





Two New Web-based Tools for Assessment and IEP Goal Development for Children with Complex Communication Needs!

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Oregon Health & Science University Portland, OR AT Now! February 24, 2015





The CSI-CY: A New Tool to Aid in Communication Goal Development

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Goals today

- 1. Justify use of the ICF-CY for AAC
- 2. Present a description of the instrument
- 3. Go through a guided completion of the CSI-CY
- 3. Discuss research findings and the usefulness of the CSI-CY for AAC goal development

THE CHALLENGE

There is no standard developmental set of skills that can guide AAC goal development.

The Problem

- Don is a 4 year old child who relies on AAC with Down Syndrome and Metabolic Strokes
- The ICD-10 describes him as 758.0
- What does this say about Don's functional communication?



ICD codes ≠ *child's functional communication*

- Individuals with CCN have communication difficulties related to a variety of different health conditions
- Health condition alone intervention methods? NO!
- Function in different environments + health condition = appropriate intervention methods

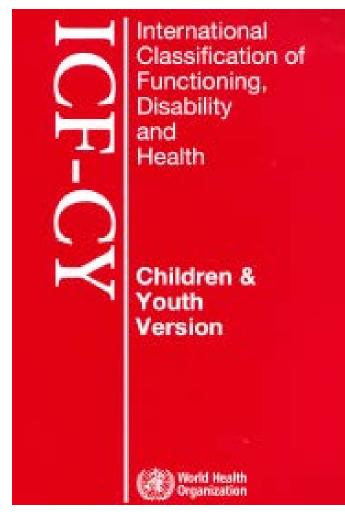
A Solution: The ICF-CY



- ICF-CY: International Classification of Functioning, Disability and Health -Child & Youth version
- Developed by the World Health Organization (WHO) to complement the ICD
- Designed to describe the *functional status* of individuals in a standardized manner

Why ICF-CY?

- *Systematic* coding scheme
- Function, instead of etiology or diagnosis (unlike ICD)
- Common language for professionals, persons with disability, family members & the public worldwide
- Can be used across education, medical and social services.



The ICF and AAC

The ICF works especially well for AAC learners, because it separates speech functions from communication functions

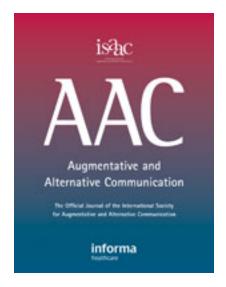
Communication ≠ **Speech**



ICF-CY system

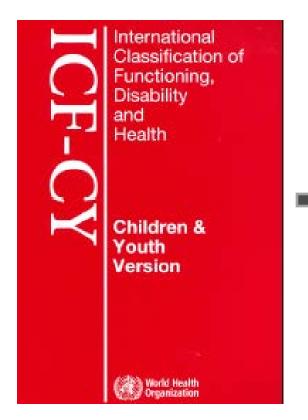
- Body Structures sometimes different or not present
- Body Functions may vary due to structure
- Activities and Participation may be limited and life situations restricted due to functions
- Environment: facilitators and barriers in every environment that affect participation

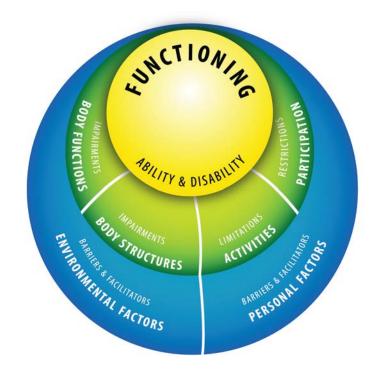
"The ICF fits our international AAC community like an old shoe that we have been wearing for many years." Fried-Oken and Granlund (2012)



Volume 28, Number 1 (March 2012) Special Issue: AAC and ICF: A Good Fit to Emphasize Outcomes

From WHO document to CSI-CY Profile





Published manual of codes

On-line interactive CSI-CY Inventory

Using the ICF as an Organizational Framework to Improve Communication Goals for AAC Users

- Population: School-aged children (in U.S.) who use AAC or are candidates for AAC
- Goal 1: Develop and evaluate the CSI-CY to describe communication strengths and needs of children who use AAC
- Goal 2: Use the CSI-CY to guide communication goal development

