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August 12, 2020

AMCHP/SPHARC Peer to Peer  
Exchange

# IOWA REGIONAL AUTISM ASSISTANCE PROGRAM (RAP)

## RAP MISSION STATEMENT

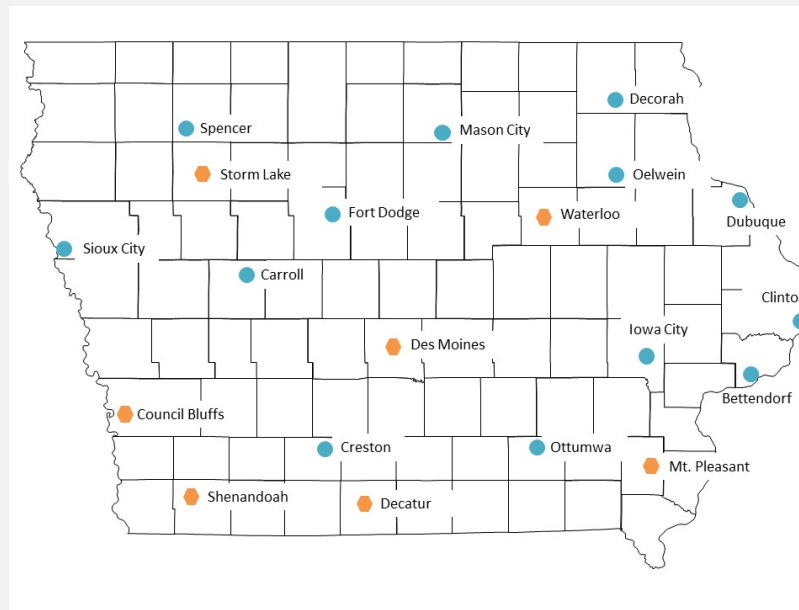
To assure community-based clinical consultation, multidisciplinary care planning recommendations, and family to family support for children with Autism Spectrum Disorder and their families.





## HISTORY OF RAP

- Created through Iowa legislation in 1990, Iowa Code 256.35
- Additional legislation passed in 2013 created the Autism Support Program
- Designed to coordinate education, medical and other human services for persons with autism, their parents, and providers of services to persons with autism
- Funded through the Iowa Department of Public Health and the Iowa Department of Education



## RAP TEAM MEMBERS

- Located at CHSC Regional Centers across Iowa
- Advanced Registered Nurse Practitioners
- Registered Nurses
- Family Navigators



## RAP TEAMS

RAP teams are committed to ensuring that lowans ages 0-21 with ASD have access to early intervention, treatment services, care coordination, and family to family support in their community

They help families to:

- Communicate with diagnostic facilities and health care facilities
- Explore insurance coverage and payment options for intervention services
- Navigate education and other systems
- Find advocacy or family support groups
- Connect with resources and information
- Coordinate care based their needs and goals

# REFERRAL TO RAP FAMILY NAVIGATORS

- Families referred to RAP include those who need help with:
  - Autism or developmental screening and/or diagnostic evaluation
  - Connecting to Early Intervention services
  - Coping with a new diagnosis or change in condition
  - Working with care teams
  - Education plans or paperwork
  - Accessing specialty care or community resources
- Families can be referred to RAP through email, fax, phone, or internally through the University of Iowa Electronic Medical Record (Epic)



**Referral Form**  
 Fill out as completely as possible, save,  
 then send copy by email or fax to:  
 Email: [Iowa-RAP@uiowa.edu](mailto:Iowa-RAP@uiowa.edu) Fax: (319) 384-6480

