



## **Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents and Young Adults with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements**

WISCH Transition Affinity Group Members: Jane Hankins (chair), Sheila M Anderson, Michael Barnett, Fernando Barreda, Wondwessen Bekele, Suzanne Bell, Jeannie Byrd, Mary Campbell, Yvonne M Carroll, Maria Champigny, Miralda Charles, Alice Cohen, Audrey R Cole, Lori Crosby, Donna Dixon, Mark Goodwin, Oba Hollie, Ashley Houston, Alana Lopez, Kelley Mansker, Michael Matthews, Owita Mays, Brandi McClain, Amanda Norton, Wanda Payton, Jerlym Porter, Michael Regier, Sandra Sledge, Amy Sobota, Marcus Stevenson, Marsha Treadwell, Lauren Whiteman, Andrea Williams, Michelle Williams



## Introduction

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The Transition Curriculum for adolescents with sickle cell disease was developed as a joint effort with funding from the Health Resources and Services Administration (HRSA); Sickle Cell Disease Treatment and Demonstration Program (TDP) grant. The grantees consist of a network of comprehensive sickle cell centers (pediatric and adult), sickle cell community organizations, and federally qualified healthcare centers. These organizations worked in a collaborative effort with the HRSA Sickle Cell Disease for Newborn Screening Program (NBS) grantees and the coordinating center for both programs, the National Initiative for Children's Healthcare Quality (WISCH—Working to Improve Sickle Cell Healthcare) to develop this transition curriculum.

The curriculum was initiated as a result of numerous discussions among grantees concerning the dearth of guidelines available for practitioners, parents, and patients, for transition of adolescents with sickle cell disease (SCD) from pediatric to adult care. A transition affinity group was formed consisting of representatives from the TDP and NBS grantees, and WISCH representatives. The group held monthly conference calls and created a transition curriculum with input from all team members. The draft was disseminated to the TDP and NBS grantees for input, and once feedback was received, the curriculum was formatted and finalized.

The Sickle Cell Disease Transition Curriculum (SCDTC) is a reference for healthcare practitioners, patients, and parents to provide useful, practical, and meaningful guidelines to assist with the transition of adolescents with SCD from pediatric to adult medical care. It is divided into age groups; 12- 14 year olds; 15-17 year olds; and 18-25 year olds. Each age group consists of three domains: Medical, Social, and Academic. Each domain includes guidelines for medical topics, methodology, and techniques to measure efficacy. The curriculum is meant as a guideline only and should be customized to each center and each individual patient.



