



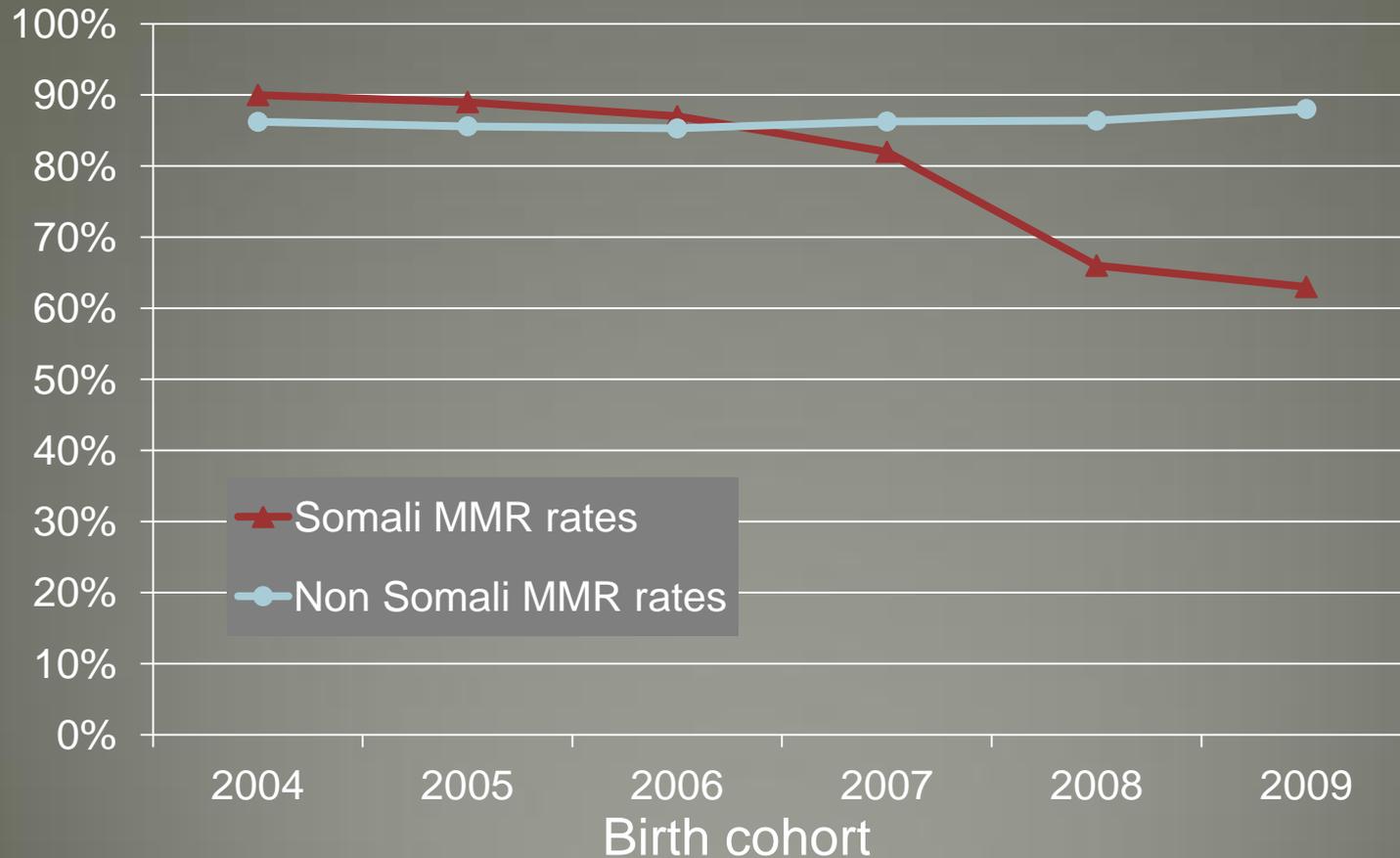
# HESITANCY ISSUE EMERGES

- ▶ Summer 2008: Hesitancy issues raised via a TV news story
  - ▶ Featured community's concern about high numbers of Somali children with autism in Minneapolis special education programs
  - ▶ "It's the vaccines." claimed a Somali parent.
- ▶ "Autism" was a new phenomenon to Somali parents
  - ▶ Reported as not seen in Somalia
  - ▶ Resources difficult to obtain, overwhelming
  - ▶ Parents linked themselves to national groups that embrace the MMR- autism claim

