately 20% of their day in a self-contained classroom for instruction in functional skills, and modified math and reading.

This was research in which ‘a personal valuing of the work [was] expected’ (Stake, 1998, p. 135). In a qualitative study, the researcher is a primary instrument of data collection and analysis. In the practice of education, the educator interacts from ‘a theoretical stance’ (Friere, 1985, p. 43). As a qualitative researcher and educator, my theoretical stance includes: a desire for equity and excellence in education via systemic reform, the preparation of teachers who work toward social justice for all children, and the recognition and valuing of children’s wisdom and competence as architects of their own schooling.
A pervasive context of a school ‘doing inclusion right’ was communicated during initial site selection. Even so, school administrators set boundaries for the study, which likely filtered out disagreements and opposition to inclusion. Inclusion was in its second year of implementation. The assistant principal had introduced inclusion over the objections of some of the teachers, by eliminating a special education resource room that served their content areas. I was not allowed to interview or observe teachers who did not participate in inclusive classes, or parents of children without disabilities who may have objected to Lynda’s inclusion. Since the study was designed to explore ‘inclusive’ situations, I accepted these restrictions.

I was permitted to interview teachers and paraeducators who participated in inclusive education for Lynda and her peers with various disabilities, and observe her classes and homerooms. I was permitted to observe and speak with Lynda, interview her parents and her sister, and observe and interview Lynda’s five special education classmates and 18 general education classmates who volunteered for Circle of Friends activities.

Circle of Friends (Hamill & Everington, 2002) is a programme designed to facilitate inclusive academic and social interactions. In Lynda’s Circle, this involved non-disabled peers ‘helping’ and interacting with students with disabilities. They served as peer instructors for academic work, played games, cooked, and did art projects. Circle of Friends activities took place in the life skills classroom for fifteen to twenty minutes, once or twice a week, at the end of the school day.

I conducted and recorded semi-structured, individual interviews with children. We met privately in the school conference room during the last twenty minutes of the school day, when they would ordinarily being participating in recess or Circle of Friends. I asked each child: ‘What is a “friend”?’ and ‘What kinds of things do you and your friends do together?’ Once definitions and activities of friendship were established, I noted that the children had volunteered for Circle of Friends. I asked them what they did, and if they knew Lynda. Since helping with school work was a Circle of Friends activity, I asked if the children had taught Lynda anything, and if they had learned anything from her. At the end of each interview, I asked: ‘If you were going to introduce Lynda to the sixth graders, who have never met her, what would you say?’ Unstructured, audio-recorded interviews with adults were held privately in an empty classroom. Each one lasted approximately 45 minutes. A typical opening question to adults was: ‘Tell me about Lynda.’

During observations, I took field notes by hand. They consisted of a running description of Lynda’s interactions with peers and adults, with the time of day recorded at ten- to 15-minute intervals. Exact words of conversations with, to, about, and for Lynda were noted. Recorded interviews and field notes were transcribed by word processing, immediately after a day in the field. Two Circle of Friends activities were audio taped. One occupational therapy session was videotaped.

During observations, and during and after transcription, I wrote memos in the margins of my notes, consisting of questions, possible reoccurring themes and possible connections to disability stereotypes. I reviewed my notes and transcriptions throughout the data collection process, collapsing categories, and eliminating themes.
that were not sufficiently supported by data. Axial and selective coding (Strauss & Corbin, 1988) were accomplished by charting emergent themes, and listing exact words and interactions that appeared to support each theme, with their dates of occurrence.

Theoretical sampling was achieved when ‘something different’ (Strauss & Corbin, 1988, p. 211) emerged from the data — an antithetical relationship between adults’ and children’s interactions — which gave density and variation to the context of ‘doing inclusion right’. As preliminary categories of inclusive and exclusive interactions began to emerge, sampling was aimed at developing and saturating those categories, within the restrictions already noted.