Questions? Call (866) 219-9119, ext. 2

Referral Source Information		
Name:	Date:	
Agency:	Role:	
Address:	City, Zip:	
Email:	Phone:	
Child's Information		
Child's First Name:	Child's Middle Initial:	Child's Last Name:
Date of Birth: ___/___/___		Gender (M / F / Other):
Address:	City:	Zip:
Home Phone:	Primary Language:	
Primary Care Provider:		
Patient's Race: (check one) <input type="checkbox"/> African American/Black <input type="checkbox"/> American/Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Declined <input type="checkbox"/> Hispanic/Latino of any Race <input type="checkbox"/> Multiracial/Two or More Races <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> Unknown/unspecified <input type="checkbox"/> White		Patient's Ethnicity: (check one) <input type="checkbox"/> Declined <input type="checkbox"/> Hispanic/ Latino or Spanish Origin <input type="checkbox"/> Not Hispanic/Latino or Spanish <input type="checkbox"/> Unknown
Parent or Guardian Information		
1 <sup>st</sup> Parent/ Legal Guardian, relationship to child:	2 <sup>nd</sup> Parent/Legal Guardian, relationship to child:	
Cell Phone:	Cell Phone:	
Email:	Email:	
Question(s)/Concern(s)		
<input type="checkbox"/> Family to family support <input type="checkbox"/> School support e.g. IEPs, 504s <input type="checkbox"/> Explore waiver, other funding options <input type="checkbox"/> Connect to community resources, providers <input type="checkbox"/> CHSC clinical services - Autism screening to assess need for further evaluation <input type="checkbox"/> Other (please explain):  		



## AUTISM SUPPORT PROGRAM

- Provides Applied Behavior Analysis (ABA) services to children under 14 years old who are not able to receive services through Medicaid or private insurance
- Children and families must meet diagnostic and financial eligibility criteria
- RAP teams help families enroll and access related services

# RAP EXPERT PANEL

- Statewide committee to develop administrative rules and guidelines for Iowa children and youth with autism and their families
- Includes Family Advisors
- Created a committee that developed the Strategic Plan
- Included many members of the panel and other stakeholders

## RAP Expert Panel Advisory Committee Members

View

Edit

- Alyson Beytien - [Hills & Dales](#)/Family Member
- Josh Cobbs - Family Advisor
- Kimberly Cooke - Family Advisor
- James Curry - Family Advisor
- Peter Daniolos - University of Iowa Stead Family Children's Hospital/Department of Child and Adolescent Psychiatry
- Connie Fanselow - [Iowa Department of Human Services](#)
- Erika Hertel - Iowa Regional Autism Assistance Program/Family Advisory
- Michelle Holst - Iowa Department of Public Health/1st Five
- Leann Hotchkiss - Family Advisory
- Marcus Johnson-Miller (Analisa Pearson) - [Iowa Department of Public Health](#)
- Aaron Kauer - [University of Iowa Hospitals & Clinics](#)
- Andrea Keith - Iowa Vocational Rehabilitation Services
- Vanessa Kimm - Family Advisory
- Shawn Kolb - ChildServe
- Toni Fuller Merfeld - Metro West Learning Center
- Steve Muller - Balance Autism
- Nathan Noble - [Blank Children's Hospital/Unity Point Health](#)
- Michelle Nuehring - Grant Wood Area Education Agency
- Kelly Pelzel - University of Iowa Stead Family Children's Hospital Autism Center
- Sacha Pence - Drake University
- Mary Roberts - Family Advisor
- Leslie Rogers - ChildServe
- Thomas Scholz - [University of Iowa Division of Child & Community Health](#)
- Kristine Steinmetz - [Autism Society of Iowa](#)/Family Member
- Blake Stephenson - Tanager Place
- Jill Stevenson - Family Advisor
- Melissa Stimmer - Family Advisor
- Rachell Swanson-Holm - Learn the Signs. Act Early./Iowa Regional Autism Assistance Program
- Wendy Trotter - Iowa Department of Education



A large, stylized, blue letter 'I' logo, which is the symbol for the state of Iowa.

**Iowa's  
Strategic Plan  
2016-2021**

***Vision: To improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families***

## STRATEGIC PLAN VISION & MISSION

- To ensure that all Iowans with Autism Spectrum Disorder have the opportunity to develop the skills and knowledge necessary to live independent and interdependent lives within their community and reach their full potential
- To build the state infrastructure for comprehensive, lifespan supports to individuals with autism and their families through access to information and resources, coordination of services, and implementation of evidence-based practices