# MISINFORMATION GROWS

- ▶ Spring 2009: MDH released analysis of enrollment data from Minneapolis Early Childhood Special Education
  - ▶ Showed higher numbers of Somali children enrolled compared to non-Somali children
  - ▶ Many caveats, not a prevalence study
- ▶ The 2009 MDH study fueled fear of autism
- ▶ Providers reported to MDH that Somali parents were refusing MMR
- ▶ 2011 measles outbreak prompted MDH to look at MMR rates

# COMPARISON OF MMR RATES AT 24 MONTHS IN CHILDREN OF SOMALI DESCENT VERSUS NON SOMALI, 2004-2009, MINNESOTA



# OUTBREAK RESPONSE

- ▶ Leaders:
  - ▶ Must educate the community
  - ▶ Address autism before addressing immunizations
- ▶ Met with community:
  - ▶ Attendees: parents of children with autism and ad hoc members of the Vaccine Safety Council of Minnesota



# OUTBREAK RESPONSE CONT.

- ▶ Parents who have children diagnosed with autism:
  - ▶ Cannot say “vaccines don’t cause autism” and then say “we don’t know what causes autism”
  - ▶ “I would rather my child die of measles which is destiny than get autism which is punishment.”
  - ▶ MDH has told us that Somali children have more autism, what are they doing about this? Maybe MDH doesn’t care.

# ADDRESSING MMR VACCINE HESITANCY: 2011-2012

- ▶ Formed a loose Coalition:
  - ▶ HCP, public health, parents, Somali health professionals
  - ▶ Suggestion of peer-to-peer educational outreach originated from parents in this group
  - ▶ Interest/participation of Somali members waned quickly

