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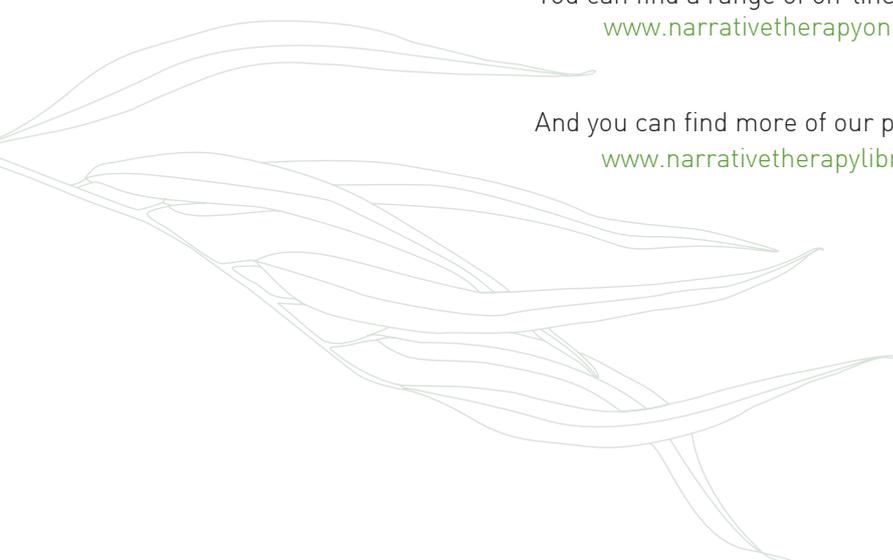
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# *Conversations with children with disabilities and their mothers*

**By Maksuda Begum**

Maksuda Begum (MA, in Bangla Language and Literature from Dhaka University) has been an employee of the Bangladesh Protibondhi Foundation since 1999. She has completed a diploma degree in Special Education and a Masters in Special Education from the Bangladesh National University and has worked as a counsellor since 1998. She is also a trainee of Certified Transactional Analyst (CTA). Maksuda Begum is involved in research, publications and providing training and workshops for professional development.

This paper from Bangladesh presents an overview of narrative approaches to work with mothers and their children who have intellectual disabilities. In what can be traumatic contexts, this work is based on mothers' and children's skills, knowledges, values, and connections. Through the course of both individual and group work, blame and stigma are externalised, and the love and care mothers have for their children – as well as their children's 'special abilities' – are brought more to the fore. This paper also presents an alternative intake questionnaire that can help to diminish the effects of pathologising language, and elicit accounts of care and connection.

Keywords: disability, children, mothers, Bangladesh, stigma, intake questionnaires

Formal counselling is still quite a new concept in Bangladesh, where I live and work. As in other cultures, however, when people face stress or sudden trauma, they can lose touch with their sense of self, their abilities, and their wishes and values in life. Finding culturally-appropriate ways to provide counselling services is something that I am very passionate about.

I work for the Shishu Bikash Clinic, a child development centre, in the Bangladesh Protibondhi Foundation<sup>1</sup> ('protibondhi' means disabled in Bengali). We mostly work with children who have intellectual disabilities or are considered 'developmentally delayed'. Stress, anxiety, and depression are common concerns for both the parents and children who consult with me. However, I have found that narrative approaches offer a sense of creativity and energy which can play a vital role in minimising the discomfort that people feel with their lives. This paper offers a narrative conversation framework for working with children with disabilities and their mothers.

Disability in children's lives can have significant effects not only on children, but also the rest of their families (Beresford, 1994; Mc Conachie, 1991). When parents first discover that their child has a disability, they can become confused and go into shock. Many parents exclaim: 'This can't be happening to me! What did I do to deserve this?' The parents' own anger and shame, as well as broader social disapproval, can make parents feel helpless. They may even ask themselves, 'Am I being punished for something I have done wrong?' Some parents have even told me that they secretly wished that either their child, or they themselves, would die. In this context, it is easy to understand that the lives of the children with disabilities and their parents who come to see me are often problem-saturated.