Two-part CSI-CY

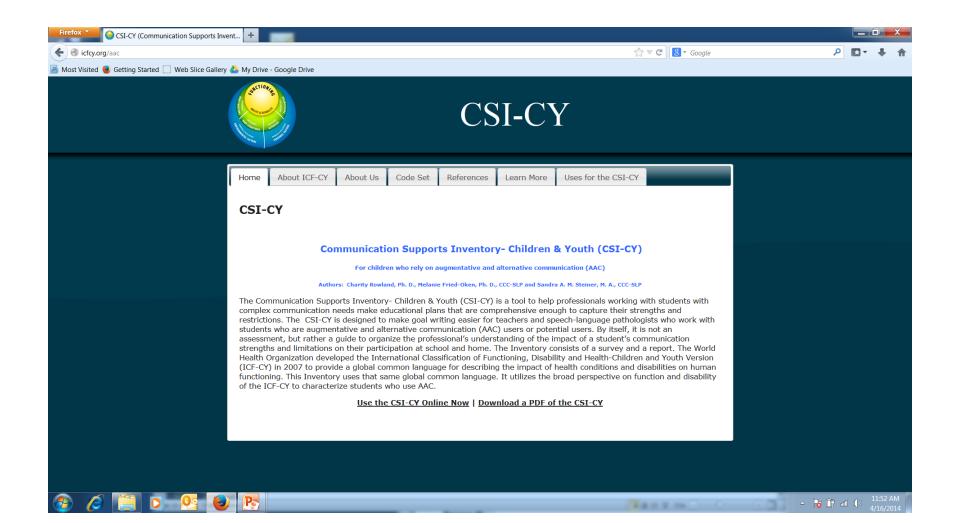
- 1. Code Set surveys:
 - participation restrictions,
 - communication limitations,
 - functional reasons for them,
 - environmental facilitators and barriers

2. <u>Report:</u> prioritizes identified items to facilitate IEP goal development process

Code Set Items

- 112 items in 14 sections
- Plus 1 open-ended text box for each of 14 sections
- Total items = 126
- The ICF-CY codes are listed next to each item

www.csi-cy.org



Participation Restrictions:

- 1. School-related Activities
- 2. Interpersonal Relationships

Communication Limitations: *Rate limitations in...*

- 1. Receptive Language and Literacy
- 2. Expressive Language and Literacy
- 3. Functions of Communication
- 4. Rules of Social Interaction in Conversation
- 5. AAC: Receptive Communication
- 6. AAC: Expressive Modes and Strategies
- 7. AAC: Motor Access

Body Functions:

Rate impairments that limit communication...

- Hearing
- Vision
- Touch
- Oral Motor

- Respiratory
- Intellectual
- Gross and
 Fine Motor

Environmental Barriers and Facilitators*

- 1. Physical environment
- 2. Assistive technology
- 3. People
- 4. Services and policies

*This often corresponds to the special education and related services and supplementary aids and services sections of the IEP.

SAMPLE OF CSI-CY INVENTORY

2012 - Mozilla Firefox t <u>View His</u> tory <u>Book</u> marks <u>T</u> ools <u>H</u> elp		(Calculate) (Second Second	
/ (Communication Supports Inv 🛛 🍚 CSI-CY 2012	× +		
survey.i cfcy.org /survey		🏠 ⊽ 😋 🚼 ⊽ Google	۹ ج
Visited 🧶 Getting Started 🗌 Web Slice Gallery 🝐 My Drive -	Google Drive		
64. Other social interaction rules? Writ	e in response.		
Augmentative and Alternative	Communication: Receptive Strategie	es	
Considers the student's understanding of the s	/mbols included in a particular AAC system , such as un	derstanding the meaning of PECS cards or manual signs	
65. Comprehending the meaning of boo	ly gestures (eg., facial expressions, posture, h	hand gestures, movements)	
Skills are above those of typical peer No limit ICF-CY Code: d3150 HELP?	tation $\ensuremath{ extsf{0}}$ Mild limitation $\ensuremath{ extsf{0}}$ Moderate limitation $\ensuremath{ extsf{0}}$ Severe	limitation $\ \odot$ Complete limitation $\ \odot$ Not applicable $\ \odot$ Don't know	
66. Comprehending 3-dimensional obje	ects/representations used to communicate		
Skills are above those of typical peer No limit ICF-CY Code: d3150 HELP?	tation $\ensuremath{^{\odot}}$ Mild limitation $\ensuremath{^{\odot}}$ Moderate limitation $\ensuremath{^{\odot}}$ Severe	limitation igodoldoldoldoldoldoldoldoldoldoldoldoldol	
67. Comprehending the meaning of dra			
	wings and photographs used to communicate		

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Take a trip with us through the CSI-CY

Let's describe Nicole, a 6 year old girl with Rett Syndrome....