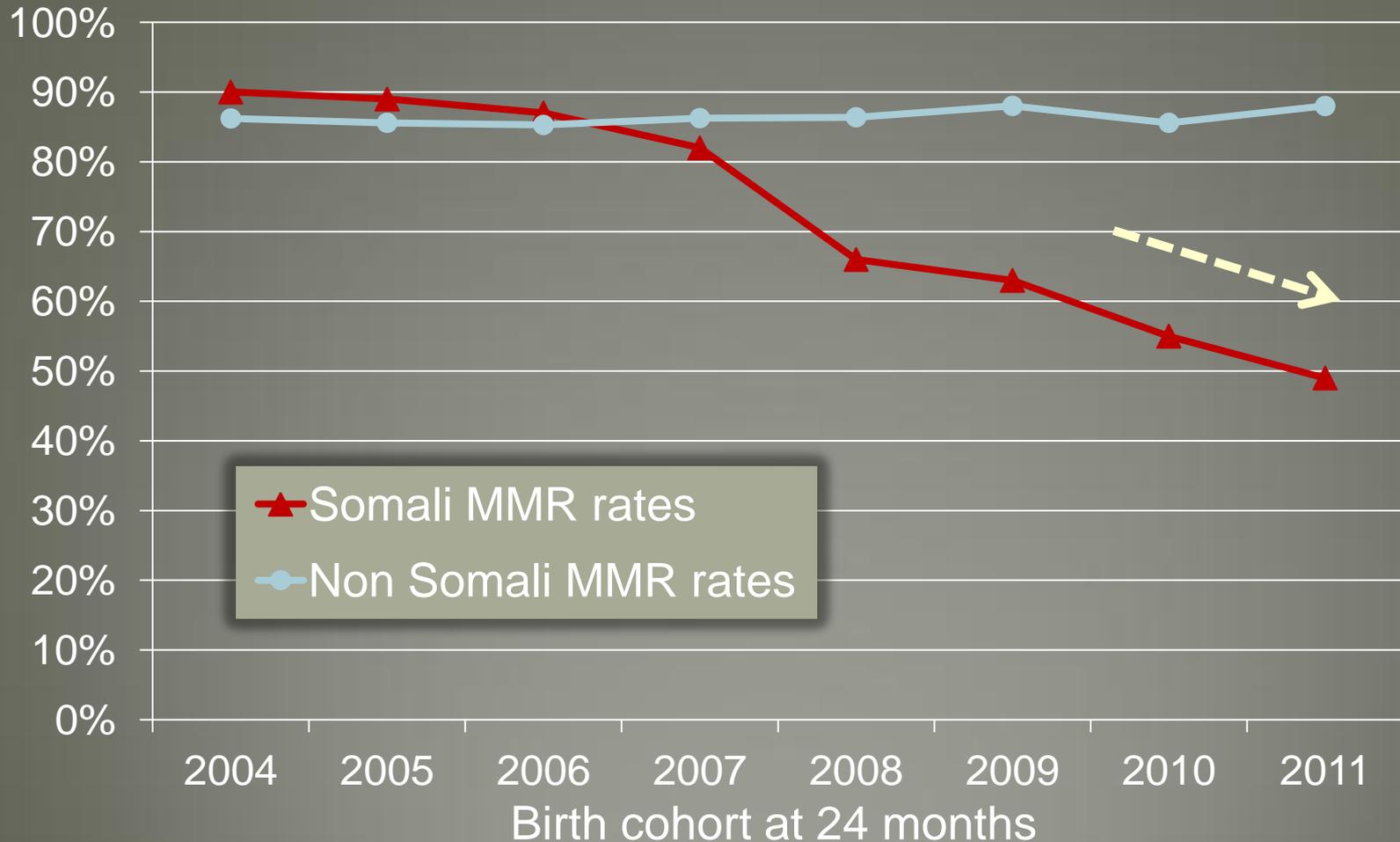
# BEYOND OUTBREAK RESPONSE

- ▶ Diverse media outreach – focused on measles disease and importance of vaccination
  - ▶ Promoted Mayo's YouTube video
  - ▶ Developed a travel PSA
  - ▶ Posted a video of an interview with mother of child who almost died from measles
  - ▶ Radio announcements



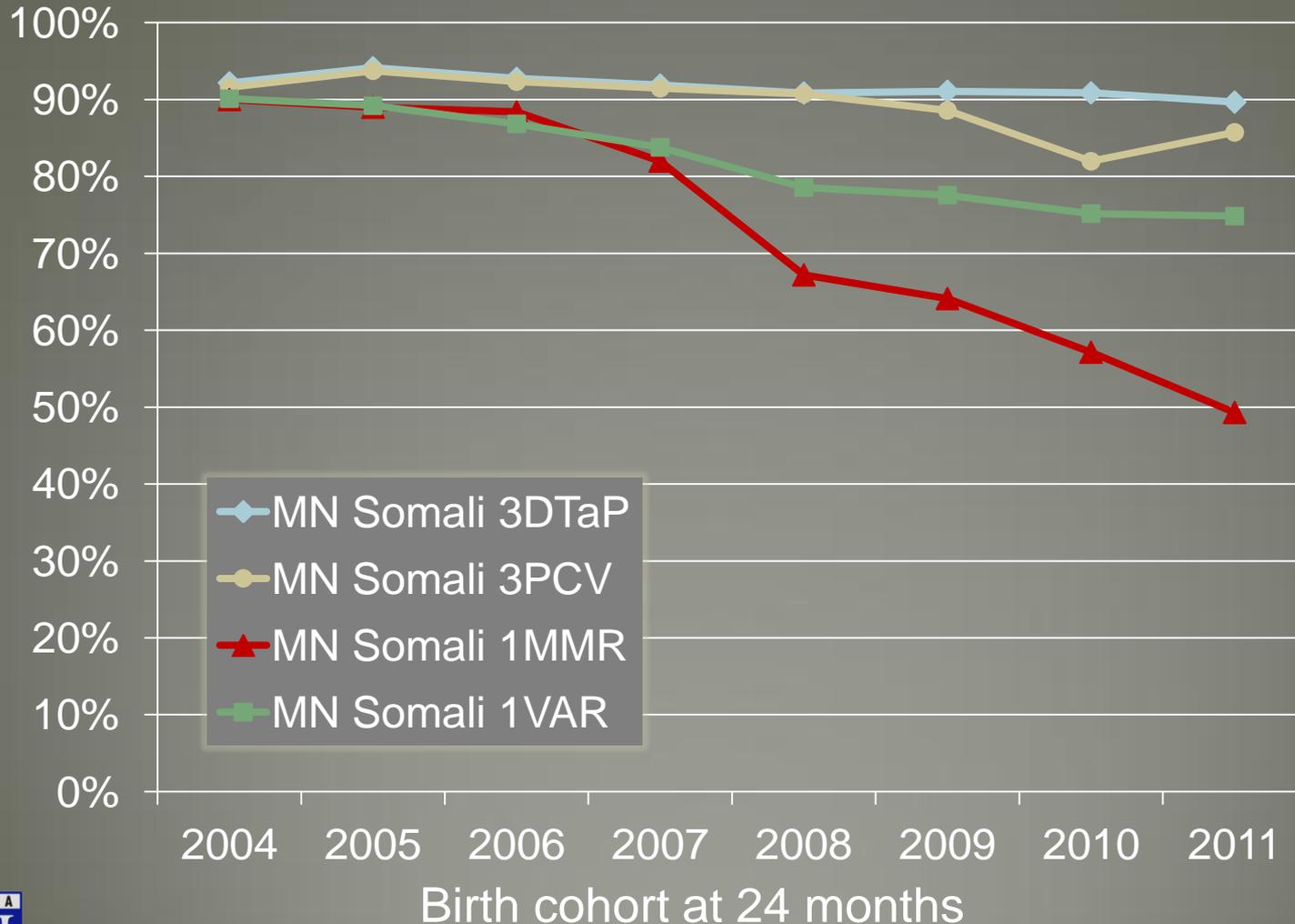
## 2013 REASSESSMENT:

# COMPARISON OF MMR RATES AT 24 MONTHS IN CHILDREN OF SOMALI DESCENT VERSUS NON SOMALI, 2004-2011, MINNESOTA



Data derived from Minnesota Immunization Information Connection, April 2014

# IMMUNIZATION RATES IN MINNESOTA CHILDREN OF SOMALI DESCENT AT AGE 24 MONTHS, 2004 - 2011



# TIME TO REGROUP

## ▶ What did we know?

- ▶ Perspective of parents of children with autism
- ▶ Parents were generally consenting to immunizations and specifically refusing MMR (12 month shots)
- ▶ Autism fear was driving factor
- ▶ Broad educational campaigns were not working

## ▶ Where were the gaps?

- ▶ No “in” to the community
  - ▶ Was the source of misinformation only coming from parents of children with autism
  - ▶ How can we invite community members to trainings
- ▶ What message would be effective
- ▶ How to address fear of autism

# TIME TO REGROUP

- ▶ Consulted with CDC
- ▶ Developed cross-division team
  - ▶ Autism program
  - ▶ Immunizations
  - ▶ Communications Office
  - ▶ Refugee Health
- ▶ Hired Somali staff
  - ▶ RN – Children & Youth with Special Health Needs (CYSHN)
  - ▶ Outreach worker – Immunization Program



# GATHERING INFORMATION

- ▶ Parents: 20 interviewed
  - ▶ 12 of 20 (60%) reported MMR refusal, 12 of 12 stated autism fear as reason
  - ▶ Fear autism more than measles –they avoid a diagnosis when they suspect that something is wrong
  - ▶ Only 7 parents could say what autism is, however receptive to education
  - ▶ Most (85%) named healthcare provider as their trusted source of medical information
    - ▶ Yet family and community influences were significant contributors to their vaccine hesitancy

# GATHERING INFORMATION: CLINICIANS

- ▶ - Four clinics selected and interviewed
- ▶ - Interviewees included physicians, nurses, Somali outreach worker
- ▶ “MMR causes autism” belief is entrenched
- ▶ A deeply rooted oral tradition and the addition of a language barrier increases the creates difficulty in addressing misinformation
- ▶ Professional translators are used, and providers gave mixed responses regarding trust in the translators

# GATHERING INFORMATION

## ▶ MDH SOMALI STAFF

- ▶ Women frequently attend national/international conference calls
- ▶ Parents tell the provider they don't want "the vaccine that causes autism" - the provider says "okay"
- ▶ Some translators tell parents not to get the MMR
- ▶ Parents don't understand the milestone checklist
- ▶ Parents are afraid to talk to their HCP if they think their child has autism

# APPROACHING MMR VACCINE HESITANCY: TAKE 2

- ▶ Address perceived risk<sup>1</sup> – autism
  - ▶ Focus trainings on child growth & development and autism first
- ▶ Change the script
  - ▶ From “we don’t know what causes autism” to “this is what we have learned about autism”
- ▶ Leverage social networks<sup>2</sup>
  - ▶ Use oral tradition to change the advice

<sup>1</sup>Mezaros, et al, J Clin Epidemio, 1996

<sup>2</sup>Brunson, Pediatrics, 2013



# WORK PLAN DEVELOPED

- ▶ Education and outreach
  - ▶ Oral approach – smaller groups
  - ▶ Three audiences
    - ▶ Parents
    - ▶ Influencers
    - ▶ Clinicians
- ▶ Provider/partner relationships
  - ▶ Formed a Somali Public Health Advisors group
  - ▶ Conducted an autism symposium in collaboration with the University of Minnesota

