

Social Vulnerability in RTS:

Hints and Tips

Julie Shackleton, Ramira Fernades & Jane Waite

The Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham

Members of the Cerebra Centre for Neurodevelopmental Disorders have conducted research into the behavioural characteristics of Rubinstein-Taybi syndrome. A finding of the study was that people with RTS experience difficulties with social cognition, specifically Theory of Mind (ToM). This means that those with RTS may have difficulty thinking about other peoples' thoughts, beliefs and motivations. In other words, people with RTS can have difficulty putting themselves into other peoples' shoes.

Having difficulty thinking about what a person's thoughts and motivations are can be problematic, as it may make a person socially vulnerable. This can become a particular problem for people with RTS who develop more independence as they grow older. This is because the person with RTS might be unable to assess whether a person they are talking to has good intentions.

We have developed this guide to suggest methods for supporting people with RTS to manage these difficulties. As the finding that ToM is impaired in RTS is relatively new, there have been no studies thus far examining the following methods for people with RTS specifically, but they have been found to be effective in other syndromes with difficulties with social cognition, such as autism and Williams syndrome.

It is important to remember that the effectiveness of interventions varies from person to person, so the following suggestions are not guaranteed to work; if you are concerned about your child/person you care for's behaviour, you should seek psychological support.

Avoiding financial exploitation.

Adults with RTS may be vulnerable to financial exploitation, which occurs when a person misuses the assets of a vulnerable person for their own personal benefit, and can take place in a number of ways. Ways to prevent this include:

-Teaching the person with RTS that some emails, phone calls, letters or adverts they receive, amongst other things, may not have

good intentions and may be fraudulent.

-Encourage the person to talk to someone trusted to assess whether they should give someone money.

-Supporting the person with RTS to create a spending plan or budget as a tool to set limits on excessive requests for money.

-Have a trusted person check over their bank statements to detect and report any fraudulent activity.

These strategies should always be conducted with the informed consent of the person with RTS and those supporting the person with RTS should be mindful of invading the person's privacy.

Avoiding issues related to stranger danger.

People with RTS can be very sociable. This, combined with difficulties in social cognition, could create problems with regard to strangers. There are a few steps involved in teaching someone to be aware and safe around strangers. If possible, this should be practiced from a young age and can be done in a couple of ways:

1. Behaviour/In-Situ Skills Training

-Start off by explaining what a stranger is, as well as telling the person with RTS who 'safe' strangers are, such as police officers in uniform, firemen, shop assistants etc., who they can approach for help if their caregiver is not available. Also, try and make sure there is always a way to get in touch with a 'safe' adult. For example, having an emergency contact phone number written on a piece of paper.

-Explain the different types of lures that may be offered by a stranger. For example, general lures ("come with me"), assistance lures ("can you help me carry *x* to my car?"), incentive lures ("if you come with me I will give you chocolate") and authority lures ("your mother is running late to collect you, come with me instead").

-Teach the person with RTS that they should say "no" loudly, physically move away and tell yourself or another 'safe' adult what has

happened if someone tries to lure them.

-Show them how to use these skills by acting out scenarios with another known adult.

-Once you feel they understand the procedure, try role-playing with them often.

-Make sure you try this across a range of scenarios, and support the person with RTS to learn that even if they vaguely know a person, if they feel uncomfortable it's OK to say 'no' to a person and talk to you about the situation.

2. Social Stories and comic strips

-Social Stories and comic strips are designed to show people how to act in different situations. More information can be found at <http://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>.

It is important to support the person with RTS to practice these strategies across lots of different scenarios and environments. If they are active online, a similar level of tuition will be required, to prevent both issues with strangers and exploitation.

Teach the person with RTS how to communicate under stress, so that they feel able to tell a trusted adult immediately.

Bear in mind that everyone is an individual and learns in different ways, and you should tailor how you support a person with RTS to learn these skills.

If you have any questions regarding this intervention guide, please contact the Cerebra Centre for Neurodevelopmental Disorders via the following phone number or email address.

Email: find@contacts.bham.ac.uk Phone: 0121 414 7206