

# Prevention of Human Rights Violations in a Learning Environment for Children with Autism Spectrum Disorder

## MY CHILD'S S.O.S. RIGHT: *"I want my mother\*"*.

This is my child's basic right when s/he is in fear or distress and should be complied with immediately. S/he may express it verbally or non-verbally (by crying out, pointing to the door, pointing to my photo, etc). I will indicate to the institute/professional my child's preferred way for communicating this right.

*\* Throughout the document, mother, parent & legal guardian are interchangeable.*

## MY CHILD'S RIGHTS

- My child deserves respect in all circumstances. S/he is a human being first who happens to have autism.
- My child understands even if s/he cannot express it to us. Do not talk about him/her in an unpleasant or condescending manner in his/her presence.
- My child deserves a safe and accommodating learning environment at all times.
- My child deserves to learn without fear in a non-stressful manner.
- My child's self-stimulatory and similar needs will not be viewed as rebellious/stubborn behaviour and will not be dealt with as disciplinary/control issues. <sup>1</sup>
- My child deserves to have professionals who are patient with him/her. <sup>2</sup>
- My child deserves to be given time to finish most of the tasks himself/herself as best as s/he can and to be patiently assisted and aided to accomplish these better. <sup>2</sup>
- My child will not be bullied/threatened/terrorized/traumatized/abused to perform against his/her will. <sup>3</sup>
- My child deserves to be treated with kindness. S/he learns better when taught in humane ways.
- My child will not be humiliated or given emotional punishments by the teachers/professionals. <sup>4</sup>
- My child will not be given corporal punishment, secluded or restrained, in the guise of "teaching/disciplining" him/her or for any other reason. <sup>5,6,7</sup>
- My child will not be medicated through coercion of his/her family by teachers / other professionals, so that their life becomes easier (except in situations where the family agrees it is necessary).

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1. Anxiety is known to heighten self-stimulatory behaviours. They subside best when the root cause for anxiety is addressed. Converting these situations into **control issues only adds to the child's anxiety.**
  2. **Being Patient:** My child should be given appropriate time to take in sensorial and cognitive inputs in order to perform the expected task – especially a new task. If the task involves some courage on my child's part (e.g. climbing a ladder, swinging, swimming, picking up and/or tasting a new food item, talking to a stranger etc.), enough time and encouragement should be given to him/her and I should be consulted.
  3. **My Child's Right to Refuse Forceful Compliance:** Professionals do not have the right to pressurize/threaten my child with ASD to perform against her/his will, to perform under duress, or rush him/her to perform tasks in order to show results. Just as a regular child will not be forced to do unpleasant and cruel things e.g. eat cockroaches or a child in a wheelchair will not be asked to run, my child's autism needs to be addressed and accommodated. What may appear as a straightforward and easy task for others may appear life-threatening or impossible to him/her. If my child refuses to comply with your command to perform the task even after your encouragement, then respect his/her choice and do not force him/her to do comply. You may re-approach the task in an alternative, humane manner and consult me.
  4. **Humiliation and Emotional Punishment:** My child will not be subjected to any actions that will emotionally hurt him/her.
    - a. My child should not be neglected and left to languish because s/he does not cause any 'trouble' or 'disruption' in a group situation. (This is not the same as putting a particular behavior on extinction as part of the child's IEP, after consulting with me.)
    - b. My child will not be compared with others and/or discriminated against.
    - c. S/he will not be humiliated, pitied, called typecasting/labeling names or adjectives (e.g. "Thunder/Toofan", "Fatty/Lattu", "Angry young man / Jamadagni", "Lazy bum / Laatsaab", "Shy Chuimui", "Poor fellow / Bechara" etc.); made to parade around with or without the teacher or a label on/with him describing his/her behavior undesired by the professional.
    - d. My child will not be shouted at, verbally abused, taunted, criticized, talked to out of irritation/frustration by the professional.
    - e. He/she will not be stripped partially or fully, or be made to sit in soiled clothes etc. as a form of punishment.
  5. **Corporal (Physical) Punishment:** No corporal punishment, however mild, will be used to 'discipline' my child. This includes:
    - a. Being forced into a posture/position that is uncomfortable/hurting/humiliating as a form of punishment e.g. made to stand on the bench; do sit-ups or push-ups; take rounds of a field; sit/stand out in the sun; stand for a long time until the body hurts; made to kneel down, hold his/her ears with hands passed under the legs, stand as a wall chair, keep the school bag or a book or other objects on her/his head, stand with hands raised etc.
    - b. Being denied his/her food/water as a punishment.
    - c. Being flicked or pinched with fingers, slapped, hit, bitten, punched, have hands or hair or ears or any other body part or clothes pulled or clamped or twisted; held with force in order to hurt; pushed or thrown or hurled; hit with any object or be pushed onto an object; be subjected to unpleasant sensory assault e.g. forced under a shower, into a pool, under bright/psychedelic/strobe etc lights, into darkness, endure agonizing sounds/noises; forced to consume harmful ingredients e.g. chilli powder, foods which may be unpalatable/agonizing for the child or tortured/assaulted in any way.
  6. **Seclusion:** My child will not be secluded. Seclusion will include being locked in a room with or without anyone else in the room (whether it is a big hall or a small bathroom or store-room or specially designed seclusion or 'time-out' room or a cupboard or a box or a bag etc) or being subjected to other ways of forced isolation from which my child cannot escape.
  7. **Restraint:** My Child will not be restrained. Restraint will include:
    - a. Forced restriction or immobilization of my child's body or parts of the body using manual restraint involving various "holds" for grabbing and immobilizing him/her or parts of him/her; or using mechanical restraint (straps, cuffs and other devices to prevent movement and sensory inputs/outputs); or electrical restraint (wires or invisible electric fencing); or chemical restraint (medication to dull his/her ability to move and/or think).
    - b. Being subjected to restrictions on senses like blindfolding, gagging, taping mouth or eyes or any other part of the body, closing of nostrils, hands/feet/legs being tied up or chained to a chair/table/pole etc., being suspended in the air by any method.
    - c. Being sat upon; held to the floor face down with hands pinned behind; or subjected to a grip that could adversely affect his/her breathing.
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## **Additionally, my Child will NOT**

