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Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

Five-year Vision: Adults living with autism will have the opportunity to be valued, contributing members of their communities based on their unique strengths, differences and challenges.

(As identified at the AFAA National Town Hall)

<http://www.afaa-us.org/core-issues/community-integration>

Strategy #1: Create a comprehensive public awareness campaign that enables the general public to better understand, engage and support adults with autism and their families.

Public awareness is critical for engaging public support at the individual, local and federal levels. Increased understanding about the challenges facing an adult with autism each day is the first step towards greater acceptance and support by the public. Public awareness can happen through many channels: television, movies, social media, internet, PSAs, school education, etc. A strong and unified autism community implementation of a coordinated, national public awareness strategy will lead to greater success. An important component of this coordinated effort will be that the content and messaging reflect the wide spectrum of autism so people can see the whole picture. A successful campaign will be comprehensive and celebrate differences. Government grants for these campaigns will be a smart investment - essentially leveraging government dollars to increase the public's engagement and support at the citizen and community level. Not only does an effective public awareness strategy make community integration more possible, it can help reach families with little exposure to autism spot the symptoms in their child, leading to earlier diagnosis and earlier, more effective intervention. Additionally, as the average age of a person with autism increases, so must the age of a person with autism portrayed in the media. Currently, the media primarily depicts high-functioning children with exceptional talents when featuring a person with autism. It is now time for a shift in the media to also include adults and individuals with autism that need more supports. To be most effective, awareness campaigns must start at a very young age, teaching young children about autism in school curriculums and through compelling, age-appropriate mediums so children understand autism early in life. With the right exposure and experiences, fears can be greatly reduced or eliminated, and acceptance and compassion can grow in its place. The broader the reach of such campaigns, the brighter the future of adults with autism.



Continued on page 2.

COMMUNITY CONTINUED....

Strategy #2: Educate local recreation organizations as well as the community about the positive benefits of including adults with autism in their programs.

Many participants felt that recreation is a key ingredient to successful community integration, overall health, self-esteem and social skills. All of these factors are necessary to live a full and independent life. Currently, there are far more recreation activities for children with autism than for adults. Many children age out of these programs at 18 or 21 years old. Given the dramatic increase of teens transitioning into adulthood, it is critical to extend these programs into adulthood - essentially allowing these programs to age with their participants. We can look to seed autism integration programs in large organizations like the YMCA or JCC, creating a best practice and paving the way for other public and private organizations to follow. These programs can play a substantial role in better integrating adults into the community. Education for such programs should be two-fold. There needs to be autism education for the staff of the recreational organizations, as well as education for the individuals with autism so that all are better prepared for positive interactions. Just like for any "typical" adult recreational opportunities, choices should extend beyond sports and games. Parks, libraries, theaters, churches and coffee shops are all forms of recreation that provide people with a rich quality of life and should be accessible to adults with autism.

Strategy #3: Educate first responders about the challenging behavior that might arise in dangerous situations involving adults with autism so they are prepared to handle these occasions in the safest and most effective manner.

Educating first responders about autism is a priority. First responders must be prepared to handle occasions involving adults with autism in a safe and effective manner. National standards and mandated trainings are fundamental for the safety and protection of adults with autism. In many cases, first responders are not prepared to deal with an adult with autism and may improperly or inaccurately interpret the adult's reaction to an emergency situation. A survey of individuals with autism and their families indicated that 23% have had interactions with first responders because of wandering (Autism Information for Law Enforcement and Other First Responders, Autism Society of America Report). The development of a national autism safety kit for first responders may be an appropriate way to increase awareness of how to best support an adult with autism during emergency situations. The training should be expanded to include emergency room personnel, judges, mall security guards and other individuals in the public domain. There is some uncertainty as to whether this initiative should be handled at a national or local level. Different communities may have varying degrees of difficulty with this issue. In turn, individuals with autism also need to be educated about emergency situations and first responders. Understanding that first responders are there to help them and keep them safe will decrease the likelihood of a person with autism behaving in a manner that could result in harm. In order to reduce the number of incidents, relationships between the autism community and police and fire departments must be built. Education of the first responder, the person with autism and their family is critical for improving this aspect of community life.

Strategy #4: Assist adults with autism to access public and private transportation making it possible for them to live, work and recreate where they choose, including providing training for transportation service providers enabling them to be more responsive.