Meet: Nicole Age: 6 years Medical Diagnosis: Rett Syndrome

CURRENT COMMUNICATION IMPAIRMENT

• Profound expressive and receptive communication impairment

BACKGROUND INFORMATION

 Personal/Social: Nicole was born prematurely and was diagnosed with Rett Syndrome at the age of two years. Due to this neurodevelopmental condition, she has orthopedic impairments, constant hand wringing, inability to speak, and digestive issues. She has received speech therapy for three years and recently received a Tango speech generating device, which she brings to school. She is nonambulatory and non-verbal, but definitely can get her needs met by vocalizing with laughter, protests, crying, smiles, and eye contact. She presents as a happy child who loves attention. She enjoys human contact and only complains when she is in discomfort.

Complete CSI-CY at www.csi-cy.org

Firefox CSI-CY (Communication Supports Invent... +

🗲 🕙 icfcy.org/aac

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CSI-CY

Home	About ICF-CY	About Us	Code Set	References	Learn More	Uses for the CSI-CY		
CSI-CY								
Communication Supports Inventory- Children & Youth (CSI-CY)								
For children who rely on augmentative and alternative communication (AAC)								
Authors: Charity Rowland, Ph. D., Melanie Fried-Oken, Ph. D., CCC-SLP and Sandra A. M. Steiner, M. A., CCC-SLP								
The Communication Supports Inventory- Children & Youth (CSI-CY) is a tool to help professionals working with students with complex communication needs make educational plans that are comprehensive enough to capture their strengths and restrictions. The CSI-CY is designed to make goal writing easier for teachers and speech-language pathologists who work with students who are augmentative and alternative communication (AAC) users or potential users. By itself, it is not an assessment, but rather a guide to organize the professional's understanding of the impact of a student's communication strengths and limitations on their participation at school and home. The Inventory consists of a survey and a report. The World Health Organization developed the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) in 2007 to provide a global common language for describing the impact of health conditions and disabilities on human functioning. This Inventory uses that same global common language. It utilizes the broad perspective on function and disability of the ICF-CY to characterize students who use AAC.								

Use the CSI-CY Online Now | Download a PDF of the CSI-CY

Finish Nicole's CSI-CY

To resume the survey where you left off, please go to

Final output: Profile Report

ICF-CY for AAC, survey 1028

Areas of Concern

Communication Limitations

Receptive Language and Literacy 22. Intentionally attending to human touch, face and/or voice

Expressive Language and Literacy

32. Using body language, facial expressions and gestures to communicate

Functions of Communication 45. Refusing or rejecting something

Rules of Social Interaction in Conversation

55. Orienting towards communication partner through eye contact or body positioning

Augmentative and Alternative Communication: Receptive Strategies

68. Comprehending the meaning of manual sign language (eg., ASL, finger spelling, signed English, etc.)

 Comprehending the meaning of body gestures (eg., facial expressions, posture, hand gestures, movements)

69. Comprehending the meaning of AAC signs/symbols (eg., MinSpeak icons, Bliss symbols,

Augmentative and Alternative Communication: Expressive Modes and Strategies

71. Using 3-dimensional objects/representations to communicate

Impairments in Body Functions that Limit Communication

Impairments

91. Hearing function

Environmental Factors that Serve as Barriers or Facilitators for Communication

Assistive Technology

 Assistive products and technology for generalized use in school (eg., prosthetic and orthotic devices; glasses, hearing aides, cochlear implants, etc.)

People

 Knowledge of skills needed to support communication in school (eg., knowing manual sign language, knowing how to use the communication device, etc.)

Better than average skills and environmental facilitators

Environmental Factors that Serve as Barriers or Facilitators for Communication

Assistive Technology

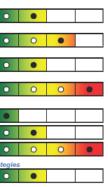
104. Adapted or specially designed HIGH tech products/technology developed for the purpose of improving communication (eg., speech generating device, FM system, specialized writing device)

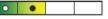
People

111. Providing physical support at school (eg., supporting body posture appropriately, making glasses available, etc.)

112. Providing emotional support at school

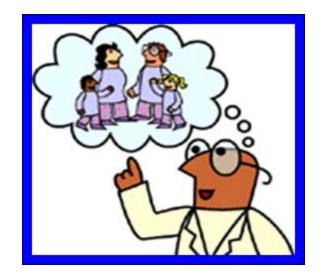
114. Providing physical support at home







Research Studies



Our Questions

- What CSI-CY subsections are prioritized by CSI-CY users?
- Are CSI-CY subsections that are prioritized also addressed in IEP content?
- Does use of CSI-CY appear to affect the content of communication-related IEP goals?
- How do users of the new tool rate its usefulness?