I spent 210 hours observing and interviewing children with and without disability labels, noting their attitudes and interactions with Lynda. I attended and observed Lynda’s inclusive academic classes, life skills classes, and Circle of Friends activities. I sat near Lynda and took field notes. I observed interactions with teachers and para-educators; but I did not assist them or comment on their interactions.

Symbolic inclusion: a social constructivist definition

My research agenda posits a socially constructed meaning of inclusion — Symbolic Inclusion — which transcends traditional, legal definitions. Symbolic Inclusion is defined as the accommodation, assimilation, appreciation, and engagement of one’s interaction partner. Symbolic Inclusion can occur in any place, at any time, when individuals choose to become conscious of and pay attention to one another. Symbolic Exclusion occurs when individuals consciously refuse or habitually fail to accommodate, assimilate, appreciate, and engage one another. Symbolic Inclusion can occur in a segregated classroom; and Symbolic Exclusion can occur in ‘inclusive’ educational contexts.

Symbolic communication as intentional behaviour

Lynda’s peers used conventional verbal communication. Lynda’s communication strategies were different. Lynda vocalized with variations in tone and volume, but she used no identifiable words. Her vocalizations produced no consistent patterns or sounds approximating phonetic syllables. Her behavioural communication repertoire included: characteristic clasping, pinching and rubbing hand mannerisms of Rett Syndrome (Sigafoos et al., 2000); eye gaze for about three to five seconds; smiling and frowning; and a few apparently purposeful body movements (swinging her feet in a kicking motion, moving her head and torso toward or away from a person or object). It has traditionally been perceived as difficult to assess whether or not these behaviours by individuals with Rett syndrome are intentional attempts to communicate (Snell, 2002). But communicative acts have been both anecdotally and empirically verified (Sigafoos et al., 2000; Von Tetzcher, 1997). Disability studies scholars encourage the interpretation of all behavioural differences as meaningful communication (Smith, 2006). For the purpose of this study, gestures, vocalizations and other
unconventional behaviours were defined as communication, if they appeared to the researcher and/or the communication partner to indicate intentionality.

**Results**

Though Lynda’s school was defined by administrators, teachers, and her parents as inclusive, data analysis led me to deduce that participants were practising both Symbolic Exclusion and Symbolic Inclusion. Excluding interactions, which were practised mostly by paraprofessionals, diminished the universe of Lynda’s social roles, and assigned negative meanings to her difference. Paraeducators removed Lynda physically from academic classes when she was most alert and vocal, spoke for her instead of to her, gave her infant’s toys instead of instructional materials to keep her occupied in class, and fed her goldfish crackers to stifle her verbal communication. One paraeducator, assigned exclusively to Lynda, cooed to her in nonsense syllables, and usurped her attention with infantilizing interactions, when Lynda was more appropriately focused on a teacher or peer. Lynda’s physical therapist spoke about Lynda as a collection of symptoms, pointing to and manipulating Lynda’s body to illustrate her medical anomalies. Teachers who witnessed these interactions did not attempt to curtail them. Since Lynda was always accompanied by a paraeducator, these excluding interactions served as negative models for her peers.

Sapon-Shevin (2007) has noted that adult professional educators, trained and experienced in traditional models of special education, still interpret ‘inclusion’ in terms of time and place; and even parents of children with disabilities are reluctant to force their children into a vaguely defined, contentious inclusive model, where their child may not be welcome. The excluding actions of adult professionals toward Lynda were especially significant in the context of a school in which inclusion was described as an overarching philosophy and practice.

Yet within this context, which fell far short of authentic inclusion, Lynda’s peers with and without disabilities clearly modelled Symbolic Inclusion. They accommodated, assimilated, appreciated and engaged her as an interaction partner. They invited and expanded Lynda’s presence in a variety of social roles, and assigned positive meanings to her differences. Lynda’s peers showed an instinctive capacity to practice research-based strategies that have been identified as inclusive best practises. From a single case study by a single researcher, I offer the following inclusion strategies, conceived and practised by children, as ‘lessons from the 1%’.

