HEARTLAND GENETICS SERVICES COLLABORATIVE:

ARE WE MAKING A DIFFERENCE?

Annual Report: 2012-2013

Individualized Health Plan

HRSA Priority 1

Key Findings: Baseline Data

- IHP Learning Community was rated positively and viewed as potentially making an impact on children and youth.

Results

- 76% were highly satisfied with process
- 87% felt the work could have an impact on children
- 79% reported high trust among team members

Key Findings: Baseline Data

- Few IHP team members rated their implementation process as effective and identified areas for improvement

Results

- 40% rated the effectiveness of current IHP practices as good or higher
- 20% felt that their school's current criteria were identifying students in need of an IHP.
- The assessment and diagnostic process were rated below standard by 50% of the participants.
- 60% of the participants were somewhat or not satisfied with their IHP's development and use.

Key Findings: Preliminary Follow-Up Data

Communication

- Communication is key
  - Parents and School
  - Health providers and school
  - Children and School

Actions

- Implement training on family-professional partnerships and family engagement

Key Findings: Preliminary Follow-Up Data

Improved quality of IHP Process

Actions

- Changed implementation process
- Increased quantity of IHPs implemented
- Helping stakeholders to see the bigger picture
- Obtain family buy-in

Transition

HRSA Priority 1

Key Finding: Qualitative Data

- Genetics team staff provide insight to help build an integrated transition system which helps to define the specialist role.

THE GREAT TRANSITION

Necessary Desirable Possible

Recommendations

- Develop a team-based transition model that integrates contribution of the specialists
- Clearly define transition roles and responsibilities
- Develop an assessment process that informs a transition action plan.
- Address system's barriers related to adequate billing
- Expand expertise and transition practices of the Heartland region to bring together work groups to address transition to develop effective implement strategies.

Do Heartland Collaborative members like pie?

Collaborative Partners Project

HRSA Priority 3

Key Findings: Follow-Up Data

- PCPs accomplished identified goals (70% agreed)
- Gained knowledge regarding NBS and genetics (100% agreed)
- Resources developed for just-in-time information

Clinical Services Needs Assessment

Data based on 125 respondents (3.3% return rate).

HRSA Priority 3

Key Finding: Needs Assessment

- PCPs serve a variety of children with genetic disorders and need resources to support their delivery of quality services.

Results:

- 96% PCPS seeing patients with genetic conditions
  - Down Syndrome (89%)
  - Cystic fibrosis (45%)
  - Sickle cell anemia (42%)
  - Neurofibromatosis (41%)