Who participated?

- N = 61 SLPs and Special Educators (30% SE; 69% SLP; 1% other)
- From 55 states
- Work settings: Elementary (64%), Middle School (15%), Secondary (21%)
- Disability of targeted students: autism (28%), multiple disabilities (13%), Down Syndrome (7%), CP (7%), deaf/HOH (5%)

Random Assignment to Control and Experimental Groups

 Control participants (n = 25) simply provided current IEP

 Experimental participants (n = 36) viewed training webinar, administered CSI-CY prior to developing next IEP, then submitted new IEP

Coding the Content of IEPs

- Coders were blinded to whether the IEP came from the experimental or control groups.
- From each IEP, all communication-related goals & objectives, accommodations, modifications and services were extracted.
- Each item was scored as to whether it addressed any content in each of the 14 CSI-CY sections.
- All items coded by 2 raters and consensus agreement obtained on all items.

IEP data

- Great variety in the 35 IEPs
- # communication-related goals & objectives per IEP:
 - Mean = 9.8, range= 1-31
- # communication –related accommodations/modifications/services per IEP:
 - Mean= 5.0, range= 1-26

What sections of CSI-CY were prioritized in Experimental IEPs?

- These CSI-CY subsections were prioritized by at least 50% of participants:
 - Interpersonal Relationships
 - Receptive Language/Literacy
 - Functions
 - AAC-Expressive
- These CSI-CY subsections were prioritized by less than 20% of participants:
 - AAC Motor
 - Body Functions
 - Environemnt-Physical
 - Environment-AT
 - Environment-People
 - Environment-Services/Policies

Relationship between CSI-CY Sections Prioritized versus Addressed in Content of Experimental IEPs

CSI-CY subsection	% who prioritized in CSI-CY report	% who addressed in IEP
AAC-Expressive	69%	83%
AAC-Receptive	31%	17%
AAC-Motor	19%	6%

QUESTION: Are we paying enough attention to the receptive and motor aspects of AAC?

How Did Content of Control versus Experimental IEPs Compare?

We calculated the # times that CSI-CY content was addressed in goals/objectives of experimental versus control IEPs.

- In experimental IEPs CSI-CY content was referenced a mean of 23 times
- In control IEPs CSI-CY content was referenced a mean of 16 times
- This difference is statistically significant (p = .041)

Consumer Satisfaction Study

- CSI-CY made publicly/anonymously available online (without cost) and users were forced to answer a 3-item satisfaction survey before gaining access to the report.
- Results. % who responded "strongly agree" or "somewhat agree" (n = 166) to each question:
 - The CSI-CY helped me to write more effective communication goals for this student's IEP (82%)
 - I considered areas of concern that I had not thought of before using the CSI-CY (81%)
 - I would recommend the CSI-CY to another colleague (89%)

Conclusions

- There is great variability in goal development for children who rely on AAC.
- Use of the CSI-CY appears to affect the content of IEPs. An attitude shift?
- There are ICF constructs that appear rarely in IEP goals.
- We need to address the foundations of using AAC systems, not just expressive use of the system/device.
- CSI-CY users expressed high satisfaction with this new tool.
- Use of this tool may fill a demonstrated need of SLPs to understand AAC better (Fallon & Katz, 2007).
- The ICF-CY served as a useful foundation for this AAC-related tool.

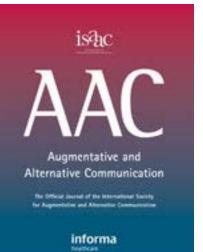
Where can I find the CSI-CY?

At CSI-CY.org you will find 3 versions of the instrument, all available without cost:

- Online version
 - Restricts users to prioritizing 3-20 items
 - Automatically generates report
 - May print out/save report and survey responses, but YOUR DATA ARE NOT SAVED ONLINE
- Fillable PDF to be answered online, then printed/saved
- PDF for printing and completion by hand

Future Options

- Codify the iterative PROCESS that we have developed for use by other groups to generate code sets for a specific health condition or functional problem
- Apply the AAC codes to electronic medical records
- Develop a parent version of Profile that could be used to mediate conflicts between home/school



AAC Volume 28, Number 1 (March 2012) Special Issue: AAC and ICF: A Good Fit to Emphasize Outcomes

Rowland, C., Fried-Oken, M., Steiner, S.A.M., Lollar, D., Phelps, R., Simeonsson, R. and Granlund, M. *Developing the ICY-CY for AAC Profile and code set for children who rely on AAC*.