**Dynamic communication assessment**

Communication skills in children with labels of severe disabilities are divided into two categories: receptive (understanding) and expressive (being understood) (Reichle et al., 2002). Receptive communication skills have traditionally been considered difficult to assess with any certainty in a child who does not speak, and has a label of cognitive impairment (Westling & Fox, 2004). The receptive communication of children with Rett syndrome has rarely been systematically assessed; and there is room
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for considerable individual variation (Von Tetzcher, 1997). Receptive vocabulary assessments may underestimate children’s receptive comprehension (Reichle et al., 2002). Snell (2002) recommends dynamic assessment — building on existing vocalizations, gestures and behaviours — to foster the growth of more complex communication. Dynamic assessment is appropriately conducted by: using familiar contexts for assessment, relying on information gathered over time and with people who know the learner, increasing communication output by manipulating the environment, and probing potential for learning rather than simply describing current performance.

Lynda’s peers with and without disabilities took the initiative to assess and comprehend her unique communication strategies. They assessed her communication within the familiar contexts presented by the school environment. They relied on information gathered over time, and actively discussed what she might be thinking or trying to achieve. They explained to me that she had her own way of talking — ‘Lynda’s way’.

Sometimes she’ll rub her eyes; kinda like with the side of her hand. That means she’s tired. And when she’s like this — ‘aaaaaah’ — she’s happy. That’s her way of talking to people.

A boy who got to know Lynda from inclusive academic classes explained:

You can tell when she’s really happy. She’ll be smiling and talking in her way. And when she’s sad she’ll get a frown, and sometimes be very quiet or sometimes be very loud. And sometimes, when she’s just, I guess, just being Lynda — she’ll kind of pick up something and start banging it on the table. She really likes noise. … I think it’s because if everybody else is making lots of noise, why not make some noise too? Sometimes when the class is really quiet she’ll go ‘Yeahhh!’ I think she’s saying that she wants to be a part of everything, and not be left out.

A clear example of manipulating the environment and probing potential for learning occurred in Lynda’s inclusive general education social studies class. The teacher had the children count off by threes, with each group forming a political party. Each party was to choose a presidential candidate, design a symbol, write and deliver a campaign commercial, and coach their candidate for a debate. A paraeducator brought Lynda, in her wheelchair, over to her group. The presidential candidate spontaneously held out a list of jobs (campaign worker, press contact, etc.) and read them aloud. The children waited patiently for several minutes while Lynda willed her finger to point to a choice of assignments. ‘She picked campaign worker’, the candidate said. He used the same technique several days later, waiting for Lynda to put her finger on a list of topics she would like him to debate: ‘We would have ideas written down, and she would keep a finger on it. We would sorta, like, check it with everyone. Cause I think they were all good ideas.’ (Lynda’s candidate was elected president of the class.)

If Lynda were given choices of pictures, objects, or even a list whose content was verbally described by a communication partner in other situations, what would Lynda do? Her classmate’s spontaneous probe could serve as a valuable model of dynamic assessment for adult practitioners.
The presidential candidate’s spontaneous adaptation of the curriculum can also be viewed as an effective example of ‘curriculum overlapping’ (Giangreco, 2007, p. 36), in which a student like Lynda, who presumably has learning outcomes that are significantly different from those of her classmates, shares an activity (mock election), but may have learning goals of communication within the curriculum area (social studies).

Structured over-interpretation

Von Tetzcher (1997) recommends the use of structured over-interpretation for girls and women with Rett syndrome, whose communicative behaviours are similar to Lynda’s (i.e., their eye contact with intended communication partners is inconsistent, brief, and considered difficult to determine as intentional). Structured over-interpretation is to be conducted by significant persons in the environment of the individual with Rett syndrome; and Lynda’s peers were significant. When utilizing structured over-interpretation, significant persons interpret behaviours that indicate interests, needs and preferences as communicative strategies. Von Tetzcher (1997) notes that these strategies contribute to a ‘responsive and predictable’ environment (p. 33), and are useful for communication partners. Lynda’s peers developed a set of strategies for consistently interpreting her communication behaviours — an instinctive and effective form of structured over-interpretation, which led to a deeper understanding of Lynda’s expressive verbal and behavioural vocabulary.