Issues Faced by PCPs

EHDI Program Exchange

Key Finding: Preliminary Findings

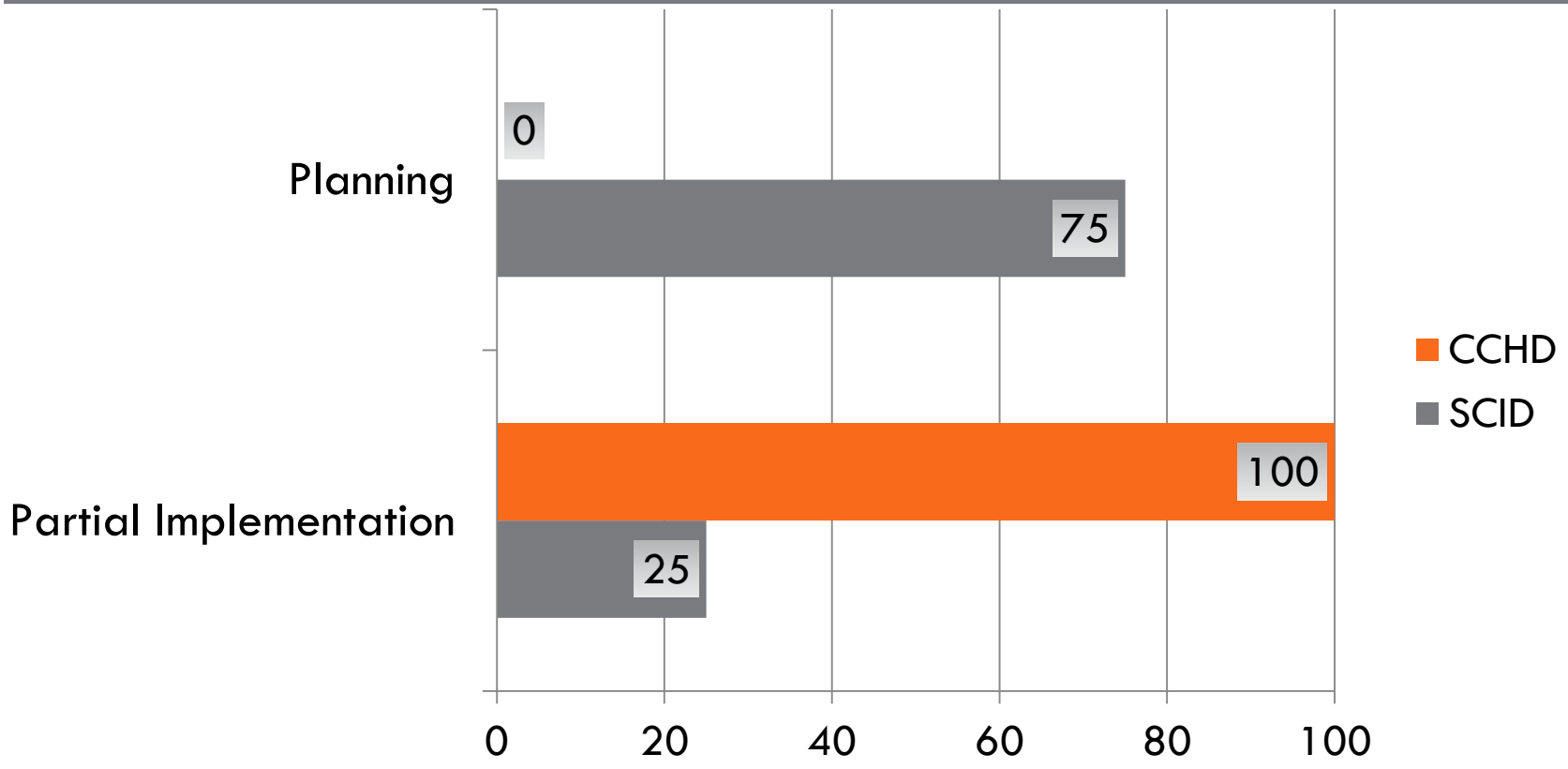
- EHDI Program Exchange resulted in changes in implementation practices.

Results

- Better trained hospital staff → reduced referrals & fewer false positive assessments.
- Increased linkages with PCPs → improved child assessment follow-up.
- State allocation of resources to hire a data manager → improved follow-up data system.

CCHD & SCID Screening for Newborns

Heartland Implementation of SCID and CCHD Screening



Hispanic Families Access to Genetics Services

Key Finding: Needs Assessment

Key barriers to access to genetic services by Hispanic families were identified through a needs assessment process.

Barriers

- Finances
- Lack of transportation
- Lack of translated materials and bilingual staff
- Language
- Culture
- Fear of immigration services