# WORK PLAN CONT.

## ▶ Outbreak control/mitigation

- ▶ Increase community awareness of low rates through radio interviews, Somali newspapers, Somali TV
- ▶ Internal/LPH planning for outbreak response –
- ▶ Monitor MMR rates and provide outreach where Somali children congregated:
  - ▶ Somali-owned day care centers
  - ▶ Somali-attended charter schools





# THE IMPACT OF MINNEAPOLIS SOMALI ASD PREVALENCE STUDY ON THE THE SOMALI COMMUNITY

- ▶ The study confirmed a community suspicion that ASD is higher among the Somali kids, 1:32 compared to 1:68 nationally
  - ▶ Many thought it was a waste of time – they already knew this
  - ▶ Some felt vindicated – finally someone listened to them
- ▶ The study finding that 100% of Somali kids with ASD also had Intellectual Deficiency rang a huge alarm bell.
  - ▶ This community was horrified by this
  - ▶ Many, even those far from Minneapolis, or Minnesota, or outside the U.S. are wondering if their child is less intelligent

# COMMUNITY GENERALIZATIONS/QUESTIONS:

- ▶ What causes autism?
- ▶ Why our kids affected more than the others?
- ▶ The common response by the health professionals to Q # 1 is:
  - ▶ “The cause is not known” – this leaves the vaccine question easy prey

# A BETTER RESPONSE COULD BE:

- ▶ Discuss what we do know about ASD - “up to now”
  - ▶ Millions of dollars in research; much has been learned over past 5 – 7 years
- ▶ There are many causes for multiple types of ASD
- ▶ Research is showing that Autism likely occurs before the baby is born or right at birth
- ▶ There are different exposures during pregnancy that make a child more likely to have an ASD, including
  - ▶ Environmental- extreme stress, certain types of pollution is being researched, nutrition
  - ▶ Biologic, such as viral illnesses
  - ▶ Genetic factors

# A BETTER RESPONSE COULD BE:

- ▶ Most scientists agree that genes are one of the risk factors that can make a person more likely to develop ASD.
- ▶ Hereditary factor account for up to 20% of autism diagnoses
  - ▶ Children who have a sibling with ASD are at a higher risk of also having ASD.
- ▶ ASD tends to occur more often in people who have certain genetic or chromosomal conditions

# APPLYING THIS CLINICALLY: TOOLS - FOR YOUR CONSIDERATION

## ▶ You and your time

- ▶ Personalize the encounter – use the baby’s name
  - ▶ Look at the parent, not the translator
  - ▶ Learn to say hello in Somali – “Iska waran”
  - ▶ Ask them something personal before “getting down to business”
- ▶ Parents trust the provider for factual medical information
  - ▶ Provide advice with confidence – options are confusing
- ▶ Predicting future consequences is not meaningful – the future belongs to Allah

# TOOLS - FOR YOUR CONSIDERATION

- ▶ Parents want to understand autism and the threat of it to their child
  - ▶ If a mother is refusing , invite the father to come discuss these issues at the next visit
- ▶ Parents need to understand the importance of developmental milestones
  - ▶ Show them what you are looking for
- ▶ Ask them if they understand what vaccines their baby is receiving

# TOOLS - FOR YOUR CONSIDERATION

- ▶ Your interpreters - are an extension of you
  - ▶ What is their understanding of developmental milestones, autism
  - ▶ Are interpreters hearing triple letter but telling you MMR?
  - ▶ Does the interpreter have personal concerns about MMR and autism?

# TOOLS - FOR YOUR CONSIDERATION

- ▶ Clinic staff – are they providing a pro-immunization environment
  - ▶ What is their understanding of MMR and autism?
  - ▶ Do staff have other vaccine-related concerns?
  - ▶ Adopt specific educational outreach activities
    - ▶ Reviewing the meaning of the milestone checklist
    - ▶ Discussing vaccines baby will receive
    - ▶ Instructing the parent about how to treat fever and sore limbs after vaccination

# CLINICAL APPLICATION: TOOLS

## ▶ Policies

- ▶ Extra time for well child appointments that require an interpreter
- ▶ Consistent clinician or consistent approach when seeing 0-24 month-old children

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