Access to safe and effective transportation is a key ingredient to community integration, opening up employment, housing and recreation opportunities. The right transportation gives an adult with autism greater choice and control over where they live, work and play, which in turn increases self-esteem, empowerment and a sense of belonging. Currently, transportation is a major roadblock to other services and is very often the single most restricting factor. While there are some transportation solutions that can be handled by local officials and service providers, there are larger accessibility issues which are national in scope. Much like the training needed with first responders, we must teach transportation employees how to interact with adults with autism and to handle situations involving adults with autism. In turn, it is important to teach adults with autism from an early age how to use the public transportation system. Transportation education should be part of transition programs and taught at younger ages. Public transportation is everywhere in big cities, but we need to make sure people outside cities have access to transportation services to access their housing, jobs and communities. In areas where public services are lacking, we need to expand private services so there is sufficient coverage. There must be policy changes and increased funding to improve transportation.



A photograph of two Black men sitting in a vehicle simulator. The man in the foreground is wearing a brown jacket and is smiling while looking towards the right. The man behind him is wearing a light green shirt and is looking forward. They are seated in black seats with red accents. The background is a blue wall with a curved orange stripe.

Navigating the Social World

THE IMPORTANCE OF TEACHING AND
LEARNING THE HIDDEN CURRICULUM

BY JUDY ENDOW, MSW

PHOTO COURTESY OF ATC

One of the key elements for all of us to get along in daily life is our understanding of and ability to navigate the social landscape in the world around us. How we actually do this is referred to as our social skills. For those of us with autism, like me, it is said that we lack social skills—that is, we fall below the acceptable social standard, not displaying the myriad of social skills that seem to come automatically to most people. The reason for this is our autism neurology, meaning that unlike typical people, our brains are not wired to enable us to automatically pick up, incorporate and then effectively use the often elusive and transient information that is all around us. This information is called the “hidden curriculum.”

What is the Hidden Curriculum?

The hidden curriculum is based on the work of autism researcher Brenda Smith Myles. It is the social information that is not directly taught but is assumed that everybody knows (Myles, Trautman, & Schelvan, 2004).

Continued on page 3.

HIDDEN CURRICULUM CONTINUED....

The hidden curriculum refers to those unstated rules or customs that, if not understood, can make the world a confusing place and cause those of us who are not neurologically wired to automatically “get it” feel isolated and “out of it” (Endow, 2009a, 2010). In fact, whenever you think or say things like “everybody knows....,” “common sense tells you...” “it is quite obvious that....” or “I shouldn’t have to tell you, but....” that is the hidden curriculum. As an adult with autism, I have learned that whenever somebody says one of these phrases what is coming next is an explanation of some sort of social sin I have committed. Not understanding the hidden curriculum contributes to the often pervasive feeling that goes far beyond not fitting in, to feeling that you are not part of the human race. During my growing up years, I believed for a long time that I was an alien (Endow, 2006, 2009b).

For me, the most difficult part of having someone notice my social missteps is the underlying assumptions others then make about me. Here are two examples.



Example #1

The bakery lady at my grocery store chased me down shouting, “What is wrong with you?” when I merely took free cookies like the sign indicated.

The hidden curriculum item that I was unaware of was the sign in the bakery says, “free cookies” (even though the word “cookies” is plural), it means only one cookie per person (Endow, 2009b). Although I never would have taken more than one cookie had I known, it was nonetheless assumed by the bakery lady that I intentionally taken more than my fair share.

Another customer commented aloud for all to hear, “What a pig!” It felt awful to know I was thought of in this way, even if it was by strangers. I am not a thief or a pig, even though I did take more than my share of free cookies. I am not an inherently bad person, but because of my behavior I was a social outcast in the moment. When I make a misstep with acquaintances, it can be even worse. I means I may be forever banned from the group. Many times I never have a clue as to what I did, other than figuring out I must have committed yet another unforgivable social sin.



Example #2

When the police officer asked why I was speeding, I answered as truthfully as possible by saying that I had depressed the accelerator with more force that needed to achieve the posted speed.

I was not trying to be a smart aleck with the officer—something that could make a bad situation even worse. At the time I was wondering how this guy ever graduated from the police academy without understanding how speeding occurs, but knew it would be disrespectful to say so having previously learned the hidden curriculum dictates to always be respectful to police officers. What I did not know was the additional hidden curriculum rule that says if you are stopped for speeding it is best to apologize and promise to be more careful from now on. Even though my behavior pegged me as a smart aleck or a speed demon. I have gotten a total of three speeding tickets over 40 years of driving.