Structured over-interpretation (Table 1) can be used to construct a communication signal inventory (Reichle et al., 2002), which helps the communication partners of a non-verbal individual understand and respond to unique vocalizations and gestures. The inventory serves as a guide for consistent and appropriate communication interactions with adults and peers. Observations, interviews, and field notes made it possible for me to construct a communication signal inventory for Lynda, using information I obtained primarily from her peers. Communication signals were perceived independently, and clearly explained by peers, with no coaching from Lynda’s family, teachers, or paraprofessionals. Peer signals were consistently interpreted by as many as ten peers; and their interpretations remained consistent over time. These data indicate that professional educators can solicit peer participation, and be guided by children’s keen observations, and naturally occurring structured over-interpretation, when constructing a communication signal inventory.

Ecological assessment

Ecological assessment, also referred to as functional or environmentally referenced assessment, focuses on assessing the support needs of a person with cognitive impairment and severe disabilities in her current environment and culture (Schalock, 1999). Academics are only one domain of this focus (Hamill & Everington, 2002). Ecological assessment is recommended for children with labels of severe disabilities because of its reference to specific individuals and environments, rather than a standardized
Table 1. A communication signal inventory utilizing structured overinterpretation

<table>
<thead>
<tr>
<th>Signal</th>
<th>What it means</th>
<th>How to respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>What Lynda does</td>
<td>What Lynda’s communication partner thinks the signal means</td>
<td>How partners should or could consistently react</td>
</tr>
<tr>
<td></td>
<td>[Information provided by]</td>
<td>Frequently describe the signal immediately after it is performed.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Comment perceived meaning. Interact with appropriate response. (‘You’re pulling your hair. That tells me you’re sleepy. You can lie down now.’)</td>
</tr>
<tr>
<td>Vocalizes</td>
<td>‘I’m here!’ (loud, with smile)</td>
<td>*Greet Lynda; acknowledge her presence</td>
</tr>
<tr>
<td></td>
<td>[Mom, peers, participant observation]</td>
<td>*Adult partners need to find and assess alternative, consistent reactions to replace stuffing food in Lynda’s mouth, covering her mouth with their hands, or removing her from class.</td>
</tr>
<tr>
<td></td>
<td>‘I’m participating!’ (Lynda’s volume and pitch matches volume and pitch of another speaker or group of speakers)</td>
<td>*Greet Lynda; acknowledge her presence</td>
</tr>
<tr>
<td>Frowns and whines; cries with or without tears</td>
<td>‘I hurt’</td>
<td>Peers should alert teacher or paraeducator.</td>
</tr>
<tr>
<td></td>
<td>[Mom, peers, participant observation]</td>
<td>*Adults should figure out source of discomfort and respond accordingly</td>
</tr>
<tr>
<td></td>
<td>‘I have to go to the bathroom’</td>
<td>*Could a more consistent eating, drinking and bathroom schedule should be implemented to avoid removal from class?</td>
</tr>
<tr>
<td></td>
<td>[Paraeducators]</td>
<td></td>
</tr>
<tr>
<td>Pulls on her hair</td>
<td>‘I’m sleepy’</td>
<td>*Adults should tell Lynda if/when she will be able to rest</td>
</tr>
<tr>
<td></td>
<td>[Peers]</td>
<td>*Peers should recognize that Lynda is sleepy. (Lynda’s peers indicated accurate interpretation of this signal.)</td>
</tr>
<tr>
<td>Walks toward a person or object and stands in front of it</td>
<td>‘I am interested in this person or object.’</td>
<td>*Allow, observe, and assess walking communication</td>
</tr>
<tr>
<td></td>
<td>[Mom, peers]</td>
<td>*Incorporate walking communication into instruction and social interaction</td>
</tr>
<tr>
<td>Makes eye contact for three to five seconds</td>
<td>‘I am making purposeful eye contact with this person or object.’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[Participant observation, Mom, peers]</td>
<td>*Interact with Lynda and/or the object of intent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>*Be alert for, recognize, and capitalize on occasions of purposeful eye contact</td>
</tr>
<tr>
<td>Grasps and pulls a person or object toward herself, or reaches toward a person or object grasp it</td>
<td>‘I want to interact with this person or object.’</td>
<td>*Provide opportunities to interact with the person or object</td>
</tr>
<tr>
<td></td>
<td>[Life skills teacher, Mom, peers, participant observation]</td>
<td></td>
</tr>
<tr>
<td>Pushes a person or object away, or turns their head away</td>
<td>‘I don’t want to interact with this person or object.’</td>
<td>*Recognize protest behavior and do not force unwanted interaction with a person, food, drink, or object</td>
</tr>
</tbody>
</table>
Questions asked by Lynda’s peers comprised a spontaneous ecological assessment of the skills she would need to succeed in her current and future environments, with an emphasis on communication and self-determination:

Can she walk? Can she see? Can she write? Can she express her feelings? Can she cry? Can she hear people? Does she try to talk back? When something’s bothering her, how can you tell? How do you know if she’s mad? How’s she gonna get married? How’s she gonna drive a car? How’s she gonna have a baby? How’s she gonna earn money?

The salience of the children’s questions, and their observed skill in recognizing functional environmental needs, illustrates the value and applicability of peer interaction and understanding to assessment and curriculum development.

Partial participation

Partial participation in instruction is recommended for students with cognitive impairment and severe disabilities. The term does not refer to limiting participation, but rather to increasing and enhancing it. Partial participation refers to being flexible about how children participate in environments where they do not have all of the skills the environment requires (Turnbull et al., 2004). Inviting Lynda to participate in the mock election in social studies class is a clear example of partial participation initiated by her peers. Although she could not speak, and was not perceived as being able to read a list of topics for the presidential candidate to discuss, she could indicate her choice of topics by pointing to one, as a peer read them aloud. The presidential candidate let Lynda make the initial selections by pointing. Her choices were then approved by the rest of the committee through traditional, verbal discussion. Lynda’s peers were creative and flexible in their ideas for including her in instruction by partial participation.

Transdisciplinary transition planning

Lynda’s peers in life skills class troubled the discourse about her adult life (‘How’s she gonna earn money? How’s she gonna drive a car? How’s she gonna get married?’) Such probing questions would be appropriate for the process of transition planning, which is traditionally conducted by a child’s special education transdisciplinary team of teachers, parents, and related service professionals (Hamill & Everington, 2002).
(In Lynda’s case, related service professionals would include a physical therapist, occupational therapist and speech therapist.) The transdisciplinary team prioritizes goals and objectives that will generalize across people, settings, time and materials. These goals and objectives are supported with curriculum, instruction, and opportunities for interaction with non-disabled peers in school and community. Missing from a traditional transdisciplinary planning team, in most cases, is an emphasis upon the wisdom of the child with labels of severe disabilities for whom the team is planning, and the peers with whom the plan is supposed to maximize interaction. Lynda’s peers were skilled at recognizing some valuable adult goals and objectives. Though adults may have seen them as overly optimistic, the goals children saw for Lynda are worth discussion, and traditionally ignored, when individuals with cognitive impairment are traditionally portrayed and treated as eternal infants (Barton, 2001; Wehmeyer, 2000).

Person-centred planning

Peer questions and comments related to Lynda’s Rett syndrome were in line with a recommended instructional planning approach: the McGill Action Planning System or MAPS (Hamill & Everington, 2002). The steps of MAPS include asking and answering the following questions by a team comprised of family members, general and special education teachers, and peers:

1. What is (Lynda’s) history?
2. What are your dreams for (Lynda)?
3. What is your nightmare for (Lynda)?
4. Who is (Lynda)?
5. What are (Lynda’s) strengths, gifts, and talents?
6. What are (Lynda’s) needs?
7. What would an ideal day at school look like and what must be done to make it happen? (Hamill & Everington, 2002, p. 117).