# STRATEGIC PLAN FOCUS AREAS



Get a Good Start

Have Access to and Obtain Needed Services

Have Well Informed, Empowered, and Supported Families and Caregivers

Successfully Transition to Adult Life

Be Assured of Ongoing Coordination of Systems of Care and Support

# Navigating Iowa's System of Care: A Caregiver's Guide to Autism Spectrum Disorder

## *First Steps After Diagnosis*



## CAREGIVER GUIDE

- Developed in partnership with other statewide organizations serving families of children and youth with autism
- Provides information about services and supports available for families following a diagnosis
  - Understanding autism
  - Individuals with Disabilities Education Act (IDEA)
  - Early Intervention
  - Medical interventions
  - Respite and waiver services

# AUTISM INFORMATION

- Autism Spectrum Disorder Fact Sheet
- Is it Autism Spectrum Disorder or something else?
- RAP Brochure

Translated into Spanish, French, Arabic, and Karen

## Common Medical Interventions for Children with ASD

### Speech Language Therapy

- \* Used to help children understand speech processes and language use in social situations
- \* Can be beneficial for children who may struggle with communication or have difficulty understanding social cues when talking with others

### Occupational Therapy

- \* Involves physical and motor skills
- \* Develops age-appropriate

### Physical Therapy

- \* Focuses on problems with
- \* Addresses challenges with
- \* Can also improve coordin

### Applied Behavior Analysis

- \* Depending a child's need communication, or appro
- \* A therapist determines h
- \* Focuses on positive reinf
- \* Teaches children how to interfere with learning
- \* Uses rewards for positive

### Behavioral Health Services

- \* Typically provided by soc
- \* May be helpful for child behavior disorders, depre
- \* Can involve just the child
- \* Can help children learn n behaviors

### Sources of Information

- Autism Speaks (2016) <https://www.autismspeaks.org/press-releases/2016/03/23/autism-speaks-releases-new-research-report-on-early-diagnosis-of-autism-spectrum-disorder>
- Autism Speaks (2016) <http://www.autismspeaks.org/press-releases/2016/03/23/autism-speaks-releases-new-research-report-on-early-diagnosis-of-autism-spectrum-disorder>
- CDC (2016) <http://www.cdc.gov/autism/earlydiagnosis/>
- CDC (2016) <http://www.cdc.gov/autism/earlydiagnosis/>

## Autism Spectrum Disorder Fact Sheet

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. People with ASD may communicate, interact, behave, and learn in ways that are different from other people. Their learning, thinking, and problem solving skills may be severely challenged. Some people with ASD may have exceptional skills in certain areas while others need less. Signs of ASD begin in early childhood and last throughout a person's life.

### Examples of Communication Issues

- Delayed speech and language skills
- Repeats words or phrases over and over
- Reverses pronouns (says "you" instead of "me")
- Gives unrelated answers to questions
- Does not point or respond to pointing
- Uses few or no gestures (does not wave goodbye)
- Talks in a flat, robot-like, or sing-song voice
- Does like to pretend during play (like pretending to "feed" a doll)
- Does not understand jokes, sarcasm or irony

### Examples of Usual Interests and Behaviors

- Lines up toys or other objects
- Plays with toys in the same way every time
- Likes parts of objects, like wheels or the very organized
- Gets upset by minor changes
- Has obsessive interests
- Has to follow certain routines
- Flaps hands, rocks body, or spins self

### What can you do?

- ✓ Talk with your child's doctor or nurse
- ✓ If your child is younger than three years old, contact your local Early Childhood Program
- ✓ If your child is three years or older, contact your local Early Childhood Program
- ✓ To find your EEA visit <http://www.iowa.gov>
- ✓ Contact the Iowa Regional Autism Assistance Program (RAP) at 100 Hawkins Drive, Iowa City, IA 52242. Phone: 1-866-219-9119, ext. 1. Email: [iowa-RAP@uiowa.edu](mailto:iowa-RAP@uiowa.edu). Website: [www.chsciowa.org/RAP](http://www.chsciowa.org/RAP)

## Is it autism spectrum disorder or something else?



Did you know many children are seen for possible autism, but are not diagnosed with autism?

Did you know most children diagnosed with autism are also diagnosed with something else?