The consequences of committing social sins can be anything form loss of friends to legal troubles with a resultant criminal record, depending on your age. Not understanding and following the rules of the hidden curriculum negatively impacts social functioning in all areas of life—home, community, school and workplace.

Students are at a disadvantage in school with a resulting negative impact on their education. Adults often lose more than friends when they do not understand and abide by the social rules of society. Some have lost their homes and jobs, and others have been incarcerated as a result of not behaving according to the rules of the hidden curriculum.

Continued on page 4.

Rules Change Due to Variables

A difficult thing about social rules is that they are often a moving target. The rules change depending on a whole host of variables, such as age, who you are with, gender, culture and circumstance. For example, a child might be taught that when someone says “hi” to you in the school hall, it is polite to say “hi” back (Myles & Duncan, 2008). After school, the child is in a totally different social situation where safety dictates he should not say “hi” or talk to an adult stranger who approaches him as he walks home. Different circumstances dictate employing what can seem like conflicting rules. So, even if you know many of the hidden curriculum rules, it is not always easy to know which rule to follow when.

Age

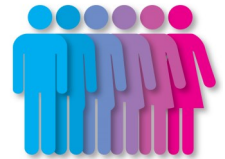
Age is a variable that can get both kids and adults on the autism spectrum in trouble if they have not learned the changing hidden curriculum rules as they grow up. Little kids often hold hands when they walk together in public places, but if a third grader tried to hold the hand of a classmate he could be teased and laughed at by peers. If a high school student or an adult tried to hold hands with someone, romantic interest would be attributed to the act regardless of the intent. This could go bad either way. The recipient might return the assumed romantic interest with a sexual overture or, if appalled by the interest, the person might shout, swear or be physically abusive. Learning the hidden curriculum for those of us with autism never stops. It is a lifelong endeavor.



There can also be serious legal ramifications depending on one’s age. If a child peers into the bedroom window of his friend’s home, it might be okay. The worst thing that might happen is somebody telling him it is not nice to look in someone’s window; one should ring the door bell instead. However, if an adult does the same thing, it is very likely the police would be called and arrest might result.

Gender

Gender is another variable in the world of social rules. This can be quite important because we have a large population of male students with ASD in our schools that are supported by female professionals. There are gender-specific hidden curriculum standards specifically for males, such as restroom etiquette rules, that are very different from the restroom rules for females. Females talk in the restroom; males don’t. If your young male student is conditioned to talk to you in the restroom, he may grow up talking to others in the restroom. If he does this as a teen or a man, whether he knows it or not, talking or even making eye contact in a public men’s room can be perceived as initiating sexual interest. Imagine the consequences for your young student as a grown man if you do not teach him the hidden curriculum for using the men’s room. Therefore, if you are a female professional supporting a male student, make sure you know and instruct your student how to behave in the restroom according to his gender—not yours.



Teaching the Hidden Curriculum

For people on the autism spectrum, learning the hidden curriculum is just as, if not more important, than learning academic skills. Yet, I rarely see hidden curriculum or social skills instruction in class schedules or in the IEPs of students needing to learn it. When a person’s brain is not wired to automatically pick up this information, he will not somehow magically learn it as he gets older. It is not something our students with ASDs will outgrow. Instead, the hidden curriculum must be taught by direct instruction to students who have a neurology that does not permit them to automatically learn it in the same way neurotypical students do.

Continued on page 5.

HIDDEN CURRICULUM CONTINUED.....

The ECLIPSE Model (Moyer, 2009) is a useful resource for teachers that includes sample IEP goals along with “pick up and use” lesson plans for teaching the hidden curriculum. *The Social Times* (Burton, 2010) is another resource for teachers, which is written directly to students in their “voice”. Each new issue offers critical information in a format that makes learning social information fun for students. Another way to teach and learn the hidden curriculum is by using the *One A Day* hidden curriculum calendars, geared to both kids (Trautman & Wragge, 2010) and older adolescents and adults (Endow, 2010). In addition, hidden curriculum items are available as iPhone applications for all ages.

However you choose to teach the hidden curriculum, know that learning it is not optional for those of use with autism. If you are a teacher, know that the hidden curriculum is likely the most important subject you will ever teach. Your school district will not mandate it, but wise teachers will make teaching it a priority.

