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“Male Puberty in the Developmentally Disabled”
Lisa Samson-Fang, MD and Philip Baese, MD

Lisa Samson-Fang: Today we have Dr. Phil Baese. Dr. Baese was a triple board resident here at the University and now is a pediatric psychiatrist who works in the Neuro Behavioral Clinic here at the University. The topic for today is a topic that was requested in the past; mental health and behavioral issues that come up in adolescent males with developmental disabilities as they go through puberty.

Dr Baese: I would like to take a few liberties if that's okay and not narrow the discussion just to males because there are often issues that come up in females, although we can certainly talk about males. What I wanted to do was touch on a couple of articles that I will make sure get attached and sent to everybody as well, these are general issues so towards the end we can have time to discuss more specific issues but I wanted to touch on some generalities around this in adolescents with developmental disabilities. I think it's important to understand the generalities before we get into the specifics. Often times the contents of the specifics can get us distracted from the more general issues related to puberty and developing sexuality in people with developmental disabilities. The first article I would like to site was authored by Dr. Nancy Murphy, who works in physical and rehab medicine. She was the lead author on a clinical report just published by the American Academy the title of it is *Sexuality in Children and Adolescents With Developmental Disabilities*. I think there are very relevant points that she makes that I wanted to raise with everyone. First of all, people with disabilities are often erroneously thought to be childlike, asexual or in need of protection. By erroneously I mean there are certain points, like the need of protection that are debatable, particularly when we look at sexual abuse rates in people with disabilities. The other side of the coin is that they may be viewed as inappropriately sexual or having uncontrollable urges when in fact much of what they are going through is normal but their disability distracts people from understanding the normal developmental process and has them overly concerned about behaviors that may in fact be considered to be within the normal range. Some things that are important to realize in people with developmental disabilities is that often the onset of puberty can be earlier for reasons that are not entirely understood but on average people with developmental disabilities both male and females enter puberty earlier than non developmentally disabled people and that may have to do with neurologic or central nervous system malformations or abnormalities of the hypothalamic pituitary axis it's not completely understood why and of course I don't want you to think that every person with developmental disabilities enters puberty early, but if and when they do it creates problems because you essentially have someone who looks like they are in precocious puberty who may be socially immature, have poor impulse control and may often have altered sense of their body image, it interjects issues of hygiene and self care that they may not be capable of understanding and participating in and it often puts them in a heightened risk of sexual victimization because of the issues I mentioned. Some of the problems I clinically see, often relate to what appears to be inappropriate sexual behavior such as masturbation both in males and females though oftentimes you hear about it more in males, you'll have a family coming in asking what do we do with this issue how do we handle it. A couple of other statistics I wanted to mention from that article that I think are also relevant relate to the risk of sexual abuse with people with developmental disabilities. Studies show they are twice as likely to experience sexual abuse than a child without