### Possible diagnoses other than autism spectrum disorder:

#### Intellectual Disability (ID)/Global Developmental Delay

- Learn at a slower rate than expected
- Thinking and everyday life skills are delayed
- Movements like children with autism, such as hand flapping

#### Anxiety Disorders

- Too much worry or fear
- Compulsive or rigid
- Shyness or avoiding others
- Refuses to do something they find scary

#### Speech/Language Disorders

- Delays in understanding of words and/or talking
- Trouble saying words right
- Problems doing tasks that use words
- Do better on visual tasks, such as puzzles
- Struggle in social settings needing words

#### Nonverbal Learning Disorder (NVLD)

- Good at doing tasks that use words, but trouble with visual tasks such as puzzles
- Social problems because reacting social cues and body language are visual tasks
- Good vocabulary skills, which can make them sound unusual

#### Attention Deficit Hyperactivity Disorder (ADHD)

- Problems paying attention, staying still, and waiting
- Difficulty playing with others
- Over-reacts to sensory input like children with autism.

#### Social Communication Disorder

- Social problems are similar to those of children with autism
- Have good nonverbal communication and few or no restricted or repetitive behaviors.
- Can be diagnosed when autism spectrum disorder does not fit. Cannot be diagnosed with this and autism spectrum disorder.

#### Disruptive Behavior Disorder/ Oppositional Defiant Disorder

- Trouble doing what they are told
- Hit or do other dangerous or harmful things
- Difficulty playing with others

### How to reach us

Phone: 866-219-9119 ext. 2 Email: [iowa-RAP@uiowa.edu](mailto:iowa-RAP@uiowa.edu)  
Website: [www.chsciowa.org/regional-autism-assistance-program.asp](http://www.chsciowa.org/regional-autism-assistance-program.asp)

# WEBINARS & TRAININGS

## **AUTISM SAFETY INITIATIVE** First Responder Training

Free!

**Thursday, D  
Oelwein Mid  
300 12th A**

**Presenters**  
Mary Roberts  
University of Iowa Childr  
Renee Speh  
Iowa Regional Autism As

Questions? Email Brittney



### **Autism Spectrum Disorder: A Primer for Case Managers**

Tuesday, June 23, 2020, 10:30am - 11:30 am  
Kelly Pelzel,  
Todd Kopelman, P

#### **Learning Objectives:**

1. Increase familiarity with symptoms c
2. Gain preliminary understanding of c why some adaptive skills are difficult fo
3. Identify interventions for individuals v supported by research.
4. Describe options for individuals with individuals and/or families who are
5. Provide resources for families in Iowa

#### **Webinar Registration:**

<https://attendee.gotowebinar.com/register>

Certificates of attendance will be avai recorded, sent to registered participar [www.chsciowa.org](http://www.chsciowa.org).

#### **Questions?**

Erika Hertel  
[erika-hertel@uiowa.edu](mailto:erika-hertel@uiowa.edu)  
319-384-9284



**RAP**  
Iowa Regional  
Autism Assistance  
Program

### **Autism Basics**

**Presenter: Kelly Pelzel, PhD**

*Free four week webinar series for parents or primary caregivers of children with a new autism diagnosis.*

Tuesdays:  
February 18, February 25,  
March 3, and March 10, 2020  
12:00 pm- 1:00 pm

1. **What is Autism?**
2. **Autism Interventions**
3. **Challenging Behavior**
4. **Educational Programming**



#### **To register:**

<https://attendee.gotowebinar.com/register/6110442817151189772>

Registration limited to 100 participants. After registering, you will receive a confirmation email containing information about joining the webinar. Certificates of attendance available following each webinar.

**For more information:** Contact Erika Hertel, RAP Program Coordinator, 319-384-9284 or [erika-hertel@uiowa.edu](mailto:erika-hertel@uiowa.edu)



University of Iowa  
Stead Family  
Children's Hospital  
Division of Child and Community Health

Sponsored by the University of Iowa Division of Child and Community Health

# TRANSITION HANDBOOK

Topics include:

Learning about health needs,  
diagnoses, and medications

Understanding health care records  
and privacy

Finding adult health care  
providers

Understanding health insurance  
and health care forms



## TRANSITION TO ADULT HEALTH CARE QUICK GUIDE

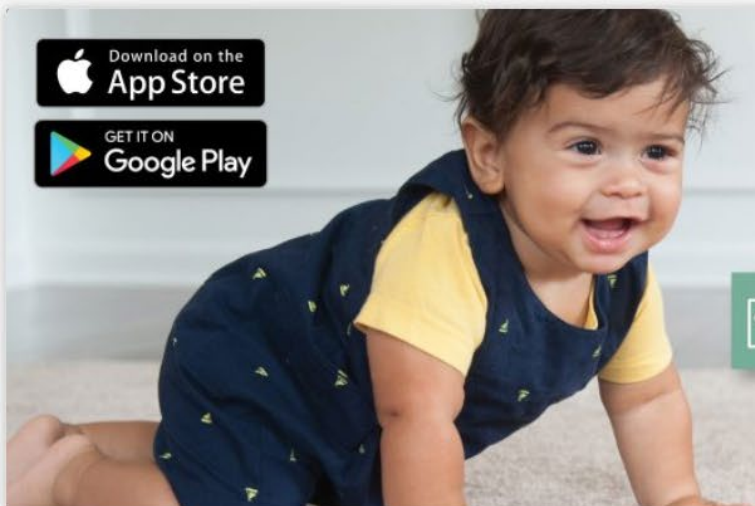
Handbook for Youth, Young Adults,  
and their Families

April 2019



University of Iowa  
Stead Family  
Children's Hospital  
Division of Child and Community Health

## Learn the Signs. Act Early.



# Download CDC's FREE Milestone Tracker App



Track Milestones



Share a Summary



Get Tips & Activities

Learn more at [cdc.gov/MilestoneTracker](https://cdc.gov/MilestoneTracker)

[Español \(Spanish\)](#)



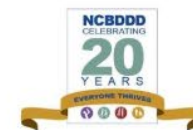
*Families: During COVID-19 you can still schedule appointments for well-child visits, developmental screening, and immunizations. Continue to monitor your child's development between visits.*

From birth to 5 years, your child should reach milestones in how he plays, learns, speaks, acts and moves. Track your child's development and act early if you have a concern.

Milestones

Free Materials

[View events in NCBDDD's history »](#)



LEARN THE SIGNS. ACT EARLY.



HEALTH EDUCATION  
CAMPAIGN



ACT EARLY  
AMBASSADORS



RESEARCH AND  
EVALUATION



## Your Baby by 6 Months

Talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What most babies do by this age



### Social/Emotional Milestones

- Knows familiar faces and begins to know if someone is a stranger
- Likes to play with others, especially parents
- Responds to other people's emotions and often seems happy
- Likes to look at self in a mirror

### Language/Communication Milestones

- Responds to sounds by making sounds
- Strings vowels together when babbling ("ah," "eh," "oh") and likes taking turns with parent while making sounds
- Responds to own name
- Makes sounds to show joy and displeasure
- Begins to say consonant sounds (jabbering with "m," "b")

### How you can help your baby's development

- Play on the floor with your baby every day.
- Learn to read your baby's moods. If he's happy, keep doing what you are doing. If he's upset, take a break and comfort your baby.
- Show your baby how to comfort herself when she's upset. She may suck on her fingers to self soothe.
- Use "reciprocal" play—when he smiles, you smile; when he makes sounds, you copy them.
- Repeat your child's sounds and say simple words with those sounds. For example, if your child says "bah," say "bottle" or "book."
- Read books to your child every day. Praise her when she babbles and "reads" too.
- When your baby looks at something, point to it and talk about it.
- When he drops a toy on the floor, pick it up and give it back. This game helps him learn cause and effect.
- Read colorful picture books to your baby.

## Your Child at 3 Years



Child's Name \_\_\_\_\_ Child's Age \_\_\_\_\_ Today's Date \_\_\_\_\_

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by age 3. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

### What Most Children Do by this Age:

#### Social/Emotional

- Copies adults and friends
- Shows affection for friends without prompting
- Takes turns in games
- Shows concern for a crying friend
- Understands the idea of "mine" and "his" or "hers"
- Shows a wide range of emotions
- Separates easily from mom and dad
- May get upset with major changes in routine
- Dresses and undresses self

#### Language/Communication

- Follows instructions with 2 or 3 steps
- Can name most familiar things
- Understands words like "in," "on," and "under"
- Says first name, age, and sex
- Names a friend
- Says words like "I," "me," "we," and "you" and some plurals (cars, dogs, cats)
- Talks well enough for strangers to understand most of the time
- Carries on a conversation using 2 to 3 sentences

