

REiNS Neurocognitive Committee

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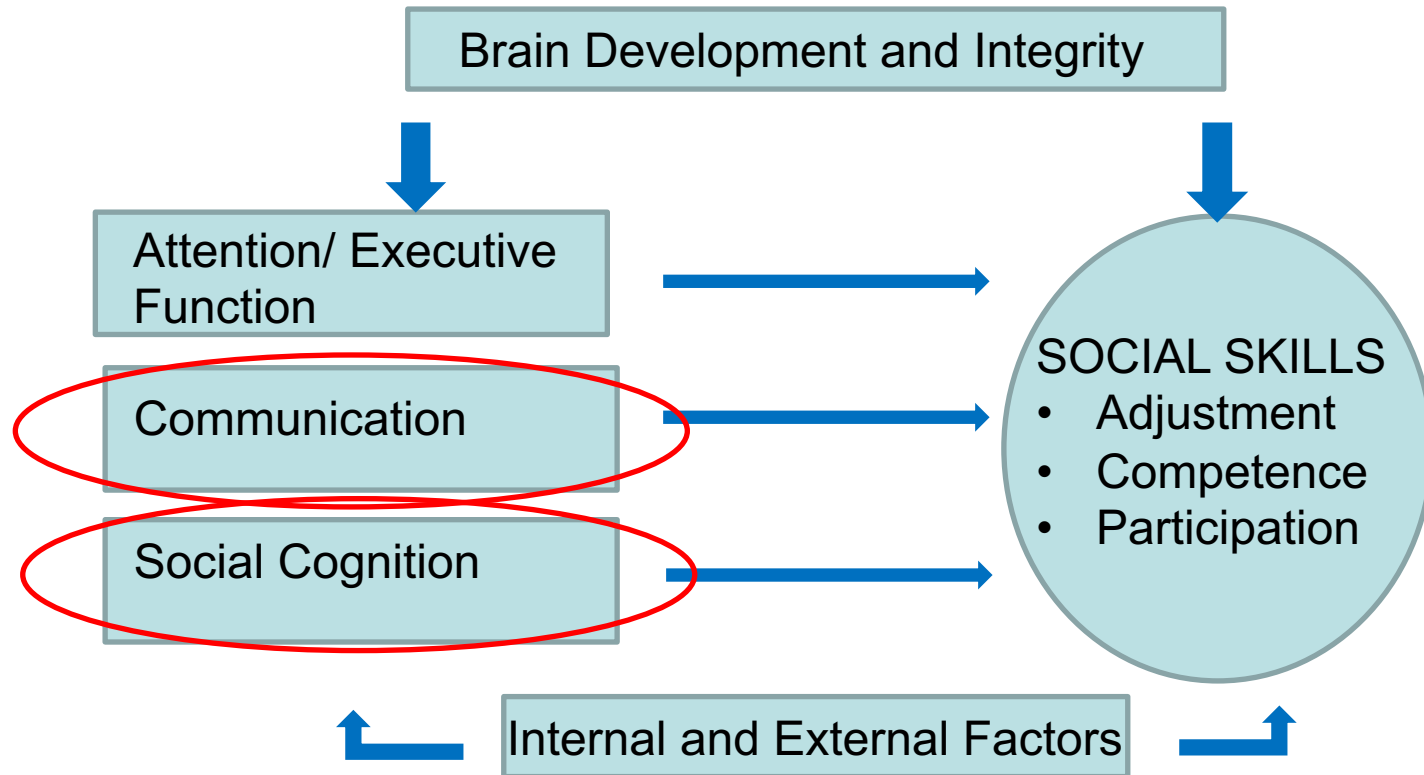
Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

Current Focus

- Social function outcome measurement
- Broad range of functions that relate to social function
 - Attention
 - Executive Function
 - Language
 - Social Cognition
 - Emotional Functions
- In considering social functioning, best to work from a theoretical model



Socio-Cognitive Integration of Abilities Model (SOCIAL; Anderson and Beauchamp)



Working group previously
focused on attention & EF in
future

Identifying Appropriate Measures- What do we look for?

- Measure areas we are interested in
 - Communication and social cognition
- Well-designed measures (good psychometrics)
- Easily administered in clinical trials setting
 - Focused on parent questionnaires
- Previously used in clinical trials where social skills are an outcome measure



Measures Reviewed

After comprehensive literature review, the following measures were identified as relevant:

- Social Communication Questionnaire
- Social Skills Questionnaire
- Autism Social Skills Profile
- Profile of Social Difficulty
- Social Skills Checklist
- Socialization scale, Vineland Adaptive Behavior Assessment System
- Social Competence Questionnaire
- Social Skills Rating System/ Social Skills Improvement System
- Social Responsiveness Scale-2
- Children's Communication Checklist-2



Measures Reviewed

After review by the working group, three measures met criteria for use in clinical trials (we have high standards!)

- ~~Social Communication Questionnaire~~
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Problems with these measures included poor test characteristics, too narrow focus, and limited use in clinical trials



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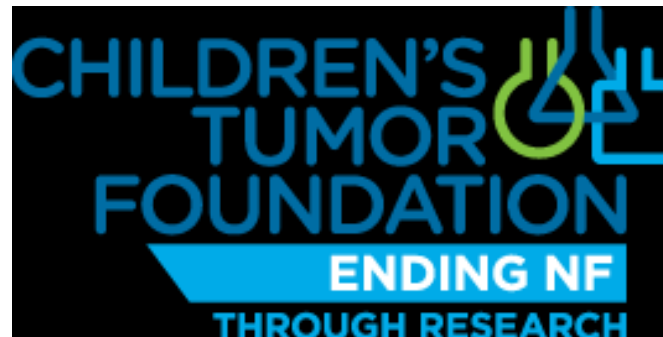
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These three measures were rated highly to capture social language, communication, and social cognition



Current Work / Next Steps

- Psychometrics Study
- Engagement in Cognitive Research Survey
 - Thank you to the CTF - Pam Knight & Kate Kelts, RN



Patient Engagement Survey

- Survey developed by Children's National (DC) team and collaboration with patient representative (Maureen Hussey)
 - Adults with NF, Parents of children with NF, and children with NF (ages 10-17)
- Approved for distribution through the NF Registry by CTF
- To date ~ 649 participants!!
- If you want to participate please grab a flyer or see me!



How you can get involved and help?

- Breakout session (today!)
 - Target of social function, what matters?
 - Interest and engagement in cognitive research
 - Intervention studies –
 - What's required
 - web-based v. in person - preferences
- Take the survey