developmental disabilities. I think even more important is that 70-80% of females with developmental disabilities over their lifetime will be sexually assaulted and less than half of them will seek legal or mental health treatment. The reasons for this are complex of course, but it probably has to do with their dependence on others for their more intimate types of care like hygiene, increased exposure to a lot of caregivers, potentially inappropriate social skills, poor judgment, inability to seek help and report abuse and the lack of ability to strategize or defend themselves against people who are inappropriately approaching them. For me this all often culminates in an over protection, a response that oftentimes makes it more difficult to deal with the actual behaviors such as fear of talking specifically about sexuality because there are beliefs that it will lead to or promote sexual behavior and that can all present a significant barrier to both caregivers and parents sitting down and putting the issues out on the table and discussing them. I would point out a goal of education both for parents and children that adolescent developmental disabilities really isn't all that different from those without which is to give them the sense of being attractive as members of their own gender with the expectations of having satisfying adult relationships. That is a general statement I realize that is something we normally expect as kids and adolescents go through their development and for the most part assuming that people with developmental disabilities want the same that their capacity to achieve may be differentially affected by their disability depending on what it is of course, physical versus cognitive disability. But I think one thing we all have to recognize as well is that we can't do this in the context of the child or adolescent but we have to incorporate the values of the family and the issues that range from personal modesty to adult sexuality and all of the context that families bring into that situation. So these are some of the general points that Nancy Murphy makes in her article I think it's well worth reading. I do want to leave time for questions I won't summarize things but I want to mention another article that I'm going to include which I find very helpful for dealing with not only about inappropriate or difficult sexual behavior but other behaviors which in my clinic usually fall in what I call the "big three" – 1. self-injurious behavior 2. aggression 3. inappropriate sexual behavior. I'm going to include an article entitled *Managing People With Challenging Behavior*. It outlines what I think is critical to look at from a primary care standpoint which is a comprehensive plan and acknowledges that there are not usually one step solutions for these problems. Unfortunately they are behaviors that are often not indicative of a specific syndrome or a psychiatric diagnosis, but really represent complex interplay of behavior and environmental response of their behavior and their disability and usually requires management by multiple specialties including potentially a psychiatrist but also a therapist, a behavior specialist and pediatricians as well, who are often on the front line dealing with these problems on a day to day basis. I refer you to that article which I think is useful to review in terms of the approaches and breaks it down into biological, psychological and social factors that need to be addressed when dealing with these challenging sets of behaviors. From my own practice, I can give you some examples that are potentially more extreme than some of the things you deal with. I would like to make sure I could entertain some of the specific questions that come up. The general topics that I find coming up include things like use of androgen suppression in males- that comes up as a frequent question. Admission of females or males of reproduction age with developmental disabilities comes up quite a bit. I will also attach a very nice article from the American Academy Bioethics Committee of which Dr Botkin here locally was on that addresses this specific issue as well. These are topics I find come up quite a bit in dealing with behavior issues around puberty, if those spark anyone's thoughts about a patient they have seen I'm happy to entertain any questions.

Dr Lisa Samson: does anybody have a question?

I have question regarding contraception and girls with developmental disabilities. I had a parent come to me with a 17 year old girl with mild to moderate mental retardation. She requested an IUD and we were able to steer her toward the possibility of Depo injections. This girl already has a 6 year old daughter, so she was molested with she was 11 year old, the perpetrator is unknown they just noticed she was pregnant one day. Her mother felt there was no way she could constantly protect her because she goes off with whomever. We decided to give her Depo and that's what we are doing now but I wondered what your experience is with contraception methods and the idea of contraception for someone who can't really decide for themselves what to do about contraception.

Dr. Baese: I think you raised a couple of extremely important points. One of which highlights the point I made earlier about the vulnerability of this population and their risk of being exploited. You also highlighted something that traditionally in the developmentally disabled population, particularly in minors, hasn't really been well considered. The historical approach, and by the way I haven't practiced that long, I finished my residency in 2002. I wanted you to have a context so I'm talking about the way it was handled before I practiced. I think the general approach to sexuality in people with developmental disabilities was to supersede their participation in the decision making process. That's not to say everybody, depending on their cognitive ability is fully able to participate in the process. The general approach these days is to allow them to participate to the extent that they can understand in the discussion around being sexually active and what their intentions and desires are, and treat them from that stance and then involve their care providers, - and it was a parent who I think you said- because of the past history and the potential for re-exploitation. I think you addressed the appropriate things because I think its incumbent on us to try and make sure she's in an environment that's not going to happen again. The next issue is how to approach contraception with someone who is vulnerable but not sexually active at this point. There are several reasons for using contraception in this population such as regulation of menstrual cycles and its important to discriminate between the two. That article I cited that Nancy Murphy authored brings up important things to consider for example many of these people are on a variety of other types of medications including anti-epileptic medications like Tegretol which may reduce efficacy so you have to be aware of things like that. Things like Depoprovera long term and the effects on bone mineral density are obviously issues to consider. She points out mobility issues and people with cerebral palsy or confined to a wheelchair have the potential for hyper coaguable and things like that are important to consider as well. This person you mentioned is 17 and still a minor. You are getting to a critical age where I've seen a lot of people fall through the cracks when they turn 18 and they don't have a responsible parent or adult in their life who is interested enough to take guardianship and participate in these issues, so they often end of in this grey zone of being 18 but clearly not able to make decisions. Unless there is an interested parent or guardian you are left in a difficult position.