Murphy, J. and Boa, S. Using the WHO-ICF with Talking Mats as a goal setting tool.

Raghavendra, P., Olsson, C., Sampson, J., McInerny, R. and Connell, T. School participation and social networks of children with complex communication needs, physical disabilities and typically developing peers.

Clarke, M. T., Petrides, K. V., Griffiths, T., Lysley, A. and Price, K. An examination of relations between participation, communication and age in children with complex communication needs.

Granlund, M., and Pless, M. Implementation of the International Classification of Functioning, Disability and Health (ICF/ICF-CY) and how this relates to Augmentative and Alternative Communication.

Simeonsson, R., Bjork-Akesson, E. and Lollar, D. *Communication, disability and the ICF-CY.*

Our team



Funded by:

The Institute of Education Sciences U. S. Dept. of Education Grant #R324A090028 Charity Rowland, PI



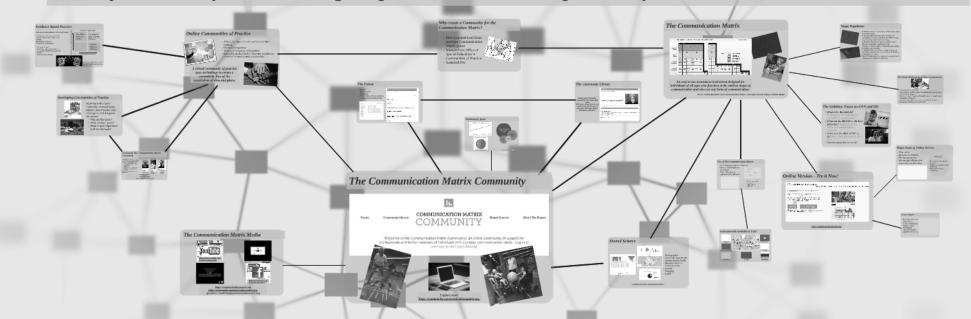
Education Programs

www.icfcy.org/aac

- CSI-CY tool
- Code Set
- Reference list
- Publications
- Presentations



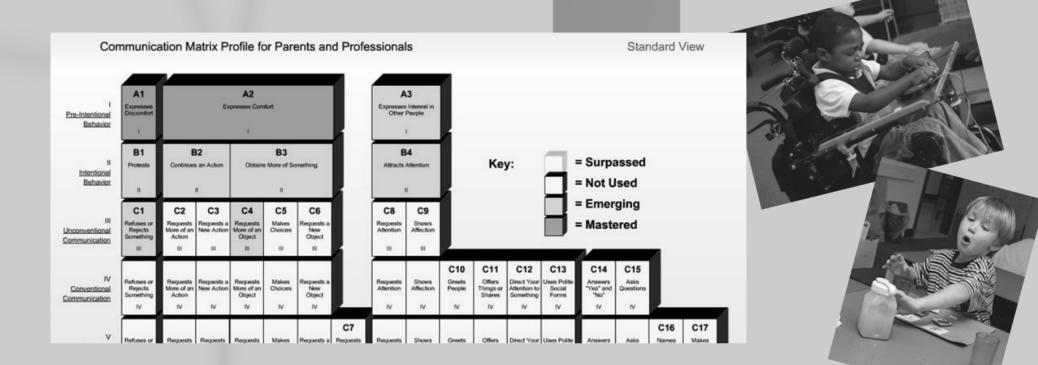
Ask questions on facebook during the presentation! Go to https://www.facebook.com/CommunicationMatrix



The Communication Matrix & the Community

Charity Rowland, Ph.D Alexandria Cook Oregon Health & Science University

The Communication Matrix



An easy to use assessment instrument designed for individuals of all ages who function at the earliest stages of communication and who use any form of communication.

See Dr. Charity Rowland's work: Communication Matrix: Description, Research Basis and Data (2012)

Target Population





- Individuals who are functioning at the earliest stages of communication.
- In the typically developing child the range of communication skills covered by the Matrix would occur between 0 and 24 months of age.
- Individuals who use any type of communicative behavior, including "augmentative and alternative" (AAC) forms of communication and presymbolic communication.
- Individuals who experience any type or degree of disability, including severe and multiple disabilities.
- Individuals of all ages.
- But NOT individuals who already use some form of language meaningfully and fluently.

