

## Community Institutional Review Boards

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## Community IRB

- Decided to house at Special Service for Groups because of strong internal resources and support
- Had staff and executives from both SSG and OCAPICA leading the development of the IRB and the policies and procedures



## Why was the Community IRB started?

- Received funding from CDC REACH 2010, BCRP, and First5 LA for community based participatory research
- Reviewed other community based IRB committees and received advice from Papa Ola Lokahi's Imi' Hale Project
- Experience with university IRBs
- Community was lacking from university IRBs
- Multiple university IRBs with minimal community representation



## How was the Community IRB started?

- Initiation by the CDC REACH 2010 – Promoting Access to Health for Pacific Islander and Southeast Asian Women (PATH for Women) project
- Support of leadership
- Dedicated staff person and intern
- A year's work in research and development
- Developed policies and procedures
  - IRB application, review, and renewal forms (and associated forms, as appropriate)
  - Meeting protocols
  - Review guidelines
  - Training tools for IRB members and organizational programs

## When did the Community IRB start?

- Initiated in 2004
- Reviewed and approved by US DHHS OHRP
- Official IRB number and seal
- Recruitment from organizations and community leaders for IRB members
- Training of IRB members
- Renewal in 2007



## What is the purpose of the Community IRB?

- Provide guidance for human subjects protections
- Engage and educate community programs and partners on the importance of IRBs
- Empower community programs and partners in the IRB process
- Empower community programs and partners to be equal research partners
- Give a voice to under-represented communities regarding research, especially involving human subjects
- Build capacity



## How does the Community IRB function?

- Accepts IRB applications on a quarterly basis for review
- Provides application and forms to interested projects
- Currently an internal review board for SSG programs, affiliated organizations, and community partners
- Requires a report at year-end
- Reviews renewal requests



## How is the Community IRB maintained?

- Roles and Responsibilities
  - Maintain record of all applications
  - Document all processes of the IRB
  - Coordinate application review requests
  - Communicate with IRB application contact person for materials and review process
  - Provide workshops and TA on research design, methodology and human subjects protection
- Structure
  - Staff person who coordinates all efforts and requests
  - Support provided by Special Service for Groups
  - In-kind support of efforts, meetings costs, etc.
  - Volunteer participation by IRB members

## How is the Community IRB maintained? (cont'd)

- Case Load
  - On average, 3 applications per year (not including renewals)
  - Looking at expanding; requests have been made by external organizations
- IRB Renewal
  - Not burdensome to applicants
- Recruitment of Members
  - Initially recruited diverse members from the organization and affiliated community members
  - Will review terms and ask for recommendations from the current Board and groups that have submitted applications

## What are the benefits to the community?

- Community owns the data; SSG does not have any ownership
- SSG serves as a conduit to provide oversight on human protections
- Community organizations and members become more aware of the IRB process
- Empowerment of communities' role in the IRB process



## What are the benefits to the community? (Cont'd)

- Sharing of best practices, research methods and tools, and solutions to common challenges
- Benefits from the research process (beyond research findings)
- Conflict resolution



## What are the projects that have been approved by the Community IRB?

- Assessment of Southeast Asian families to support young children
- Impact of services for refugees who are torture victims
- Adaptation of evidence-based child abuse prevention program in Korean and Cambodian communities
- Identification of sustainable outcomes for minority adolescent clients in a occupational therapy program



### What are the projects that have been approved by the Community IRB? (Cont'd)

- Assessment of Pacific Islander communities to reduce cancer disparities
- Adaptation of evidence-based programs to help re-entry individuals transition back into their communities
- Assessment of LGBT South Asian community and their health needs
- Exploration of Southeast Asian women's navigation of breast health services



### What are some common issues addressed by the Community IRB?

- Informed consent
  - Voluntary – subjects can still receive service even if they don't participate
  - Sensitive topics: HIV/AIDS, criminal activities, abuse
  - Contact people and information
  - Length and format of consent form
  - Data use and dissemination
- Language (e.g. conversational and non-scientific) – translation, interpretation, verbal consent



### What are some common issues addressed by the Community IRB? (Cont'd)

- Subject recruitment and selection (e.g. experimental design)
- Role conflict for provider/researcher (e.g. mandated reporting, confusion to subjects)



### How and when to start a Community IRB?

- Review and assess the resources in the community
- Review and assess the resources to develop, conduct and maintain the IRB
- Work with existing resources to improve status quo



### Challenges and Successes

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| <ul style="list-style-type: none"> <li>■ Successes                     <ul style="list-style-type: none"> <li>□ Helps in applications that we have our own IRB and everyone has been trained on the purpose and human subjects</li> <li>□ Communities feel empowered and know they have a source they can go to, to review their research and they aren't dependent upon a university partner</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>■ Challenges                     <ul style="list-style-type: none"> <li>□ Must have a dedicated staff who are extremely organized and ensures that policies and procedures are followed through</li> <li>□ Staff should understand the research process</li> <li>□ Must have the resources for ongoing support, training and technical assistance</li> <li>□ Applicants should understand the a community IRB can be more challenging than a university IRB</li> </ul> </li> </ul> |
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### Resources

- Sieber, Joan E. Planning Ethically Responsible Research: A Guide for Students and Internal Review Boards. Applied Social Research Methods Series, Volume 31. SAGE Publications 1992 Newbury, CA.
- US DHSS Office of Human Research Protections & Belmont Report at <http://www.hhs.gov/ohrp/>

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Thank you!

■ Contact Information

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