If you are a person on the autism spectrum, know that you will need to keep learning the hidden curriculum as you graduate from school and move into the world. It is great to have earned a diploma, but you must not stop there. A diploma is merely the first step into adult life. For me, keeping up with and learning new, elusive and ever-changing hidden curriculum items is crucial. It allows me to fit in more comfortably with my family and friends, in my job and in my community, and lets me be all that I want to be in the world.

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LBL ESD WEBSITE SUPPORTS

Our focus for this newsletter is community supports. We have updated supports on our website at www.lblesd.k12.or.us. Once you open the web page select the *Cascade Regional Program* link tab. After the *Cascade Regional Program* page comes up select the *Autism Program*. After that page loads select *Local Resources and Services*. There will be three different tabs that you can browse through. (<https://www.lblesd.k12.or.us/cascade-regional-program/autism-program/local-resources/> This is the link directly to the 3 tabs)

- Autism Advocacy and Support Groups
- Child and Family Services
- Supported Employment/ Job Development

If you come across a community support that you would like to add to our website please email us. We are always looking for great resources.

IPAD APPS

iDo Community – kids with special needs learn to act independently in the community



By C.E.T - THE CENTER FOR EDUCATIONAL TECHNOLOGY

A review of this app by Bridging Apps:

(<https://search.bridgingapps.org/apps/5f8a42d2-7070-48af-b8ec-71664ab6283c>)

iDo Community is a comprehensive app that addresses how to behave and participate in nine essential areas in the community. The areas include "In the Car", "In the Elevator", "At the Supermarket", "At the Shop", "At the Cafe", "At the Movies", "At the Barbershop", "At the Dentist", and "At the Doctor's Office". Each scenario includes a video with the words stated at the bottom of the screen for users to read along. Next, there is a picture sequence reinforcing what the user saw in the video. There is an option for users to make their own video and picture sequence as it relates to their life.

At the bottom of the screen reinforcement games are provided. First, is the right sequence and then there is find the picture. Both of these activities refer back to the video and picture sequence.

This app can be used with all ages. It is particularly nice for middle school through high school because the videos present teens making it relevant to older students. iDo is particularly helpful when working with students with intellectual disabilities. The app allows students to use their strengths, either visual or auditory to apply what they see in the video.

Our reviewer uses these videos in her class of students with developmental disabilities. After exploring the app, the students replicate them in the community allowing them to transfer skills from the app to the real world. This has become a mandatory activity they we prepare students for transition from high school into the real world.

The kids also enjoy the "Let's Play!" game at the bottom of the main screen. This game reinforces skills, but also allows for social skills to be included in the activity.

(apps are suggestions from LBLES D and not endorsed)

AUTISM SPEAKS WEBSITES FOR FAMILIES

Websites for families:

This is a sample of what Autism Speaks has shared in their article “Websites for Families”. If you would like to see the rest of the websites please visit <https://www.autismspeaks.org/family-services/resource-library/websites-families>.

[Autisable.com](#)

Autisable.com is a blogging community focused on Autism, Asperger's Syndrome, PDD NOS and other Pervasive Development Disorders. Autisable's Mission is to be of service to the Autism Community by providing an open platform where anything Autism Related can be shared and discussed.

[Autism in Action](#)

Autism In Action® was founded in 2001 by Dr. Beverly Braman (BCBA-D) and Dr. Susan Catlett (BCBA-D). Their goal is to help parents, teachers, and others who participate in the lives of individuals diagnosed with autism and related disorders learn how to use applied behavior analysis (ABA) as a part of everyday life. They offer 42 "How-To" Teaching Programs, the Instructional Objectives Handbook, and the Autism and ABA: A "How-To" Handbook for Teachers.

[Circle of Moms](#)

We are a community of many mothers coming together as one. We like to discuss many aspects of our lives, drawing from our common experience as parents, family members and those caring for children on the autism spectrum.

[Dads 4 Special Kids](#)

Dads 4 Special Kids is an organization dedicated to helping men who have a child with special needs in their lives. We provide invaluable information, encouragement and support to men who are striving to improve, enrich and heal their own lives, and who are determined to provide their best to a child with special needs.

[Keesago, LLC](#)

Keesago, LLC is a new company created by parents of special needs families for other parents of special needs families. Our mission- to revolutionize the way members of the special needs community find high quality resources!