When our centre first opened, its orientation was on treating or curing disabilities, disorders, and 'dysfunction'. In this context, the idea of counselling was more than novel – it was quite controversial! Given the overwhelming focus on what was wrong with people, I wanted to find a way to work that would honour people's alternative claims about identity and ability. I also wanted to honour the connections they had formed in their families, in a context that otherwise often invited them to be dishonouring of each other.

To this end, I invited Cheryl White, Margaret Ryan and David Denborough from the Dulwich Centre Institute of Community Practice to visit our clinic while they were visiting Bangladesh. After this visit and our conversations together, David Denborough developed an alternate intake questionnaire form, which is included in this article. I have been using this alternative intake questionnaire in my work, and in this paper I wish to describe the effects this is having on the conversations I am sharing with mothers and children.

## INTAKE FORMS

Standard intake forms will usually ask a range of questions about the history of the problem, medical history, family history, developmental history, locomotion, speech and communication, socialisation, clients' appearance, perception, thought content, and mental and emotional states. The assumption is that once someone in an expert position collects this 'data', then treatment can begin.

From a narrative point of view, I'm aware that before people seek help, they have almost always already made many attempts to reduce the influence of the problem on their lives and relationships. Subsequently, the alternate intake questionnaire we developed is based not on notions of expert knowledge, but on the values of curiosity, respect, and transparency. And, given that the questions bring forth accounts of people's own knowledges, skills, and abilities, the questionnaire itself has been a very powerful tool for healing.

While it is called an 'intake questionnaire', it can really be used at any time. And, calling it a *supplementary* questionnaire means that it can be used before or after routine medical or psychological assessments. In this way, the form provides us with a certain flexibility that may not be available if we were to think that only certain kinds of information, or data, had to be collected at certain times.

The form has two purposes – first, it enables the counsellor to learn about the particular skills and knowledges of mothers and children, which can become a focus for further therapeutic conversations. The questions elicit a wealth of

material which can provide multiple entry points to subordinate story-line development. Second, the form helps scaffold conversations that counsellors can then offer responses to, based on the outsider-witness conversation map of narrative practice (Russell & Carey, 2003).

The form is used both in individual meetings and in group work. In group work, we try to arrange meetings with groups of mothers who feel particularly helpless in the face of their children's disabilities. The groups usually contain ten mothers and meet twice a week. As well as culturally-relevant activities such as meditation, I use questions drawing on the alternate intake questionnaire form to facilitate group discussion.

### **A HISTORY OF CARE AND LOVE: FOCUSSING ON SKILLS AND KNOWLEDGES**

In meeting with mothers, we often hear of the remarkable steps they have taken to find help for their child. Before people come to speak to us, there is always a history of caring for their child and trying to find them help. However, sometimes this history of care has been overshadowed by the dominant story about the disability.

Part I of the questionnaire, 'A history of care', and Part II, 'Current acts of care', draw on externalising conversations and re-membering conversations (see Morgan, 2000) to bring forth stories of the history of care and love in the lives of the mothers with whom we work.

These questions include:

- When did you first come to think that your child was different from other children?
- How did you try to respond to this knowledge?
- What steps have you taken before coming here?
- Why did you take these steps?
- Were there difficulties along with the way? If so, what assisted you to keep persisting, to keep seeking help? Why was this so important to you?
- What do you think it says about you that you have taken all these steps?
- What does it say about your commitment to your child?

- Who would be the least surprised to know that you have this commitment to your child?
- If they were here now, what might they say about the history of care?

These questions stand in stark contrast with the often evaluative questions of standard intake forms when working with disability. Rather than dysfunction and disability, these questions accord value to people's action *in the face of* disability. In this way, the questions immediately open space for a double-storied account of disability.

### **SANJU'S MOTHER'S STORY**

The value of these kinds of questions can be seen in the following account by one mother, whose daughter's name is Sanju:

*Sanju was delayed in her development. She walked with difficulty, and could not speak by the age of four. She had no concept of relational, spatial, and other cognitive areas. Before seeking professional diagnosis, my family tried all sorts of other cures, including mud and oil massages, and putting lockets<sup>2</sup> into their child's neck and arms. Despite the promises of a cure, none of these things worked. So far, we have suffered a lot mentally and financially over a long period.*

*As she got older, Sanju grew restless and aggressive. She was not able to feed, toilet, or dress herself. She does not like to stay at home, and shouts if confined, but she was refused entry at normal schools. All of these things made me distressed, helpless, and fearful. I was so terribly distressed that sometimes I didn't care for her properly.*