Lynda’s school did not use formal MAPS planning. But, at the beginning of the school year, when Lynda’s mother visited her classes to explain the characteristics of Rett syndrome, Lynda’s peers addressed nearly all of tough MAPS questions, including: ‘Is she gonna be like that for the rest of her life?’

Children’s instinctive interactions revealed complex understanding of Lynda’s present and future needs. Lynda’s peers showed they were capable of making a significant contribution to her communication, curriculum, instruction, and person-centred planning. Throughout the school year, the children noted Lynda’s strengths. They considered her a friend, and saw her as a role model.

Recognizing Lynda as a friend and role model

Lynda’s peers with and without disabilities described a friend as:
someone you hang out with; someone loyal and trustworthy; someone you play with and have fun with; someone caring … and very sweet; someone whose house you go to; someone you like to be around; someone that likes you and is friendly to you; someone you help; someone you teach; someone who helps you; someone you eat lunch with; someone that you feel what they’re feeling sometimes.

They found many of these qualities in Lynda, and participated in these activities with her. They said they would introduce her to sixth graders as ‘my friend’.

Though most positive relationships between children with and without disabilities fall into the ‘abled helper’ category (Grenot-Scheyer et al., 2001; Sapon-Shevin, 2007), Lynda’s peers saw her as a helper and teacher as well.

When I was really desperate in a test or something, Lynda would look over to me and smile, and I’d kind of perk back up again, and get that problem done and move on to the next one. She is a really sweet person. I just like her.

Three children said they learned not to judge a person by their outward appearance. A student identified as gifted learned ‘not to judge people by just what they do in class’. He said Lynda taught him a new definition of talented: ‘Even though [Lynda] can’t walk by herself, or talk, that she’s still one of the most talented people here. Since she’s gone through all that.’

Re-imagining disability

Two children expressed re-imagined meanings of disability after spending time with Lynda. One of them described Lynda and the other life skills students as ‘very gifted’. Another classmate said he enjoyed learning about Rett syndrome, because ‘I never knew anybody like that. It’s pretty cool, because it’s a different person.’

One girl said knowing Lynda had helped her understand the difference between being popular and being happy:

There’s nothing wrong with being different. [Lynda]’s so much happier than, probably, the most popular girl in school, and she’s not popular at all.

The same girl offered a thoughtful explanation of difference:

People that’s in a wheelchair, they can’t go play kickball or anything like that. That doesn’t mean that [Lynda] can’t be a good friend, or that you can’t hang out with her. You can always do something else. They’re just like you, except in a different way.

When the Circle of Friends group was making gingerbread, several classmates admired and emulated Lynda’s prowess in using a switch that ran the mixer. When, after many tries, she was able to hit the switch, a girl yelled: ‘I can’t believe she did it by herself! Tell her mom!’ Another said: ‘That’s so cool! She pushed it by herself! If I was like Lynda, I would do that!’ A boy added: ‘That’s awesome!’ Another girl said: ‘Pretend I’m a person that’s like Lynda is’, and depressed the switch herself. She flexed her arm and announced: ‘See; I have small muscles like Lynda’. In this context, Lynda’s disability was seen as a positive difference, and Lynda was seen an able role model.
Discussion

Implications for practice: the importance of conscious intent

For symbolic interactionists, the actor’s conscious intent plants within an interaction the seeds of transformation of self and society. Intentional interaction implies a choice of behaviour, a reflective, continuous development of beliefs, and a conscious, constructed presentation of the self (Blumer, 1969; Mead, 1934). Symbolic Inclusion and Symbolic Exclusion offer social constructivist definitions that can illuminate the connections and disconnections between entrenched habits and stereotypes, and conscious, intentional changes in beliefs and actions. Constructivist definitions of inclusion can measure interactions that are independent of the usual, one-dimensional concepts of inclusion as a physical place, or a period of time spent with non-disabled peers.