[KidWX](#)

KidWX is a FREE parent review-based website that allows parents to post and search reviews (WXs) of service providers who provide services for children from infant to college. KidWX takes pride in assisting parents regardless of their child's age or ability.

[The National Parks and Federal Recreational Lands Annual Pass](#)

This access pass is a free, lifetime pass - available to US citizens or permanent residents of the United States that have been medically determined to have a permanent disability - that provides access to recreation areas managed by 5 federal agencies.

[Sandbox Learning Lending Library Links](#)

Many states have non-profit foundations which support the lending of resources. These resources range from extensive libraries of sensory integration toys, augmentative communication devices, and games or puzzles designed for individuals with disabilities to simple software or low tech devices. Professionals, and in many states parents, are able to ‘check out’ a device online and have it delivered to their home or visit designated centers to borrow items. Since many devices and toys for children with disabilities are very expensive, these programs are an excellent way for people to test augmentative communication devices or adaptive materials before purchasing them. This website lists resources from each state.



Experience Speaks

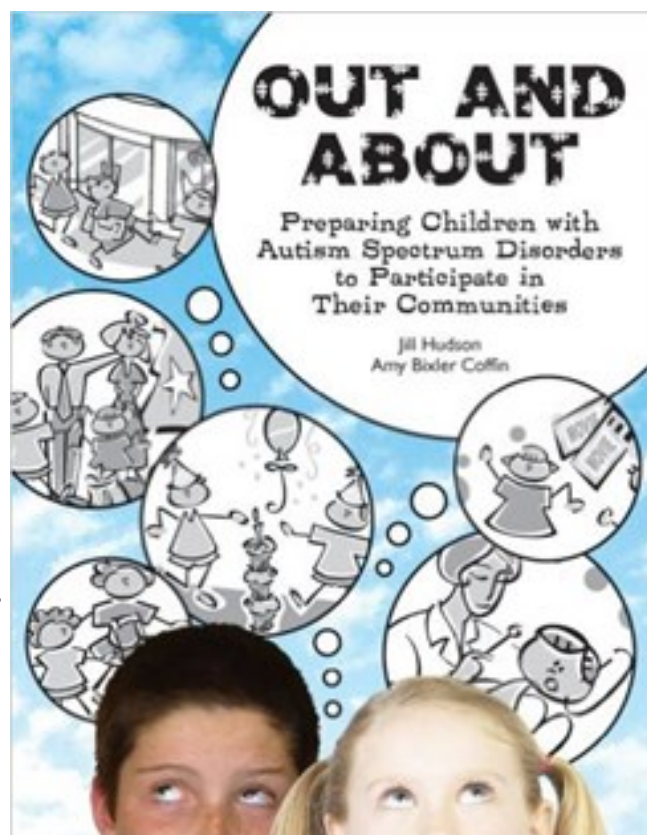
Autism Speaks Facebook Group Members Share Ideas to Help with Socialization

