



# **Consent or assent and confidentiality**

*issues in studies on*

**institutionalized adolescents**

*living in childrens' homes under the*

**Integrated Child Protection Scheme**

*(ICPS), Kerala*

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# Introduction:

- **Integrated Child Protection Scheme: 2014** in Kerala
- Childrens' homes, observation homes, special homes...
- **Juvenile Justice Act, 2000** (amended in 2015)
- 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...*

**As in research ethics..!!**

*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??”*

**Home A**

*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*

## **During data collection :**

### *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...



A Play  
By the Children.....  
For the Children.....





**Finally, what should be prioritized??**

**Law or Ethics??**

**OR**

**Is there any misunderstanding??**

**Where are the “rights” then ???**

*Thank you...!!!*