

# Iowa Family Participation Project

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# IFPP Goals

Explore perceptions and experience of parents from “under-participating” communities regarding the newborn screening programs in Iowa

# IFPP Goals

Increase participation in planning, implementation, and evaluation of Iowa's newborn screening programs



# *Work Groups*

# Non-English speaking refugee parents



*"...they gave us papers to read  
and told us to take them to  
someone who could read  
this for us."*

# Parents from community of alternative health care practices

*"... we have the right to choose.  
We shouldn't get hounded or  
lectured."*



# Families from social-religious community



*"...we have a deal with you  
and we trust you to honestly  
meet our needs."*



# Parents of adopted/fostered children

*"...we were informed by the social worker [of newborn screening results] even though we didn't have access to records . . . We were lucky ... that doesn't always happen."*



# Parents of children with a “true” positive screen

*“...we have to be strong advocates for our child – can’t trust child care providers and providers of acute health care to know how to best treat our child.”*



# Parents of children with a “false” positive screen

*“ ...very worrisome and stressful to wait for final results. I needed more reassurance from providers.”*



*“ More information about the chance of a false positive might have helped. I trust the program doctors to decrease the chances of getting a false positive result.”*



# Common theme?

What do you see as a common theme?



# Conclusions

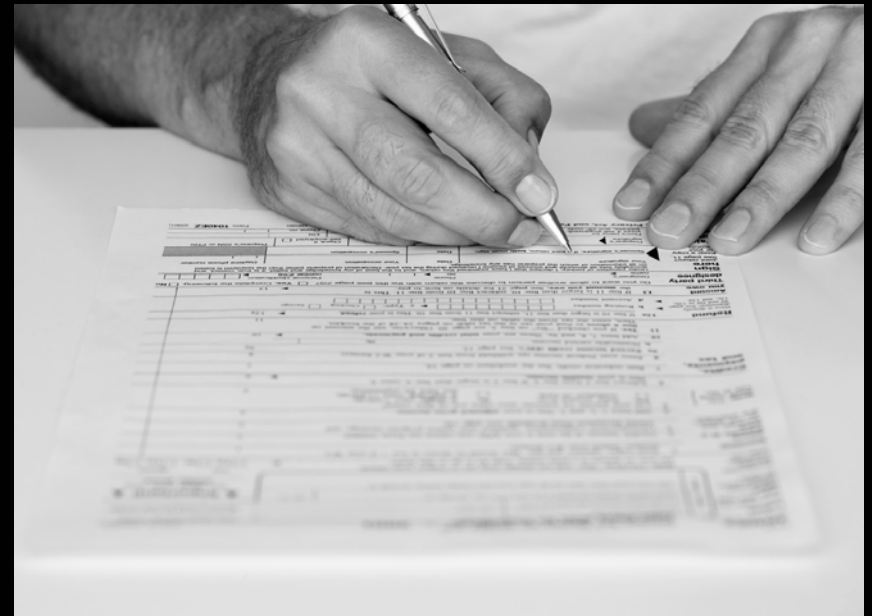
- Participants want to be a part of the process
- Information needs vary across groups
- New models are needed that build on family health care patterns
- Trust is a fundamental element in NBS program and policy design

# Now What?

Finalize pictogram  
for newborn dried  
blood spot testing  
process, pilot &  
evaluate



Continue work with  
Iowa Department of  
Human Resources  
re: communication  
between adoption  
case workers and  
parents



# Conduct hearing screenings in social/religious communities





Provide educational materials  
to providers of acute health  
care (emergency room staff)



Provide educational resources  
to child care providers



Continue to recruit and engage families in advisory committees and program development activities



# The Bottom Line