*However, one day she just suddenly uttered the sound 'mum'. I picked her up, and rushed to the rest of the family, and asked Sanju to call out to me again, and she did. I was so pleased; there was no bounds to my happiness. I took my child around to everyone, and got her to call 'mum' again and again. All of my friends and relatives encouraged me a lot, and I have decided to do more work to develop her speech and communication.*

*My plan was not to bother Sanju all the time, as I know that if I worry too much, this might cause more problems. I know I have to be patient with her. I have even followed this as she threw temper tantrums at times, and I have reminded myself of*

where she has come from. Sanju is now able to run, move around a lot, and throw things. Showing love and care is a creative way to handle children with these kind of special needs.

There have been many other difficulties to overcome in this long journey. I have had to cope with many untrue beliefs and preconceptions. Along with these, I was blamed for giving birth to a different kind of baby. However, the love and care of motherhood assists me to keep up my persistence and seek help. It's important for me to remember that I always loved my daughter, and have always cared for her, even though things have been very hard for us at times.

It is easy to forget all of the things I have done to encourage my daughter – to help her with her speech, feeding, toileting, dressing, and communication. Because my efforts were often erased because of the intellectual delay, I often lost sight of hopefulness and became depressed and hopeless. It is important to remember all that I have done, and all that she has achieved in the face of such challenges.

My grandmother would be the person least surprised to know that I have these commitments to my daughter. If she was here now, I think she would express profound acknowledgement of me for loving and caring for such an exceptional little girl who is struggling with all of these difficulties and disabilities. I think my grandmother would say many things about the potency and power of the 'love and care' that gave me such endless energy to keep up the hard work in caring for my daughter.

## **RESPONDING TO BLAME: RAINA'S STORY**

Blame and stigma are common experiences of Bangladeshi women who have children with a disability. Part 3 of the intake questionnaire asks externalising questions about 'Blame' and 'Stigma'. These questions are very helpful in separating mothers from the negative conclusions they can reach about themselves in the face of others' blaming.

Raina explained the effects of Blame in this way:

*I was a good student throughout my academic life. After I completed my studies, I became a Bangladesh government officer. However, my in-laws*

*announced their anger about my disabled child by blaming me. According to them, because I was a career-oriented woman, and moved many times during the pregnancy for my work, my child's autism must be entirely my fault.*

*When I found out about my daughter's disability, I was thrown into a limitless, endless, deep sea. And while I was there, I didn't know how to swim. Each day it felt like I was drowning, and this affected my relationships and abilities. But then, one day, I had a sense of a focus of light. I didn't know where this light was coming from, but I knew it was related to caring for my daughter, and it resonated with my religious values and beliefs. I believe that caring for a child with disabilities can please God.*

*Professional people told me that my daughter had problems, such as she was 'not able to maintain relationships with others', 'has difficulty in integration', and she had 'manifestations of problem behaviours'. However, I was determined to not be disheartened. My daughter was also the apple of the eyes of my parents; I wondered what would happen to them if I was to always be down in the dumps.*

*So I decided to try to cope with autism. I am talking, playing, and walking with my daughter like before, and her place in the family has remained the same. Deciding to cope has made me hopeful, and peaceful in my workplace and family as well.*

## **RESPONDING TO STIGMA: AMINA'S STORY**

Amina was married when she was just sixteen years old. She is solely responsible for carrying out the household chores in her extended family which includes her mother- and father-in-law. At age two-and-a-half, her son, Lee, began to explore the world more, but due to his vision impairment, he would often accidentally break things.

Lee's grandmother became very angry with both Lee and Amina, and told Amina that Lee would become a 'blind mad'. The concept of a 'blind mad' person in Bangladeshi culture means someone who is blind and has dangerous powers. This concept can be very stigmatising, and Lee's grandmother's spreading of this label throughout their village caused a lot of trauma for Amina. Relatives and neighbours were suddenly afraid of her small child, and rejected both Lee and Amina. When mother and

son would venture out in public, children would throw stones at them, and call out 'blind mad, blind mad'.