The Need: Weaknesses of Many Assessments



- Accommodate speech only
- Don't address earliest stages of communication in sufficient detail to show progress
- May not probe for meaningful behaviors, as opposed to mere production of behavior
- Do not accommodate sensory or physical impairments
- Emphasize what the child CAN'T do

The Solution: Focus on CAN and DO

- What CAN the child do? Emphasis on the individual's strengths, not weaknesses.
- What can the child DO with these behaviors? Emphasis on the USES of communicative behaviors.
- What does the child WANT to do? What does s/he want to tell you?
- Parent perspective is crucial.



Major Goals of Online Version

- Ease of use
- Increase availability
- Encourage parents
- Encourage collaboration
- Generate scientific data

COMMUNICATION MATRIX

About | Data Entry | Results | FAQ | Custom Report | Who's using this? | New Translations

Communication Assessment for Parents & Professionals

An easy to use assessment instrument designed for individuals of all ages who function at the earliest stages of communication and who use any form of communication.









Privacy

- No identifying information collected
- Information entered is stored in database
- IRB-approved privacy mechanisms

Online Version-- Try it Now!

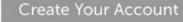
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Try It Now



Download the entire handbook. Need Adobe Reader?, get it here.

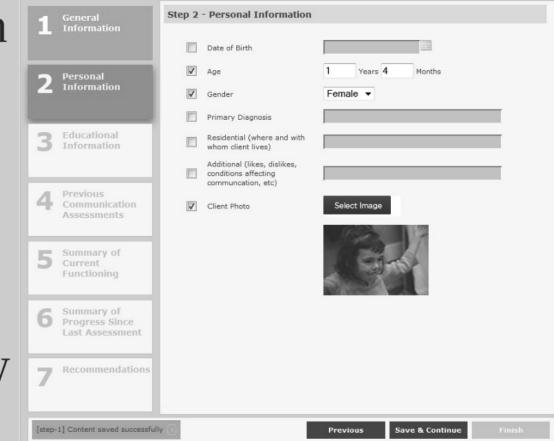




https://communicationmatrix.org

Custom Reports

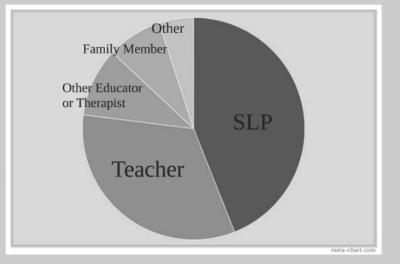
- Personal information about client
- Current functioning
- Progress report
- Educational recommendations
- English only for now



Use of The Communication Matrix

- Over 90,000 assessment completed
- On over 40,000 different individuals
- From 144 countries
- Approximately 600/week

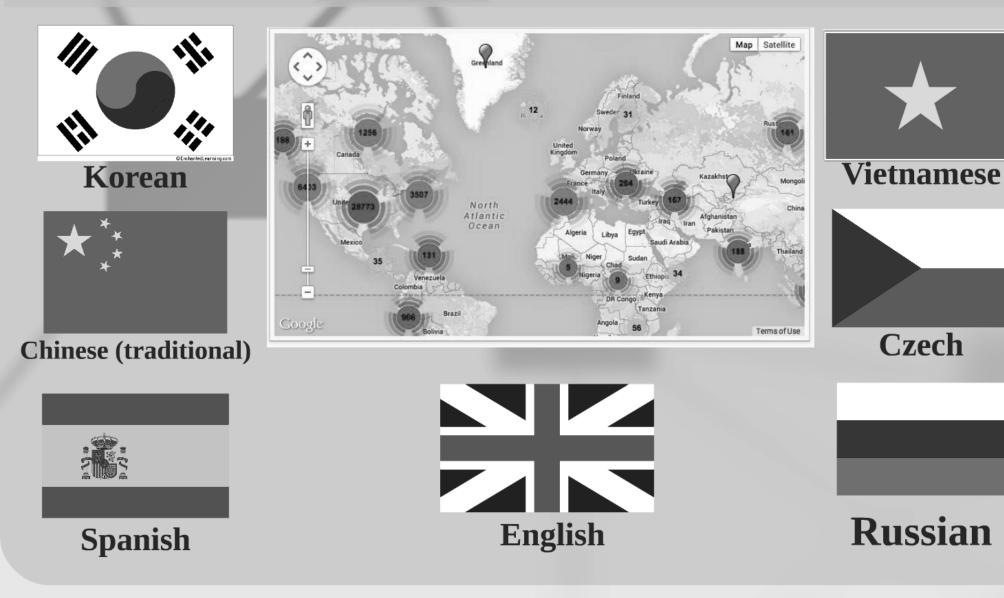
Rare Disorder	Estimated Incidence
Aicardi (n = 37)	1: 100,000
Angelman (n = 601)	1: 15,000
CHARGE (n = 402)	1: 11,000
Cornelia de Lange (n = 150)	1: 20,000
Rett (n = 443)	1: 16,000
Deafblindness (n = 3,708) in U.S. (0-21 yr.)	9,387 in U.S. (0-21 yr.)