Lynda’s peers exercised the power to resist entrenched meanings and practises, and transform beliefs, in a nascent inclusive context that was less than ideal. They were given place and time, negative interaction models by paraprofessionals, and one brief explanation of Circle of Friends by Lynda’s special education teacher that described ‘volunteering’.

At the beginning of the year I [describe] the programme: ‘You’re not gonna get paid. You’re not gonna get a grade. You’re gonna take your time out of recess or something. This is the programme we offer, to come and volunteer in our [self-contained life skills] room and to be a friend to our kids.’

Volunteering is a conscious and intentional act, which can transform access into interaction, and allow reflective choices. As children consciously volunteered to be a friend to Lynda they developed rich relationships, in which friendship, helping and understanding were reciprocal, and not just one-way transactions.

Lynda’s paraeducators were not volunteers; they were employees assigned to facilitate Lynda’s inclusion. The juxtaposition of adults’ stated beliefs that their school was ‘doing inclusion right’, and the excluding interactions observed, underscores the power and persistence of inclusion confusion and disability negatives. Lynda’s inclusion providers were caught in the paradox, perhaps because they were given no opportunity to consciously and intentionally define, communicate, and critically reflect upon their individual and collective meanings of disability and inclusion. Symbolic Inclusion and Symbolic Exclusion may serve as useful tools to guide such reflection.

Changing paradigms involves all stakeholders

Inclusive, systemic education reform calls for reflective collaboration among all stakeholders: children, families, researchers, faculty and administrators in public schools and teacher preparation programmes. Disability studies scholars have introduced powerful conceptual tools for facilitating authentic inclusion, by critiquing and re-envisioning traditional special education paradigms. Snelgrove (2005) posits a research methodology that creates spaces for children with intellectual disabilities...
to speak and be heard as valued participants. Biklen’s (2007) proposed disability studies framework for inclusive education sees each student as a competent learner, and honours the agency and validity of students’ communication. Peters et al. (2005) offer an evaluative model for inclusive education that gives voice to the basic concepts and philosophy of inclusive education envisioned by people with disabilities. Rice (2005) and Smith (2006) offer ideological critiques of special education and classroom management texts that perpetuate negative disability and educational stereotypes, with the goal of teaching future educators to develop critical consciousness.

At the State University of New York College at Cortland, the Department of Foundations and Social Advocacy offers an Inclusive Special Education Major in which advocacy, disability rights, and disability studies are woven throughout the curriculum. Renewed and expanded Professional Development School partnerships aim to pair general and special educator host teacher teams with student teacher dyads; and collaborative skills are infused throughout teacher preparation courses.

Lesson plans that seek and apply children’s contributions to inclusive strategies for curriculum and instruction can be constructed to incorporate state standards. For example, New York State ELA Standard 4 states:

Students will use oral and written language for effective social communication with a wide variety of people, [and] use the social communication of others to enrich their understanding of people and their views.

(University of the State of New York Education Department, n.d.)

Universal design for learning utilizes whole class instructional planning that incorporates varied learning styles, rather than adapting instruction only for children who are labelled with specific disabilities (Hitchcock & Stahl, 2008).

Lynda’s peers instinctively demonstrated a competence orientation (Smith, 2000, 2006), perceiving her as a whole, complex, maturing young woman. They recognized and interacted with her strengths, and demonstrated great skill in interpreting her unique communication. If Lynda’s friends were enlisted to provide professional development for teachers and paraeducators, they might begin with the salient introduction Annabelle said she would give to sixth graders, when she and Lynda made their highly anticipated transition to intermediate school: ‘This is my friend Lynda. She can’t talk and you're going to get used to it.’

Note
1. All names have been changed to pseudonyms.

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