#### Cognitive (learning, thinking, problem-solving)

- Can work toys with buttons, levers, and moving parts
- Plays make-believe with dolls, animals, and people
- Does puzzles with 3 or 4 pieces
- Understands what "two" means
- Copies a circle with pencil or crayon
- Turns book pages one at a time
- Builds towers of more than 6 blocks
- Screws and unscrews jar lids or turns door handle

#### Movement/Physical Development

- Climbs well
- Runs easily
- Pedals a tricycle (3-wheel bike)
- Walks up and down stairs, one foot on each step

### You Know Your Child Best.

Act early if you have concerns about the way your child plays, learns, speaks, acts, or moves, or if your child:

- Is missing milestones
- Falls down a lot or has trouble with stairs
- Droops or has very unclear speech
- Can't work simple toys (such as peg boards, simple puzzles, turning handle)
- Doesn't speak in sentences
- Doesn't understand simple instructions
- Doesn't play pretend or make-believe
- Doesn't want to play with other children or with toys
- Doesn't make eye contact
- Loses skills he once had

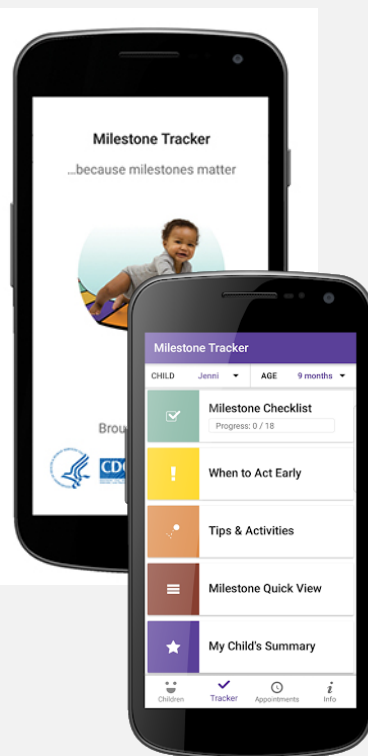
Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay and ask for a developmental screening.

If you or the doctor is still concerned

1. Ask for a referral to a specialist and,
2. Call any local public elementary school for a free evaluation to find out if your child can get services to help.

For more information, go to [cdc.gov/Concerned](http://cdc.gov/Concerned).

**DON'T WAIT.**  
Acting early can make a real difference!



# FREE MATERIALS FOR PARENTS

Developmental Milestone Checklists  
Milestone Moments Booklet  
Tracker App

- ✓ Milestone booklets and checklists designed for parents to use with children age 2 months through 5 years.
- ✓ Four domains of development
  - Social/Emotional
  - Language/Communication
  - Cognitive
  - Movement/Physical Development
- ✓ Includes activities to try at home, developmental "red flags," and space to write down questions



[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)  
1-800-CDC-INFO (1-800-232-4636)



Learn the Signs. Act Early.



- Act Early Ambassadors expand the reach of the “Learn the Signs. Act Early.” program and support their respective state’s work toward improving early identification of developmental delays and disabilities, including autism.
- Serve as a state or territorial point-of-contact for the national “Learn the Signs. Act Early.” program;
- Promote the adoption and integration of “Learn the Signs. Act Early.” resources into systems that serve young children and their families.
- To find your state’s Act Early Ambassador visit <https://www.cdc.gov/ncbddd/actearly/ambassadors-list>

# ACT EARLY AMBASSADORS

Delaware

Brittany Powers

Project Coordinator

Early Childhood Autism Initiatives

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# SOCIAL MEDIA



Iowa Regional  
Autism  
Assistance  
Program



Iowa Regional  
Autism  
Assistance  
Program



Iowa RAP

A glowing lightbulb is positioned in the center of a chalk-drawn thought bubble on a blackboard. The lightbulb is lit, with a bright white glow emanating from its filament. The thought bubble is drawn with white chalk and has a scalloped, cloud-like border. The background is a dark, textured blackboard. A white rectangular box is superimposed over the center of the image, containing the word "QUESTIONS?".

QUESTIONS?