Most Common Disabilities/Etiologies

Autism (Primary Diagnosis) Cerebral Palsy Developmental Disability/Delay Deafblindness (Primary Diagnosis) Down Syndrome Multiple/Severe Disabilities

Internationally Available & Used



Why create a Community for the Communication Matrix?

- Demonstrated need from previous Communication Matrix grants
- Interest from Office of Special Education in Communities of Practice
- Sustainability



Online Communities of Practice



- Allows for "Just in Time" and "Just for Me" learning
- Multiple Perspectives
- Sharing of resources and expertise
- Especially needed for low incidence populations
- Great for isolated or rural communities

A virtual community of practice uses technology to create a community free of the constraints of time and place.



Evidence Based Practice

Solving real world problems with scientific rigor

- Moving away from "train and fail"Implementation links research and practice
- -Knowledge translation
- -Including all stakeholders

Scaling up Our goal:

- Systematic and ongoing supports
- Conducted and synthesizing applied research
- Communities of Practice

Quest for fundamental understanding

Pasteur's Quadrant

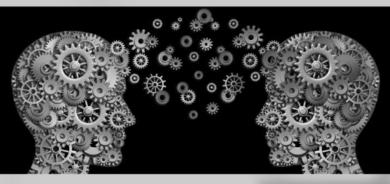
Pure Basic Research (Bohr)

Use-inspired basic research (Pasteur)

Applied Research (Edison)

Consideration of use

Smith, G. J., Schmidt, M. M., Edelen-Smith, P. J. & Cook, B. G. (2012). Pasteur's quadrant as the bridge linking rigor with relevance. Exceptional Children, 79 (2), 147-161.



Developing Communities of Practice





Working with a team including communication experts, practitioners, web developers, and designers we answer:

- Who are the users?
- What are their goals?
- What is their experience with similar tools?

Developing The Communication Matrix Community

Participants will use the Communication Matrix to assess one or more children and beta test the online Community. Participants include:

- Teachers and Speech-Language Pathologists
- Parents
- Students: 0-21 years old who use less than 3 words meaningfully together

We are recruiting more sites in the coming years





-Clackamas ESD, OR -High Desert,OR Facilitators 2014/15



-Corpus Christi, TX -Kirk School, IL



Karen Natoci Charter Member SLP Speech-Language Pathologist

> -Wing Lake Developmental Center, MI

Potential outcomes include: • better IEP goals • high parent goal satisfaction • high goal attainment • professional satisfaction with online community

The Communication Matrix Community



Forum

Community Library

COMMUNICATION MATRIX COMMUNITY

Shared Science

About The Project

Welcome to the Communication Matrix Community: an online community of support for professionals and family members of individuals with complex communication needs. Log in or join now to start contributing!



Explore now! https://community.communicationmatrix.org



The Forum

- Events
- Newest Posts
- Following
- Share videos, photos, and more
- Communication Matrix Filter

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AAC in the	Desert
	is a 3-day conference supporting students with complex communication needs. The theme is Emergent Reading, Writing, AA d at the beautiful Disability E more
posted by Gayl Bowse	r at 11/15/2014 - 0 responses
Here's the profile f	Beginning with the Communication Matrix for my previous post "Beginning with the Communication Matrix." How would you approach this child's program? more
Profile for I	Beginning with the Communication Matrix
Profile for I Here's the profile f posted by Gayl Bowse	Beginning with the Communication Matrix for my previous post "Beginning with the Communication Matrix." How would you approach this child's program? more or at 11/13/2014 - 0 responses
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The Community Library

Invited guest Moderators promote the most interesting posts Moderators include parents and experts in the field of Speech-Language Pathology, Special Education, and more!

Today's Moderate

Amy Parker, , National Center on Deaf-Blindness

https://nationaldb.org

I have nearly 20 years experience in working with people who are deaf-blind as an employment specialist, independent living teacher, in-home parent trainer and advocate. I have doctorate in special education with an emphasis in deaf-blindness and a certification in orientation and mobility in 2009 through an OSEP funded leadership and enrichment fellowship.

The Communication Matrix is one of the best assessments I have ever used to empower the teams and families of those that serve students with significant disabilities.