- ♦ My son with autism is 25, so I have tried many things. What works best is for me to explain, in detail, every glance, every smile, every touch, every sigh, and every social skill that we come in contact with. I found the he slowly began to ask, "Why?" Within a few years of this social therapy game, I reversed the positions and began to ask him, "Why?" He caught on slowly. At age 17 he asked me if he could stay with his friends at a get-together. He doesn't always participate, but he certainly follows the conversations and he definitely has an opinion on everyone's interactions. Lots of explaining, over and over. Patience is a must!
- ♦ I try to put my son in social situations as often as possible. When my son was first diagnosed I took him to the park and assisted him with cooperative play. His way of introducing himself was to grab someone else's toy or growl in their face, like a lion, and run away. I interrupted and intervened constantly, even with a newborn strapped to my chest. It was hard, hard, hard. I purposely went to parks where I didn't know too many people so I wouldn't be uncomfortable doing what needed to be done and so I wouldn't be distracted with chatting.
- ♦ I always make my son pay and talk to the cashier. It is always a forced conversation for him but he has to talk to a stranger almost every day.
- ♦ I have a six-year-old son with Asperger's and what really works with him is role play. He can intellectually tell you what he is supposed to do in a situation, but can't really implement it until he "rehearses" it. He also belongs to cub scouts, which has really boosted his social confidence. He used to belong to a soccer team, but has challenges with his coordination and used to get down on himself when he didn't score goals. Cub Scouts really focuses on the positive and he has a lot in common with the other boys.
- ♦ Stay consistent. Take them into a social situation everyday, maybe it has to be the same time each day, but then gradually make small changes (bigger social group, different time, longer, etc...) These children need to be 'stretched' out of their comfort zone slowly.
- ♦ Start out very small. I would take my boys to Wal-Mart, and start with the greeter. I would have them say "Hello, how are you?" and make eye contact. Restaurants are good also, giving them practice talking back and forth with a waiter or waitress. Church has been a wonderful social environment for them as well. I have found my church family more forgiving and they have helped a great deal with social skills and situations - if a child feels comfortable and protected, the social skills become easier.
- ♦ I expose my six-year-old son, who has Asperger's, to as many children as possible. We go to the park EVERY day the weather permits. Last night, we went and he stated crying. He had a long struggle with a boy he had been playing with who took his light saber away. I was able to jump in and figure out what the problem was. My son hadn't communicated that he didn't want the boy to take away his sword. During the struggle for the light saber, the boy thought they were still playing and was enjoying the struggle (to my son's chagrin) for the coveted sword. Because my son hadn't communicated his anger properly, his playmate didn't realize that my son didn't want him to have the sword. So, on the way home, my son and I discussed what he could say next time to let a child know he isn't playing anymore, and that HE WANTS TO KEEP HIS LIGHT SABER! Also, we discussed the notion of sharing. We discussed what he will do the next time he is in the situation and how he really needs to share. He can share if he has been prepared ahead of time that this is what's expected of him. I've found daily exposure REALLY helps! I suppose it gives you, the parent, and a way to navigate through social situations with your child.

Out and About: Preparing Children with Autism Spectrum Disorders to Participate in their Communities

by Jill Hudson and Amy Bixler Coffin

This short, to-the-point resource is sure to be used repeatedly by parents and educators. It focuses on everyday events and how to enable and support individuals on the autism spectrum to be active participants in the world around them. Created as a Blueprint to be filled in according to the child and the event being planned, the framework lists 10 areas that have been identified in best practice as effective types of support for children with an autism spectrum disorder. These include a waiting plan, communication, social, visual, hidden curriculum rules, sensory, motivation, behavior, transitions and siblings or other students. The individualized Blueprint will become second nature to its users as they become more familiar with the support the child needs and, therefore, serve as an indispensable tool in everyday life.



Make Social Learning Stick! How To Guide and Nurture Social Competence Through Everyday Routines and Activities

By Elizabeth A. Sautter

This book offers a social learning diet of concepts and actions that can be used in everyday life to increase verbal and nonverbal language, listening skills, understanding of hidden rules, perspective-taking, executive functioning, and more. The activities are recipes for social and emotional learning for which parents, teachers,



and therapists typically already have the ingredients. With close to 200 fun and easy activities, this book offers numerous ways to embrace teachable moments throughout daily routines at home and in the community without having to do extra work! Events like getting ready for school, preparing dinner, going to the doctor, and celebrating Thanksgiving become opportunities for teaching and reinforcing expected social behavior. Geared toward children in preschool through elementary school, the ideas are meant to inspire creativity that suits each specific child. Activities can be easily tailored to meet a child's developmental level, needs, or challenges.



Autism Consultants:

Skye McCloud- skye.mccloud@lblead.k12.or.us
541-812-2663

Sue Taylor- sue.taylor@lblead.k12.or.us
541-812-2676

Linn Benton Lincoln ESD
Cascade Regional Autism Program

Melissa Bermel- melissa.bermel@lblead.k12.or.us
541-812-2773

905 4th Ave SE
Albany, Or. 97321






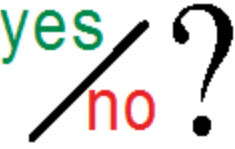









Amanda Stenberg- amanda.stenberg@lblead.k12.or.us
541-812-2676

Tel: 541- 812-2600
Fax: 541 926-6047
E-mail: webmaster@lblead.k12.or.us

Scott Bradley- scott.bradley@lblead.k12.or.us
541-812-2677

Michelle Neilson- michelle.neilson@lblead.k12.or.us
541-812-2678

VISUALS

hello 	goodbye 	my turn 	your turn 
you're to close 	Ask me a yes/no question 	yes 	no 
help 	friends 	listen 	all done 
I'm ready 	I'm not ready 	not 	no one to play with 