As Amina recounted this story, her eyes were full of tears. However, there were threads of a resistance to this stigmatising, and I soon learned that sometimes Stigma has no power over Amina and her connection with Lee. I also learned that Amina's husband has stood with her in the face of this stigmatising, although this may have caused problems for his relationship with his parents.

Following an outsider-witness retelling by the other mothers in the group (Russell & Carey, 2003), Amina said that it was important to her to express her position on these issues, and went home and clearly stated to her mother-in-law that Lee's low vision should not be a cause for such stigma. Amina and her husband also decided to urgently seek professional help for her son's vision impairment. After taking these steps, which she labelled as 'new and assertive', she experienced a new-found care and support from friends and relatives, and a more respectful relationship with her husband's family.

## **WORKING WITH STUDENTS WITH CEREBRAL PALSY**

Along with groups for mothers, our centre also runs groups for students who are living with cerebral palsy. These groups, run along narrative lines, comprise fifteen students who meet each week for an hour-and-a-half of conversations about many aspects of their lives, studies, and 'different abilities'.

The group is diverse, with students being affected differently in their speech, motor skills, and mental abilities. However, as all have cerebral palsy, all of them can do little to care for themselves, and most need a full-time caregiver. Some students are unable to speak at all, and most have difficulty learning in school. Most have a moderate to severe delay in areas of motor function (gross motor movement, gesturing, posture, fine motor hand function, and grasping); cognitive skills (logical, mathematical, and information-processing skills); speech/communication skills (verbal, linguistic, and writing skills); and ability to socialise with others.

However, drawing on specific understandings in learning theory, I believe that all students have different learning styles, and that, rather than comparing the differences between students, we can instead focus on the steps they have taken and the achievements they have made. In this context, all of these students have some skills in thinking, representation, memorising, counting and generalisation.

## **CONVERSATIONS ABOUT ABILITIES, VALUES, AND CONNECTIONS**

At the beginning of the group, I am keen to come across as flexible, patient – and smiling! I engage them in an externalising conversation about problems they face in life, especially around activities of daily living (feeding, toileting, dressing), reading, writing, socialising, speaking, and communicating. I also ask them about the alternative stories of their lives, skills and knowledges. One of the most common dominant stories is 'lack of physical strength', while an alternative story is to 'be thoughtful'.

Some of the questions I ask the group are:

- What times are you most happy?
- Who are the most precious people in your life?
- What do you most enjoy doing?
- Who are the people that care about you?
- How do they care for you?
- How do you feel about this? Why?

Students have told me that they enjoy coming to school. They especially enjoy meeting each other, playing together, learning, and participating in co-curricular activities, which they enjoy very much. Usually it is their mother who brings them to school, and then stays during the class time. At other times, however, it may also be a grandmother or aunt who accompanies them. They have told me that they like this, as they are able to remain close to their mother, grandmother, or aunt even though they are in class.

Here is a brief excerpt from one of our conversations:

Maksuda: Does anyone like picture books?

All: Yes, yes! (Loudly.)

M: It seems to me you are all thinking a lot about this; may I listen to someone's story about this?

Student: I am thinking about my favourite picture book.

M: Maybe everyone can tell the group a short story from their favourite book?

[One by one, the students relayed the stories from their favourite picture books to the rest of the group. Each story is different, and provides multiple entry points for rich story development about what values, hopes, and so on, the students connect with in the books.]

M: What story do you like?

S: I like the story about the rabbit and the tortoise.

M: What do you feel, or think about, when you hear this story?

S: I have learnt that to work with determination can bring good results.

M: What does the word 'determination' bring to mind for you?

S: For doing work, you need commitment.

M: Can you explain to the group what 'commitment' means?

S: Commitment is a way to do something so that you can complete it.

M: And what does completing something then bring to you?

S: It brings pleasure, and is fun.

M: Who has another story about pleasure and fun?

S: I know a story about honesty, where children were very thoughtful about helping another person.

M: What do you think of the idea that people should be aware of others? Who thinks that everyone can offer help or support to others who have difficulty in their lives?

A: [Raise hands and loudly agree with this.]

M: How are you feeling right now?

A: We feel good.

M: Would you like to continue these types of sessions?

A: We'd like to, as it makes us feel free and glowing. We know that we have a thinking ability, not a disability.

