Consent or assent and confidentiality issues in studies on institutionalized adolescents living in children’s homes under the Integrated Child Protection Scheme (ICPS), Kerala

Sumitha.T.S.
Group P5(d)
Introduction:

- Integrated Child Protection Scheme: 2014 in Kerala
- Childrens’ homes, observation homes, special homes…
- Eight childrens’ homes in seven districts
Childrens’ homes:

- **Children**
  
  Poverty, broken family, orphan, abuse…..

- **Staff pattern**
  
  ✓ Superintendent, caretaker, cook
  
  ✓ Permanent / temporary
Both Law & Ethics – Based on Rights

Juvenile Justice Act, 2000:
- Principle of dignity and worth
  - Participation
- Principle of best interest
  - Non-waiver of rights
  - Equality and non-discrimination
- Principle of right to privacy and confidentiality

Ethics:
Four cardinal principles
- Autonomy
- Beneficence
- Non-maleficence
- Justice
But in reality….Act or Ethics:

In the Act, chapter IX:

74. Prohibition on disclosure of identity of children

No report in any newspaper…or other forms of communication regarding inquiry or investigation or judicial procedure, shall disclose the name, address or school or any other particular, which may lead to the identification of a child in conflict with law or a child in need of care and protection…
Informed consent and assent / dissent:

Name and signature is required

My research experience...
For approval:

- Usually order issued from Integrated Child Protection Scheme (ICPS) – no identification details

Solution:

- Took more than a month to convince the officials about ethics
- New order – both consent and assent/dissent
- No school or family identification details
Confidentiality:

Data collection - only in the presence of superintendent or an official authorized by him/her

- ICPS guidelines

“No sharing of information and precautions to avoid jeopardizing their relations”

-Gatekeeper’s permission in ethics
Solution:

- Self – administered questionnaire
- Consent and assent – only the researcher could see the filled questionnaire
During data collection:

“You can not take consent and assent but you can collect data”

“There were many research works, what is that special about your institution??”

Caretaker who sat in the room was unwilling to give me sign and name in the consent

Many hours took to make them understand that this is how research must be done
During data collection:

**Home B**
Only temporary staff gave consent. Permanent staff was reluctant to accompany because of consent.

**Home C**
Nothing special but the caretakers repeatedly asked: “there will not be any problem for us, right?”

**Home D**
“This consent and assent can not be justified. We can not let you do. People there (in ICPS) can issue orders like this but it is our responsibility.”
-an official in children’s home

At last, a temporary staff was authorized to give me consent.
During data collection:

Home E

When they were told about consent and assent

“All children will go for tuition everyday, you should come around 6pm – 8pm”

“Look at JJ Act (took a book on JJ Act), it is clearly stated that child’s identification details should not be disclosed”

“See, their (children) signature is not valid, we are not using in bank documents”

“We do not want to risk our job. How did other homes let you do this work?”

- Staff in children’s home
I travelled to this place (more than 150 km) twice to get permission alone from the authorities there. Before the second trip, thrice to the ICPS officials to call them (in children’s home) and help me do the research!!!

“This will not be allowed by anybody, your college should not be this strict.

At least we are allowing you to do this study.”

- ICPS officials
Home F

“Why do you need this consent and assent? You can do your research only after getting our permission, there is no point in consent and assent”

“Okay, but do not make children write down their name in assent form, let them put their signature and if needed you can take down their names in a separate sheet of paper”
Children’s reaction:

- *Embarrassment* when asked to write name as the norm is that they should not disclose their name or identification details to others

- “This is for the *first time*, usually they (whoever comes for data collection) will not make us write our name or signature”

- “What will you be doing with this paper?”
Why we should not show our face to the public?????
- A child

The Children of the Government Children’s Home, Cordially invite you for...
Finally, what should be prioritized??

Law or Ethics??

OR

Is there any misunderstanding??

Where are the “rights” then ???

Thank you...!!!