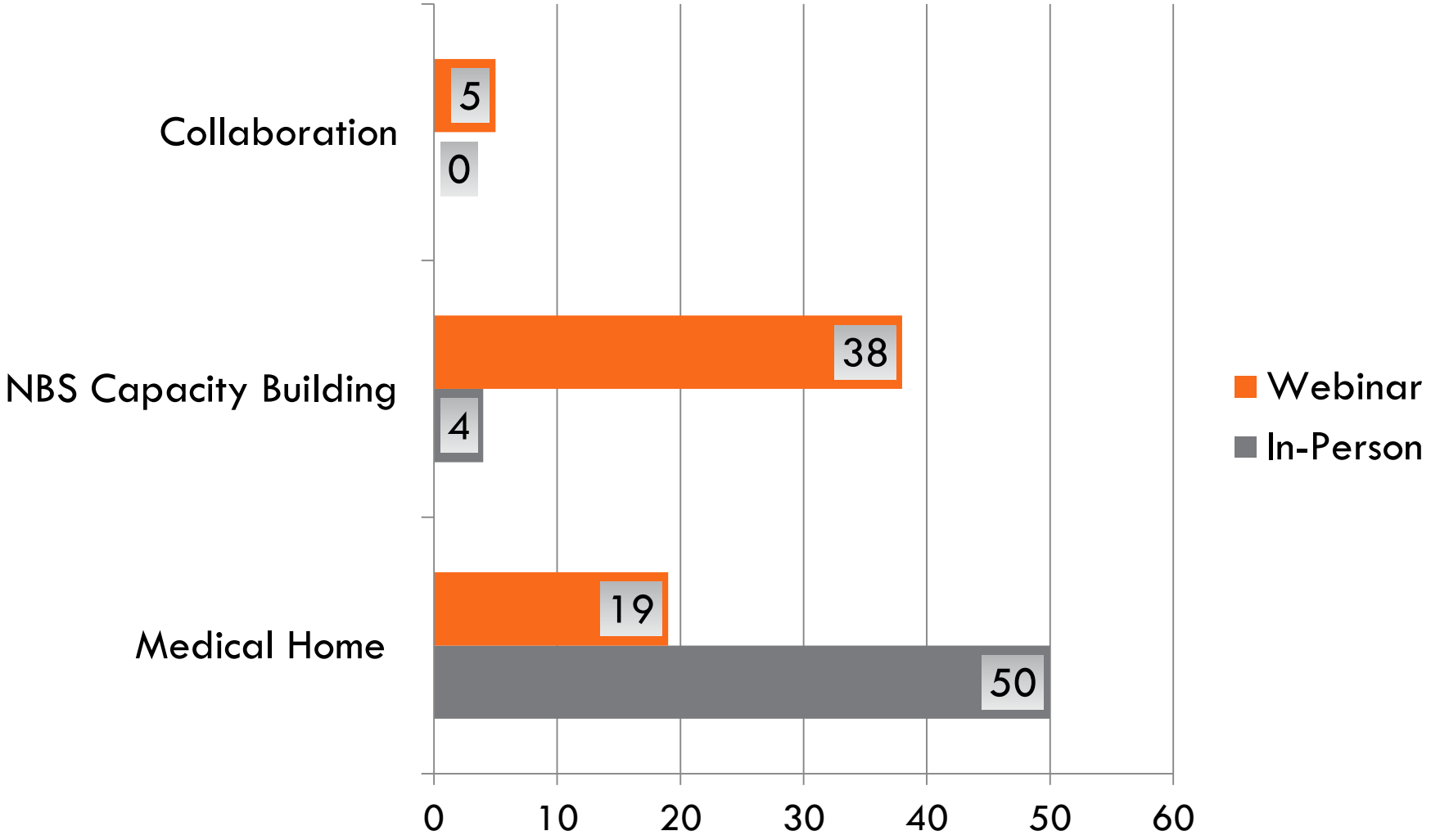
Next Steps

- Family needs assessment
- Development of and advisory board

National Evaluation

COUNTS OF PEOPLE AND ORGANIZATIONS THAT THE RC WORKS WITH				
	PROVIDERS (MD, PA, RN, Public health, etc.)	CONSUMERS (Affected Individuals & Family members)	FAMILY ORGANIZATIONS	**DISEASE-SPECIFIC or ADVOCACY ORGANIZATIONS**
# on RC mailing list	Range: 48-2,756	Range: 12-30	Range: 0-102	**Range: 1-285**
	Heartland: 70	12	0	**1**
	Total: 4,257	Total: 124	Total: 108	**Total: 334**
PARTICIPANTS IN RC ACTIVITIES				
# who attended RC annual meeting	Range: 23-133	Range: 0-16	Range: 0-7	**Range: 0-10**
	Heartland: 44	5	0	**2**
	Total: 386	Total: 58	Total: 19	**Total: 15**
# who participate on RC workgroups and committees	Range: 0-300	Range: 0-35	Range: 0-9	**Range: 0-26**
	Heartland: 99	10	0	**0**
	Total: 712	**Total: 108**	**Total: 27**	**Total: 50**

Heartland Education & Training Sessions



Websites and Social Media Website

Medical Home

NBS Screening Long Term Follow-Up

Transition

NBS Capacity Building

Areas targeted for Improvement

- Identify Strategies to increase “hits” on website (decrease in activity in 2012-2013)
- Explore additional opportunities for social media
  - Facebook
  - Twitter
  - Pinterest
  - You-Tube

Heartland Collaborative

How well are we doing?

Strengths

- Heartland is responsive to current issues
- Effective means of communication and sharing information
- High levels of trust
- Effective meetings

Areas targeted for improvement

- Need for more clearly defined roles
- Need for more targeted reflection on how well the Heartland Collaborative members are working together
- Problem with members devoting the time needed to meet the Collaborative' s goals

Celebration

Reflection

Questions?