Sort Posts By V

Chris Klein TED Talks

I am always finding myself watching TED talks for inspiration and to learn about new topics. Chris Klein uses augmentative and alternative communication to elaborates on discrimination and ignorance h ... more

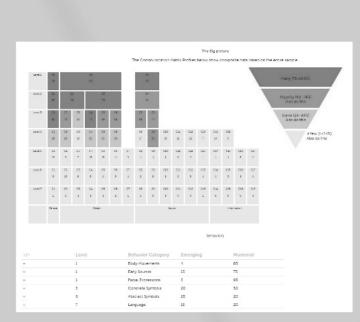
posted by Emily Dayle Guinn at 9/18/2014 - 0 responses

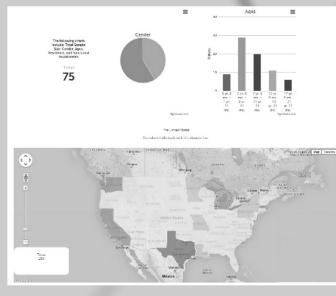
Polite Social Forms

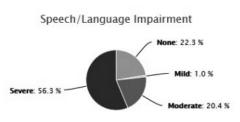
This little girl signs "hamburger please" to make a polite request. ... more

posted by CharityRowland at 8/5/2014 - 2 responses

Shared Science



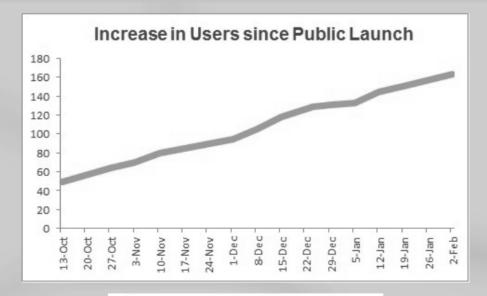




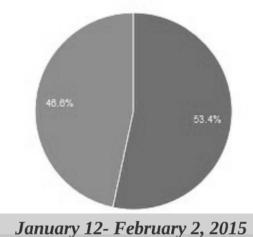
- Demographics
- Functional Impairments
- Average Matrix Profile
- Behaviors used for Communication
- Graphic
- Engaging
- Useful

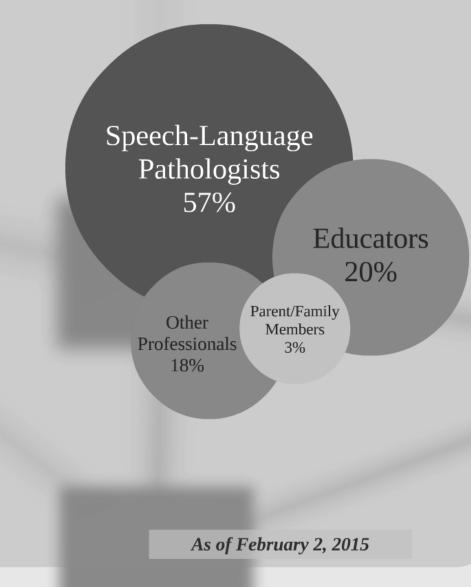
Real Data from the Communication Matrix

Preliminary Data

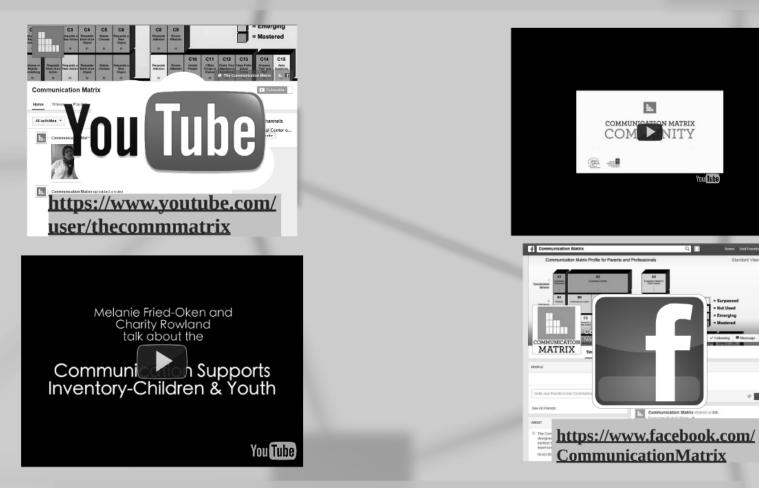


Returning Visitor New Visitor





The Communication Matrix Media



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