## CONCLUSION

In the middle of the sessions for children, we experienced an electricity failure, and we wondered if the group would be able to continue. However, the students kept attending the groups, and their mothers helped out a lot. This in itself provided a rich ground for exploring the students' commitment, patience, and joy for learning.

In contrast, it had me thinking about how little we as adults go out of our ways for them, and how much more we could be doing. All of the children are very respectful of each other in the groups, and I have been touched by their loving ways. Each time I work with them, I am both humbled and inspired.

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# *Talking with mothers and children*

## *An intake questionnaire*

**Developed by David Denborough (Dulwich Centre Institute of Community Practice) in conjunction with Maksuda Begum (Bangladesh Protibondhi Foundation).**

This questionnaire is designed as a supplementary intake tool. It has been developed in recognition of the particular experiences of mothers of children with disabilities. This intake tool has two purposes. Firstly, it enables the counsellor to learn about the particular skills and knowledge of mothers and children that can later become a focus for therapeutic conversations. Secondly, it is structured in a way that assists mothers to get in touch with their own skills and knowledges, and provides a healing way for the counsellor to respond.

This intake questionnaire is informed by a range of different narrative ideas and practices. For more information see Morgan, A. (2000) *What is narrative therapy? An easy to read introduction*. Adelaide: Dulwich Centre Publications.

### *For use with individuals*

This questionnaire can be used by a counsellor with individuals in an 'assessment' type setting. It can be used before, or after, the child has been through a medical and psychological assessment.

### *For use with groups*

This questionnaire can also be used in a group setting. The way to do this is explained at the end of this document.

## **THE QUESTIONNAIRE**

### **PART I: A HISTORY OF CARE**

In meeting with mothers, we often hear about how they have tried to find help for their child. Usually, before people come to speak with us, there is a history of caring for the child, of trying to find them help. And yet, sometimes this history isn't very well known. It will help us to know a little more about this history of care.

- When did you first come to think that your child was different from other children?
- How did you try to respond to this knowledge?
- What steps have you taken before coming here? (It is important to get all the details here.)
- Why did you take these steps?
- Were there any difficulties along the way?
- If so, what assisted you to keep persisting, to keep seeking help? Why was this so important to you?
- What do you think it says about you that you have taken all these steps?
- What does it say about your commitment to your child?
- Who would be the least surprised to know that you have this commitment to your child?
- If they were here now, what might they say about this history of care?

### **PART II: CURRENT ACTS OF CARE**

Mothers are often responsible for caring for their child who has a disability, and they do so in many different ways. Mothers' different sorts of caring,

however, are often not well known. We are interested to know about the ways in which you are currently caring for your child.

#### *Physically*

- Are there ways in which you care / support / assist your child physically? Including food, shelter, warmth, etc?

#### *Emotionally*

- Are there ways in which you care / support / assist your child emotionally?
- When he/she is upset, how do you respond?

#### *Relationships with others*

- Are there ways in which you care / support / assist your child with relationships with others [brothers/sisters/friends/other family members]?

#### *Other people's care*

- Are there other people who assist in caring for your child?
- If so, who are these people?
- Why do you think they assist in this caring?
- What do they value and appreciate about you and your child?

#### *History of these skills*

- It seems that you care for your child in many different ways; how did you learn to care for your child in these ways?
- Who taught you these skills? Who did you learn caring from?
- What would they say about the ways in which you are using these skills to care for your child?

### **PART III: RESPONDING TO BLAME AND STIGMA**

#### *Responding to Blame*

Mothers are often blamed for any difficulty in families. In talking with other mothers, we have heard that this Blame can sometimes make life very difficult. [The counsellor may like to tell a story here about some of the sorts of stories she has heard from other mothers as a way to introduce the following questions.]

- Is 'Blame' a part of your life?
- What effects does Blame have on your life and what you think about yourself?
- What effects does Blame have on your relationships with other family members?
- What effects does Blame have on your relationship with your child?
- What effects does Blame have on your child's life?
- When is 'Blame' most powerful?
- When does it do the most harm?
- Are there times when 'Blame' is not so powerful?
- Are there people, friends, family members who do not support 'Blame'?
- Who is most supportive? Why do you think they are supportive? What do they value about you? Why do they care about you?
- Are there ways in which you have found to cope with 'Blame'? When 'Blame' is present are there any ways in which you protect yourself?