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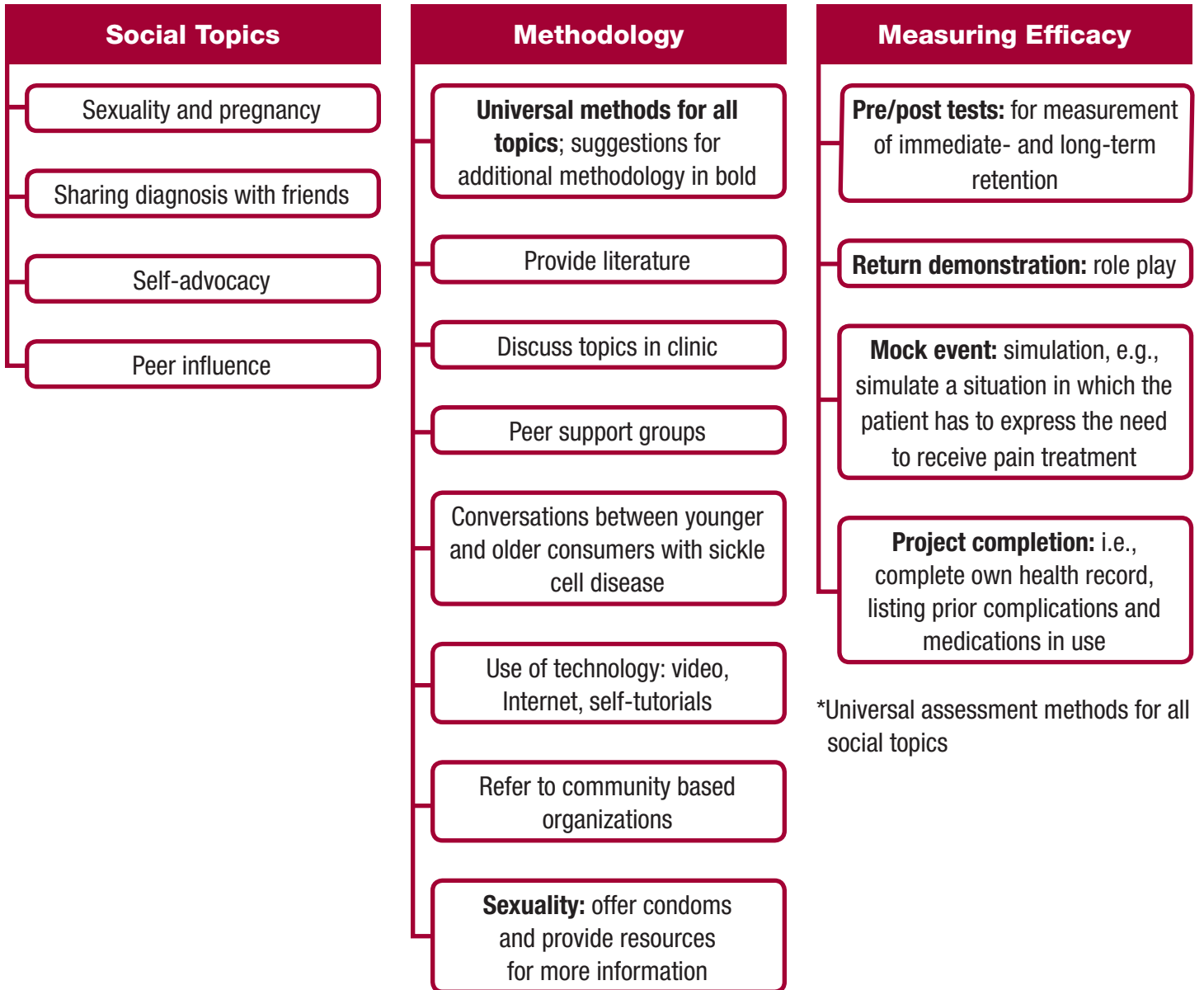


## Medical Domain 12-14 yrs

| Medical Topics  | Methodology   | Measuring Efficacy   |
|---|---|--|
| Introduction of transition policy   | <p><b>Universal methods for all topics;</b> provide literature and discuss topics in clinic or at educational forums, on-line modules<br/>(Additional methodologies per topic below)</p> <p><b>Transition:</b> use positive language and different teaching methods (video, PowerPoint slides, role playing)</p> <p><b>Pain:</b> develop individualized pain plan or diary and give copy to patient</p> <p><b>Hydration:</b> provide water bottle</p> <p><b>Labs:</b> provide copy of lab results with explanation; graph labs over multiple visits</p> <p><b>Nutrition:</b> use growth chart; discuss <i>MyPlate</i></p> <p><b>Physical activity:</b> older patient shares experience; provide community resources, i.e., YMCA</p> | <p><b>Pre/post tests:</b> for measurement of immediate- and long-term retention</p>  |
| Pain triggers/types   |   | <p><b>Self assessment:</b> ask about knowledge in a particular area; keep ongoing graph of self-perception to see change</p> |
| Disease modifying treatment options   |   | <p><b>Project completion:</b> e.g., fill out pain dairies, pill box, demonstrate how to call for appointments</p>            |
| Fever management  |   | <p><b>Surveys:</b> e.g., satisfaction and confidence with own self care</p>  |
| Hydration   |   | <p><b>Role play:</b> simulate an event and have the patient participate, e.g., "You have chest pain. What would you do?"</p> |
| Meaning of laboratory values  |   |  |
| Good nutrition habits   |   |  |
| <b>Disease complications:</b> priapism, gallstones, AVN, retinopathy cardiovascular, pulmonary, delayed puberty |   |  |
| Medical visit process/How to schedule visit, where to go, etc.  |   |  |
| Risk of illicit drug, smoking and alcohol use   |   |  |
| Importance of physical activity   |   |  |
| Knowledge of own genotype and pattern of disease inheritance  |   |  |

