

PSYCHOSOCIAL CARE GUIDELINES (2018)

- Team including a mental health professional
- Routine screening of mental health and quality of life
- Provide cognitive-behavioral interventions for concerns identified
- Refer for neuropsychological evaluation
 - Concerns with: cognitive function, attention, learning, etc
 - If evaluated, repeat every 2-3 years OR near transition points
- Transitioning planning
 - General (normative) independence, power of attorney, advanced directives, adult medical care services

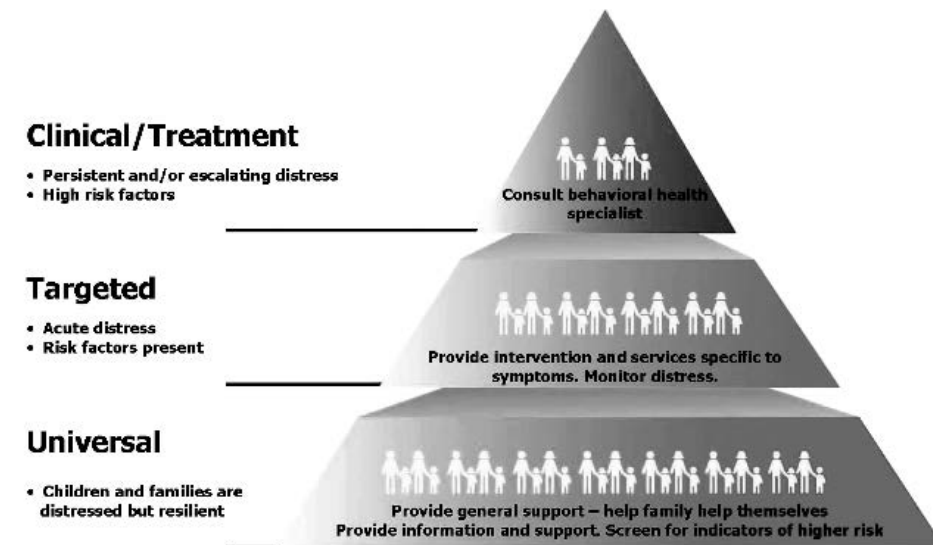


Figure 2. Pediatric Psychosocial Preventative Health Model. Copyright 2005 by the Center for Pediatric Traumatic Stress (Anne E. Kazak, PhD, ABPP, Director), Children's Hospital of Philadelphia.

COGNITIVE, EMOTIONAL, & BEHAVIORAL SYMPTOMS

- Evidence for changes in dystrophin in brain areas associated with learning, behavior, and emotions. Steroids can exacerbate.
- Increased risk compared to general population, but risk \neq will have.
- Many young men are doing well overall outside of need for physical supports

Attention/Executive Functioning & Learning

- Distractible & Impulsive
- Verbal working memory
- Decoding Fluency (reading)

- Reading Comprehension
- Larger tasks/demands
- Multi-tasking
- Flexibility in thinking
- Activities out of routine

Language

- Efficiency/Reliability
 - Word finding
 - Elaborating thoughts

- Too much verbal may be overwhelming (slower, lower, less words)

Other (Related) Concerns

- Anxiety [Mood]
- Endurance
- Task avoidance / noncompliance
- Regulation of arousal, motivation, emotions
 - Tantrums or aggression
 - General hyperarousal

POSSIBLE PSYCHOSOCIAL SUPPORTS PROVIDED

- Recognizing and managing emotions. Planned breaks, regardless of activity
- Behavior management; Strategies/supports for attention and organization
- Evidence-based (cognitive-behavioral) strategies for mood or anxiety
- Medical Regimen help
 - Problem-solving, Goal-setting, Contingency management, Exposures (BiPAP), motivation enhancement or self-talk strategies
- Disease Coping
 - General adjustment, disclosure, declines in function, social and decreased structure after school completion, logistics or resources
- Self-advocacy & transition (independence promotion)
- Finding local therapy options (as needed) for significant concerns —
 - Help improve symptoms, quality of life, family functioning