#### *Responding to Stigma*

Often there is a considerable stigma about disability. People are sometimes afraid of, or unkind to, people who have disabilities. In talking with other mothers, we have heard that this stigma can sometimes make life very difficult. [The counsellor may like to tell a story here about some of the sorts of stories she has heard from other mothers as a way to introduce the following questions.]

- Is 'Stigma' a part of your life?
- What effects does Stigma have on your life and what you think about yourself?
- What effects does Stigma have on your relationship with other family members?
- What effects does Stigma have on your relationship with your child?
- What effects does Stigma have on your child's life?
- When is 'Stigma' most powerful?
- When does it do the most harm?
- Are there times when 'Stigma' is not so powerful?

- Are there people, friends, family members who do not support 'Stigma'?
- Who is most supportive? Why do you think they are supportive? What do they value about you? Why do they care about you and your child?
- Are there ways in which you have found to cope with 'Stigma'? When 'Stigma' is present are there any ways in which you protect yourself and your child?

#### **PART IV: QUESTIONS FOR THE CHILD**

##### *A note for the counsellor about this section*

The following questions are to be asked to the child. They are designed to provide some information for the counsellor that may be useful at a later time. They are also designed so that the mother can hear about what and who is important to the child. While these questions are directed to the child, the mother may be able to assist them to answer them. This is to be welcomed, especially if the child would have trouble responding on their own.

- What are the times when you are most happy?
- Can you tell me a story of a happy occasion?
- What do you most enjoy doing?
- Why do you enjoy this the most?
- What are you thinking when you are doing these things?
- Who are the most precious people to you in your life?
- Why do you care about them?
- Are there people who care for you, who look after you, who support you? If so, who are these people?
- How do they care for you?
- Is this good? Why?
- Are there times when you try to be kind and caring to others?
- How do you try to do this?
- Why do you do this?
- Do you have any favourite toys or games?
- What do you like about them?

## PART V: OFFERING BACK A REFLECTION

When the interview is complete, it is important that the mother and child receive some sort of response back to all that they have said. They will have shared some personal stories and it is important that there is an acknowledging and healing response.

### *Individual setting*

In circumstances where the counsellor is interviewing an individual mother and child, it is possible for the counsellor to offer a reflection. This reflection can be based on the following questions:

- As you listened to the mother speak, what things did she say that particularly caught your attention or sparked your imagination?
- As you listened to her say these things, what images of her life, or of the world more generally, did you picture in your mind? What did the things the mother said suggest to you about what this mother stands for in life, about her values, beliefs, hopes, dreams, and commitments?
- Why was this most significant to you? What is it about your own life that explains why these things caught your attention or struck a chord for you?
- How have you been moved by hearing this mother's stories? Where has this experience taken you to, that you would not otherwise have arrived at, if you hadn't heard her stories? What difference has it made to you? What difference might this make to your work with other mothers?

Offering a short reflection to the mother and child based on these questions can provide a healing acknowledgement of the skills, knowledge, and stories that they have told.

### *Group setting*

In a group setting, the counsellor can interview one mother using this questionnaire, while the other mothers listen. At the end of the interview, the counsellor then turns to the other women and asks them the same four questions listed above.

Each of the other group members can have a

chance to answer these questions. Each group member may focus on a different aspect of the story they have heard the mother tell. These reflections from the other mothers can provide a healing acknowledgement of the skills, knowledge, and stories of the mother who was interviewed.

## NOTES

- <sup>1</sup> The Bangladesh Protibondhi Foundation has a long history of working with children with intellectual and physical disabilities in Bangladesh. Even before its formal inception in 1984, it has been a key institution in standardising techniques of early screening, identification and assessment of children with various forms of disability, especially intellectual and physical disability. Staff of this organisation encompasses physicians, paediatricians, teachers, special educators, physiotherapists, speech pathologists, psychologists, psychotherapists, counsellors, neurologists, ophthalmologists, audiologists, and social workers. Since 2002, the Bangladesh Protibondhi Foundation has developed counselling services for children with special needs and for their parents.
- <sup>2</sup> Parents who have beliefs in supernatural powers sometimes place threads, lockets or armlets on their child in the hope of this bringing a cure to the disability.

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