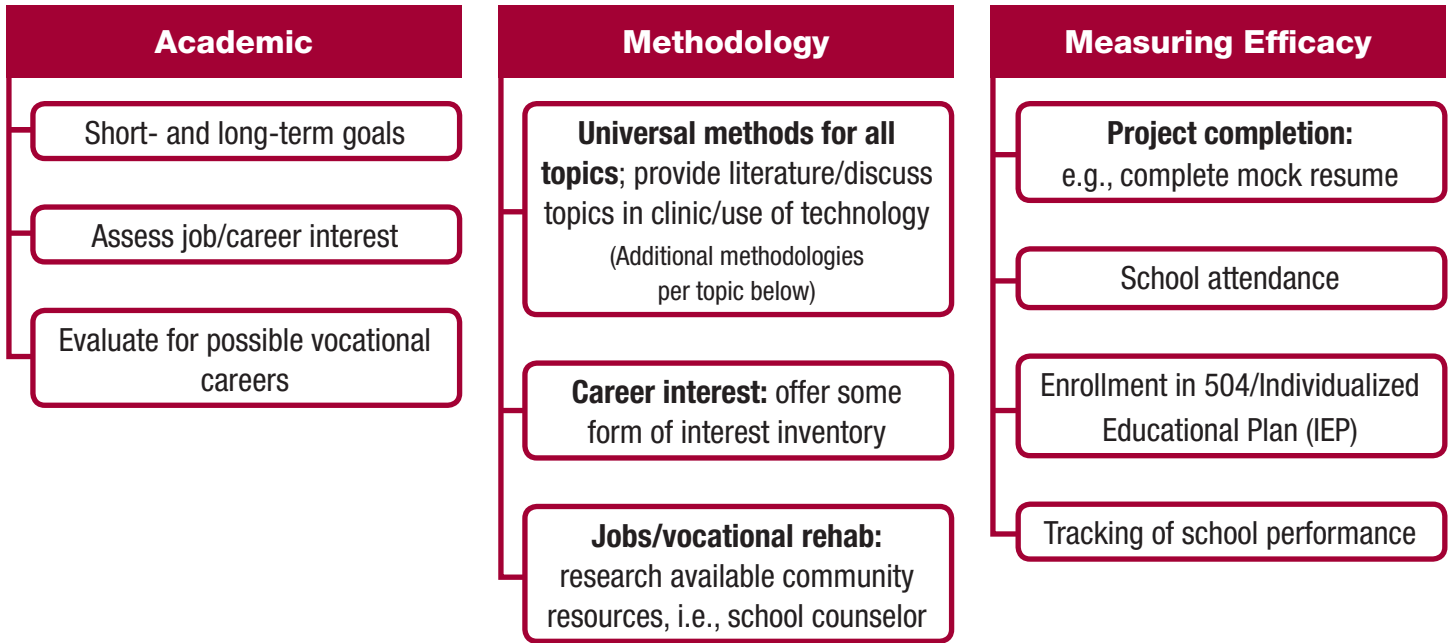
\*Universal assessment methods for all social topics