Dr. Samson-Fang: Could you expound a little bit on Androgen suppression, which is an extreme form of treatment. Could you explain your approach to the issue of sexual expression and uninhibiting sexual expression?

Dr. Baese: I think it's important to put a context around it developmentally. I'd like to read a definition that I find very useful as to what challenging behavior constitutes. "Challenging behavior

is following culturally abnormal behavior of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or the behavior is likely to seriously limit the use of or result in the person being denied access to ordinary community facilities.” So I think that uninhibited sexual behavior could certainly fall in that category, not based upon the behavior but based on the context on which it’s done. For example masturbation in public is generally going to fall within that category if it can’t be managed in a more appropriate setting it is certainly going to limit that person’s access to ordinary community facilities although it may not cause them physical harm but it will certainly limit their ability to function out in the world. That is where we try to address the behaviors.

I wanted to comment on the use of androgen suppression because this comes up in my clinic. I have one patient in the six or seven hundred enrolled in this clinic who I am actually considering putting on androgen suppression due to the level of behavior. He is not under 18 at this point, he is a young adult. Most the studies have been done in the criminal forensic population of predatory males that fall within the anti-social class. There is one study done in the late nineties with lupride in autism. There is criticism of that study that I was able to find but I think that it is certainly a reversible suppression of testosterone. There is evidence that high levels of testosterone contribute to aggression and sexual aggression. Its not inconceivable that it could be an effective treatment but I find the majority of the problems are better addressed by looking at the context in which behaviors are happening, understanding if it is within the normal spectrum and then coming up with a response pattern for the people around them to manage it- such as appropriate time and place and really using behavioral strategies to manage these behaviors. So I rarely use it personally and in the circumstances like the one I mentioned I have a patient who has had a frontal lobe tumor resected and is very disinhibited and has zero self- control. He is so vulnerable to being victimized that we are having discussions with him and his family about the potential use of androgen suppressors because its affecting his life so much. In general I think it’s a treatment that I consider as a last resort.

Dr. Lisa Samson-Fang: If a family comes in with a concern with their teen who isn’t socially adapted and is having masturbation behaviors in the home and in school, what is your first line of approach to that issue.

Dr. Baese: My first line approach is to consider the values of the family in terms of what they consider normal behaviors. In general if its behavior that falls within the range of normal behaviors, then framing it as a gap between their chronological age and their emotional or developmental age often helps it be more understandable to the family. So they understand that someone who operates at a toddler level cognitively may have some normal self-stimulatory behaviors with regards to their body, but at 13 or 14 the problems associated are disconnected because of the age difference. Pointing that out helps people to put it in context rather than blow it out of proportion. I try to normalize behavior that falls within that spectrum and ask how is this impairing their life other than being bothersome to the family. The strategy is to contain and create some tolerance for the family and create some boundaries as to where it may be acceptable, and where and when they can tolerate it -like in the boundaries of a room.

Dr. Samson-Fang: This is a very self-reinforcing behavior do you think other people reinforce this by their response to it?

Dr. Baese: Yes this is something I deal with all the time. The inadvertant reinforcement by paying attention to a behavior that is meant to draw attention. All challenging behaviors including self-injury and aggression can be reinforced by environmental response to it. This is where a behavior specialist is helpful because then they can assess the situation and come up with a program to modify the behavior and shape how people respond to it when ignoring it is what is called for.

Dr Samson-Fang: We are going to have to wind up. We want to remind everybody that our behavior clinic is a resource for children who have dual diagnosis who may be having some of these behavior concerns. We'll get back to you with our next topic and speaker.

In attendance: Dr. Samson-Fang, Dr. Baese, Chuck Norlin, Barbara Ward. Al Romeo, Budge Clinic, Clinic 6 U of U, Dinosaurland Vernal, Montezuma Creek, Redwood, Michelle