Phyllis Jones is an associate professor in Special Education at the University of South Florida. Her research interests include inclusion, insider perspectives, and the education of teachers of students with low incidence disabilities. She is currently Principal Investigator of a project that supports meaningful access to general education for students with low incidence disabilities.

When I was a young girl living in the North East of England, our main form of transport out of the small town was a public bus. My family and I would sit in the bus shelter waiting for the bus to arrive with a sense of positive anticipation of the trip we were going to take. However, on occasion we would wait and the bus would not arrive at the scheduled time; sometimes the bus was late and sometimes it did not come at all. On many of these occasions, we had to return home or change our plans for the day. We never knew if the bus that was late would actually come, and I remember vividly, the sense of worry I had about whether the bus would ever come at all.

This feeling of worry is something that I currently experience as I work in the South West of Florida. The focus of my concern is about how far we have actually come as a community to develop and support meaningful inclusion opportunities for students with severe and complex disabilities. Two recent experiences have brought this unease to the forefront.

In a recent conversation with a mom, I was told about her 3rd grade son with Down Syndrome, Sean. In his school career so far, Sean has had a series of schooling experiences that have been both inclusive and self contained. As his mom relayed his story, it illustrated to me the sketchy nature of inclusive provision in the state. For two years Sean was able to take advantage of a co-teach inclusion classroom. The next year he was placed in a general education first grade classroom with the constant support of his mother. Going into 3rd grade, he was placed in a segregated class for younger students, because he was not able to read and was not seen to ‘fit in’
academically with his age appropriate Varying Exceptionalities (VE) classroom. This story showed me how tenuous inclusive opportunities are for families and children alike. It illustrates how professionals can look at a young boy, and with the ‘best professional intentions’; adopt the most dangerous assumption, leading to segregation. The stumbling block for Sean is that he cannot read, Mom notes that he has not actually received reading instruction so far in his school career. In order to be included it appears that children must read and therefore Sean must earn his way into the general education classroom by becoming a reader.

I was reminded of another family in a similar situation in the North East of England over ten years ago. Nadia is a sister to four siblings and a vivacious daughter to Katie and Andy. She is deaf and has Cerebral Palsy. Nadia was six years old when I first met her. At the time, the family lived in a small village and Nadia attended a kindergarten class that was attached to the elementary school her brother and sisters attended. All the children walked to school together. Nadia made lots of friends and was a central part of the school community. Unfortunately, at the end of her kindergarten year the school began a conversation about a separate 1st grade provision for Nadia. Professionals believed Nadia had severe intellectual disabilities because of the complexity of her cerebral palsy and deafness. They believed the general education setting was not an appropriate placement for her. Again a ‘most dangerous assumption’ was adopted and it was suggested that Nadia attend a segregated center school many miles away from the village. I had the pleasure of meeting Nadia who indeed presented as a very complex little girl. Mom and Dad believed she was bright, but the assessment processes administered did not represent her ability, just her disability. When I met Nadia, I indeed encountered a very bright and alert young girl who enjoyed playing and teasing her brothers and sisters. She was a beautiful communicator, especially with her friends, but alas not in the formal communication systems we share as a community.

The family believed strongly that they wanted all of their children to attend the same school, so they began a search around the UK for a school that would welcome them all. They found one, over 300 miles away and decided to relocate the whole family. Ten years later, last week, I received an email giving me a progress report on Nadia. She has enjoyed a successful school career and just passed her exams that allow her to attend college. She is an active member on the local community council and is working towards a career in the health services. She has sleepovers with an array of friends, has a penchant for black nail varnish and appears very ‘up’ on fashion trends! School has clearly been so much more than academics for Nadia and illustrates the powerful impact of the hidden as well as explicit curriculum experiences in a
student’s school career. I wonder what Nadia’s story would be if Kate and Andy had acquiesced to professional advice and sent Nadia to the segregated special school.

In order to remain in general education successfully, Nadia received a tremendous amount of support. Her schools have been creative and open to learning about Nadia with the strong acknowledgement that Nadia belonged in the school. The use of Assistive Technology showed Nadia has many more abilities than her obvious impairments. As professionals, it is apparent in research, professional literature and pockets of practice that we appreciate that meaningful inclusion is complex. We appreciate it requires a systemic approach to change that acknowledges Universal Design for Learning. We also are aware of the role of positive professional attitudes and the need to believe that all children can learn.

However, I feel as if I am waiting at a bus stop and that the bus is just not arriving. In my twelve years as a teacher educator my approach to professional development and systems change has been an optimistic one, believing that we will build effective inclusive schools. I trust that I am contributing to the building of such schools slowly and strongly as I impact professional attitudes, policies and practices through my teaching, service and research. In August of 2009, I am troubled that in a few weeks, when school resumes, there are many children, like Nadia and Sean; who are waiting at ‘bus stops’ around the country for a bus to take them to their neighborhood community school. But, that bus may never come, or if it comes, as in the story of Sean, it has frequent breakdowns. I think about how many children we deprive of a rigorous and relevant general education because we use particular systems and processes of assessment and then the children do not ‘fit in’ to the status quo of current general education provision. All of this pondering poses many questions a couple of which keep coming to mind:

· As professionals, in the field of developing greater inclusion, how do we ensure more immediate positive change in attitudes, policy and practices?
· Where is the sense of urgency for change that will enable future Seans and Nadias to belong and be valued in their local school, and go onto enjoy the hidden and explicit curriculum of the school?