## Social Domain 12-14 yrs





## Academic Domain 12-14 yrs

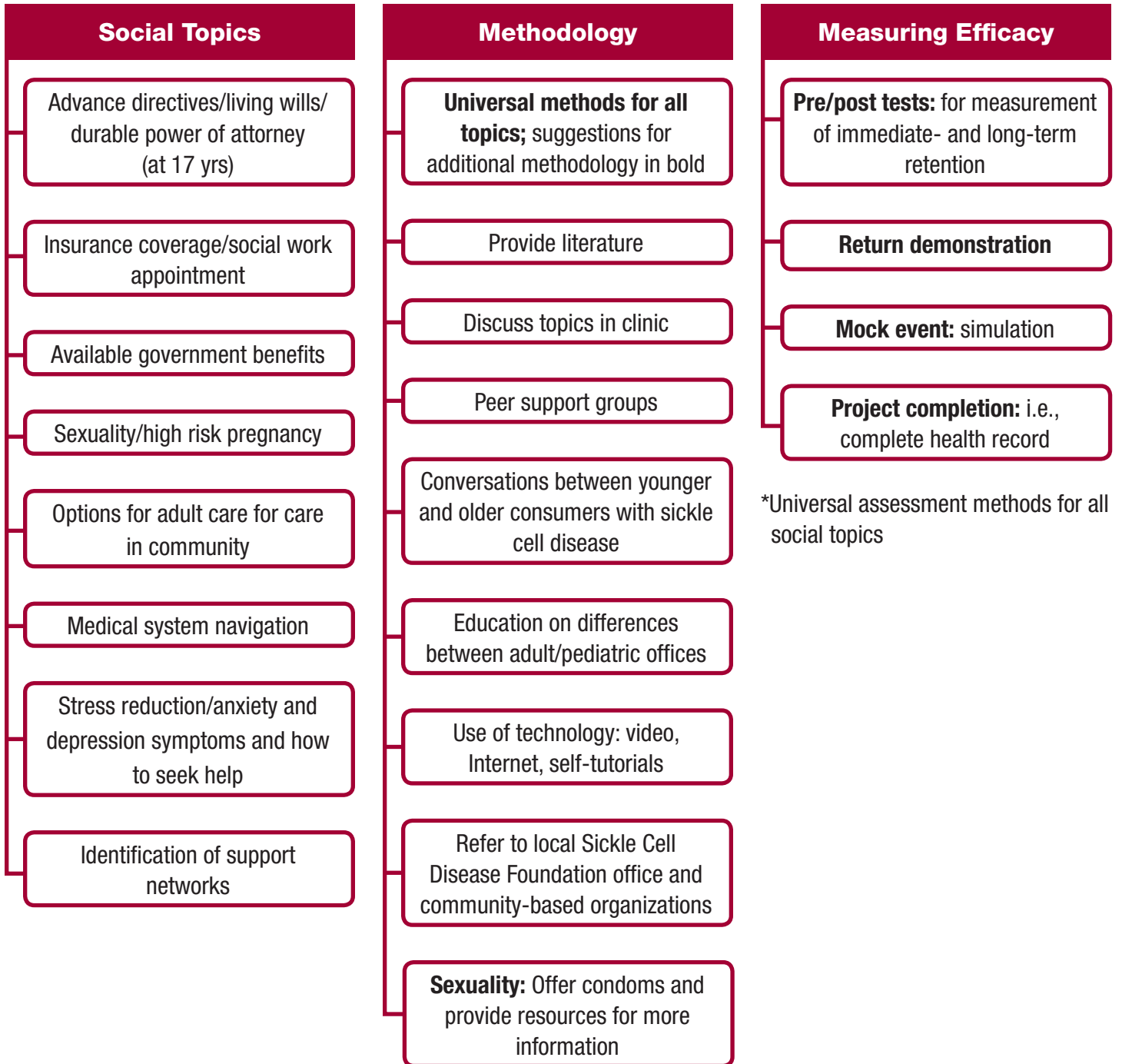


## Medical Domain 15–17 yrs

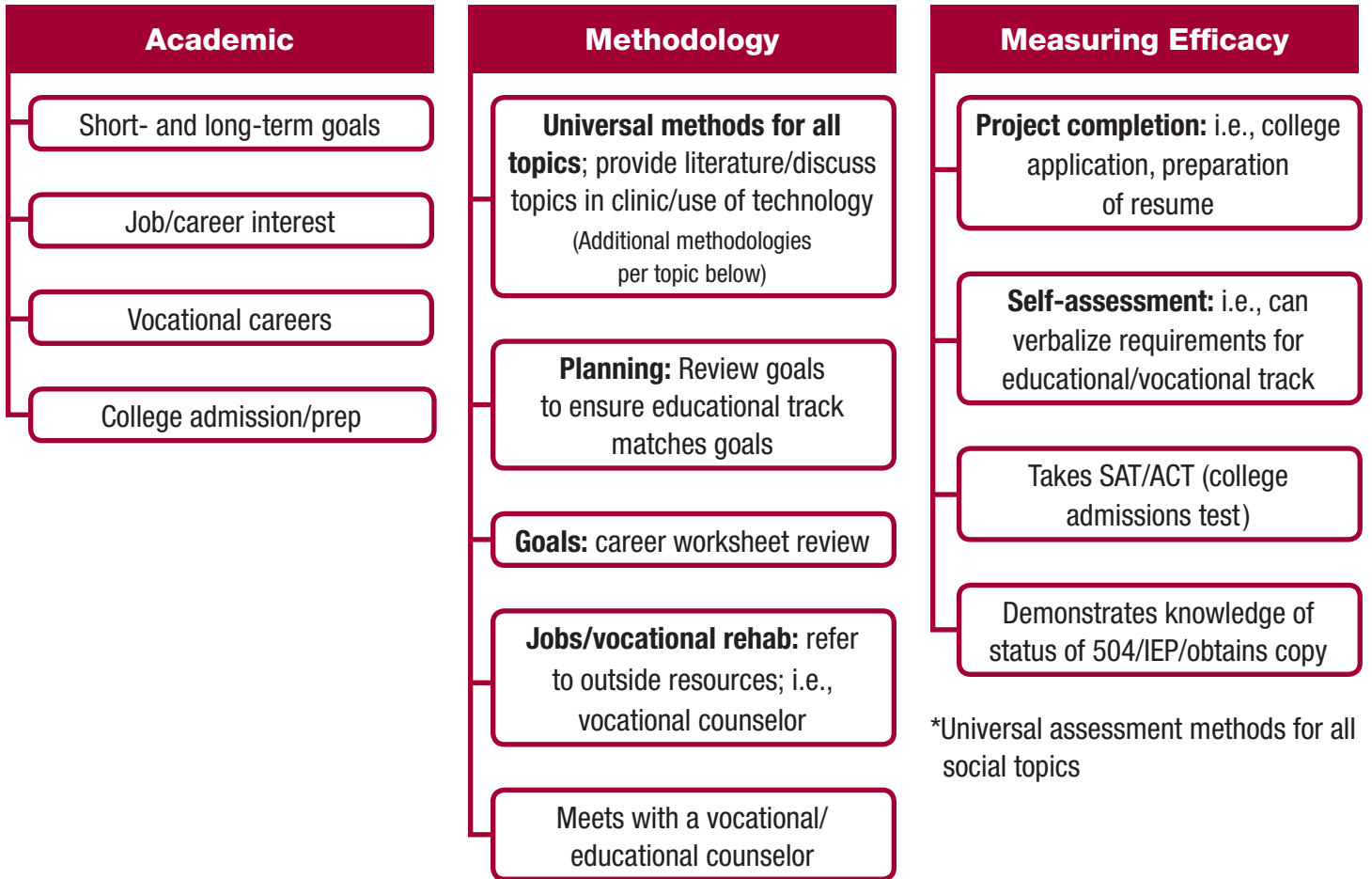
| Medical Topics  | Methodology   | Measuring Efficacy   |
|---|---|--|
| Knowledge of own genotype and pattern of disease inheritance  | <p><b>Universal methods for all topics;</b> provide literature and discuss topics in clinic, on-line modules, educational forums<br/>(Additional methodologies per topic below)</p> <p><b>Option:</b> offer private visits with parents out of the room</p> <p><b>Pain:</b> develop individualized pain plan or diary</p> <p><b>Hydration:</b> provide water bottle</p> <p><b>Labs:</b> provide copy of lab results with explanation; graph labs over multiple visits/show slides</p> <p><b>Nutrition:</b> growth chart; discuss <i>MyPlate</i></p> <p><b>Exercise:</b> have patient keep an exercise log</p> | <p><b>Pre/post tests:</b> for measurement of immediate- and long-term retention</p>  |
| Current medications   |   | <p>Return demonstration/teach back method</p>  |
| Disease complications; i.e., AVN, gallstones, priapism, retinopathy, stroke, nephropathy, delayed puberty, acute chest syndrome |   | <p><b>Self assessment:</b> ask the consumer about knowledge in a particular area; keep ongoing graph of self-perception to see change; provide summary of results at graduation (for positive enforcement of progress)</p> |
| Knowledge about transfusion   |   | <p><b>Project completion:</b> i.e., completion of exercise log</p>   |
| Pain triggers/treatment   |   | <p><b>Interactive results:</b> i.e., Punnet Square worksheet</p>   |
| Fever management  |   |  |
| Nutrition and hydration   |   |  |
| Meaning of own laboratory values  |   |  |
| Importance of exercise/sports   |   |  |
| Immunizations: influenza, meningococcus, pneumococcus   |   |  |
| Risk of illicit drugs/alcohol/smoking   |   |  |
| Compliance strategies   |   |  |