- Be made to see/hear inappropriate audio/visual content (especially depiction of cruelty, violence, sex).
- Be touched inappropriately / molested / subjected to / made to witness any kind of sexual activity.
- Be threatened that s/he will have to face humiliation/punishment/seclusion/restraint.
- Be made to witness any humiliation/punishment/seclusion/restraint done to another child/person.
- Be asked to humiliate/punish/isolate/restrain oneself by any method.
- Be made to humiliate/punish/seclude/restrain another person in any way.
- Be denied admission or be removed from a school or threatened of it as it is his right to have inclusive, appropriate education as per the Right to Education Act.

## **MY RIGHTS AS A PARENT**

- As a person who is looking after my child 24 X 7 X 365, I have earned the right to be recognized as a resource person about the child's personality, behaviours and moods and to draw up his/her IEP.
- It is my right to be present in any situation, especially legal or official and to be a part of all important and relevant decisions and actions regarding his/her education.
- It is my right to have my child's teaching-learning process monitored for possible abuse.
- It is my right to be called and informed when my child in distress asks for me, or is having a meltdown or in a similar situation.
- It is my right to not have my child's case discussed with others in the school /centre / in conferences/ in articles / in the media etc. without my written consent. The child's identity cannot be revealed without my written consent. If my child is an adult capable of taking his/her own decisions, then his/her written consent will be necessary.
- If any of my child's rights are violated, it is my right to be informed as soon as possible and also in writing within 24 hours.
- It is my right to be recognized as a client being serviced by the institution/professional.

## **BASIC SERVICES TO BE PROVIDED BY INSTITUTES/PROFESSIONALS SERVICING FAMILIES WITH ASD**

### **Institutes/Professionals Must:**

- Call and inform the parent immediately when the child in distress asks for her/him, or is having a meltdown or in a similar situation.
- Involve parent in remedial steps taken during situations of a meltdown.
- In any of the above situations, send a written note within 24 hours to the parent.
- Display credentials of professionals at centre/school and of the centre/school itself.
- Give in writing the 'good conduct' policies of the school/ centre.
- Explain to families what to expect realistically.
- Explain what is being taught, why and how, elaborating on the goals and methods being used.
- Take suggestions from the parents; involve them in arriving at the IEP.
- Have CCTV viewing available to the parent. If unavailable, parent should be allowed in the room or to watch through one way glass.
- Report changes in moods, behaviours to parent immediately.
- Report undesirable behaviour of care giver accompanying the child if noticed (for children who are accompanied by maids, drivers, etc).
- Have trained professionals in special education, occupational therapy, speech therapy and physiotherapy.
- Have physicians and mental health professionals (psychologists) who are part of the team working with the child.
- Have all professionals undergo ongoing training in working with children and adults with ASD to update their skills.
- Have a healthy coordination between Therapy Centres and Schools to avoid conflicts in addressing the child's IEP.
- Work out a step-by-step transition process for the child when switching to new school / class / teacher / therapist, etc.
- Ensure female attendants in school buses, for toileting needs etc. for girls.

### **Institutes/Professionals Must Not:**

- Resort to humiliation/punishment/seclusion/restraint in any manner, however mild.
- Ignore parents' suggestions/ideas.
- Ignore physiological/hormonal changes in the child.
- Give unrealistic claims of cure to family.
- Threaten a parent who is ensuring a child's rights, with discontinuance of service.