Comments

8 Responses to “Waiting for the bus that never comes…an analogy for inclusion in 2009”

Joan Pabisz-Ruberton on 9/5/09 6:22 PM US/Eastern

We (IEP team) received a psychoeducational evaluation on a student from a well know clinic for students with disabilities on the east coast. It was very disheartening to read in the report that although the school district was commended for educating this student in the general education program with supports, the
parents and school team should discuss this child receiving literacy and math instruction in a separate environment as the curriculum in the classroom was going to be too challenging. Why are they not aware that not every child has to learn the same thing at the same time in the classroom and that content can be modified significantly. I have been given access to communicate with the team leader at this clinic and I will have the integration vs. segregation conversation but I am appalled I need to have this conversation.
The medical model of ‘treating’ disabilities still prevails strongly in the community of ‘experts’ where parents seek answers to their child’s needs.

- **Phyllis Jones on 9/9/09 9:06 AM US/Eastern**

  Thank you Joan – your response raises issues related to Universal Design for Learning… until we accept that our schools and classrooms must be designed for all students at the outset. Kroeger (2004) talks about the curriculum of UDL being one that does not need adaptation. This is a very powerful vision that I believe is a very challenging concept for policy makers and educators, as it questions our current traditional approach to curriculum. I appreciate your response Joan – please keep up the quest for effective inclusive practice!

- **Kate on 9/13/09 3:58 PM US/Eastern**

  I share the frustration many educators are facing when attempting to include students with disabilities in the general education setting. State and Federal mandates require students to participate in standardized assessments that are grade level specific. While we can identify accommodations and modifications, the student is required to take their grade level assessment even if they are receiving instruction on a modified level. I appreciate the accountability such assessment provides, but for inclusive efforts to be realized, we must allow for individual differences to guide both the instruction and assessment for students with disabilities. Recognizing professional judgement in this area could serve to open doors for inclusive practice for many more children.

- **jodi O on 9/14/09 10:41 AM US/Eastern**

  My newest hope lies in efforts related to response to intervention/instruction. This pushes the educational system to base needs and services on the needs of an individual rather than on a label. It also requires flexible responsive grouping rather than a single classroom or service provided all the time for a designated group of students. As the system adapts to this practice, I think there will be more frequent decisions based on regularly assessments in classrooms as opposed to a psych. test. Student’s strengths will be identified and recognized as well as their needs. And it won’t take a label to get services to meet the needs.

  I believe we are moving in the right direction and see many more positive inclusion experiences than
years ago. As leaders in education, we need to keep the focus and direction clear so we don’t get pulled off course with the many obstacles that will always come up.

Fran on 9/14/09 12:52 PM US/Eastern

I appreciated reading of your experiences with inclusion and how spotty it appears to be, not just in the US but elsewhere. My experience as an educational administrator has convinced me that we really do not have any state or district expectations for meaningful inclusion. Our schools are left on their own to decide on how students with disabilities will receive their instruction. An individual school can be develop a state of the art program but they are usually on their own to do so. That cannot be acceptable if we are to make any real progress.

At the university level, expectations for inclusive practices must be part of the training for administrators and for general education teachers and must come from their general education professors. I am glad you are at our local university and can use your influence at this critical level.

Dianne on 9/14/09 9:33 PM US/Eastern

Phyllis, your comments mirror the experiences in Australia also. We do not have legislated (mandatory) IEPs or assistive technology requirements for schools, only the notion of ‘providing for students’ needs’. Although the education departments usually require some form of provision, the format is quite open. We are in the process of developing a national curriculum for all states, and there is a conspicuous lack of reference to supporting the needs of ALL students. This is very discouraging as UDL should be the focus of the new curriculum, and in fact it is the perfect time to incorporate these principles. Hopefully the bus will not pass by without picking us up.

Elaine on 9/16/09 8:16 AM US/Eastern

I agree with the earlier comment from Fran, that in order for the inclusive model to be sucessful general education teachers must receive adequate training at the university level. To expect general education teachers to teach students with special needs in a regular ed classroom with no training on how to do this is unfair to the teacher and to the student. I also beleive this training should not be restricted to 1 or 2 classes squeezed into the curriculum but should be imersed through out a teachers training/education. In this way the teacher is given multiple opportunities to gain education and training themselves. In todays world teachers who are currently working who received their post grad experience years ago are often ill equipted to educate children with special needs in a regular ed class. This is in no way the teachers fault but is a need that should be addressed.

Theresa Miers on 9/16/09 5:02 PM US/Eastern
In my role as a speech-language pathologist in the public schools of Sarasota County I have had the opportunity to be part of the inclusion model. In many ways it can serve special needs children well. However in my opinion proceeding with caution is indicated here. We must be careful that we do not rob special need students of their opportunity to an individualized education. The reality of regular ed classrooms is that the possibility of this is all to real. Teachers even when they differentiate the curriculum are not individualizing it. If so how could a teacher be expected to cover the curriculum completely in one year. I don’t feel that special need students need to earn their way in but they do need to be able to have some degree of participating with their peers. It may not sound as though I am an advocate of inclusion but I am in certain circumstances for some children. In twenty years of my school experience I have not found any one model to be the fix. I do like a blend of inclusion with support services so the child can benefit from both models. I would like to note that specialty center schools have their place in educational system. In Sarasota County we have two schools for Exceptional Student Education, each providing educational services otherwise unavailable at regular school sites. Pine View services gifted students and Oak Park services students with varying disabilities. Staff is specially trained and programs, equipment and other factors have parents opting for these types of school placements. I do agree the bus has been slow to arrive if at all.