\*Universal assessment methods for all social topics

## Social Domain 15–17 yrs



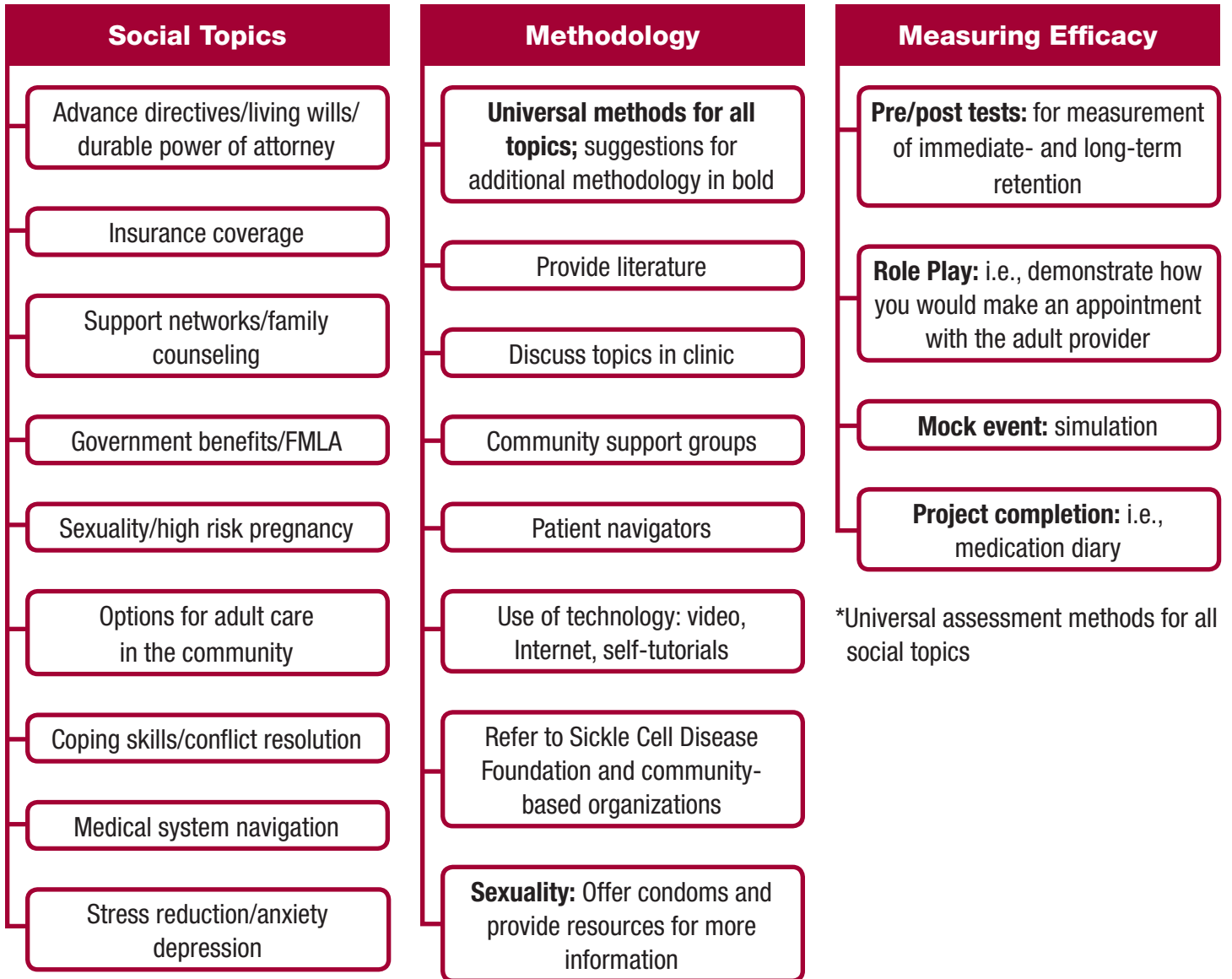
## Academic Domain 15-17 yrs



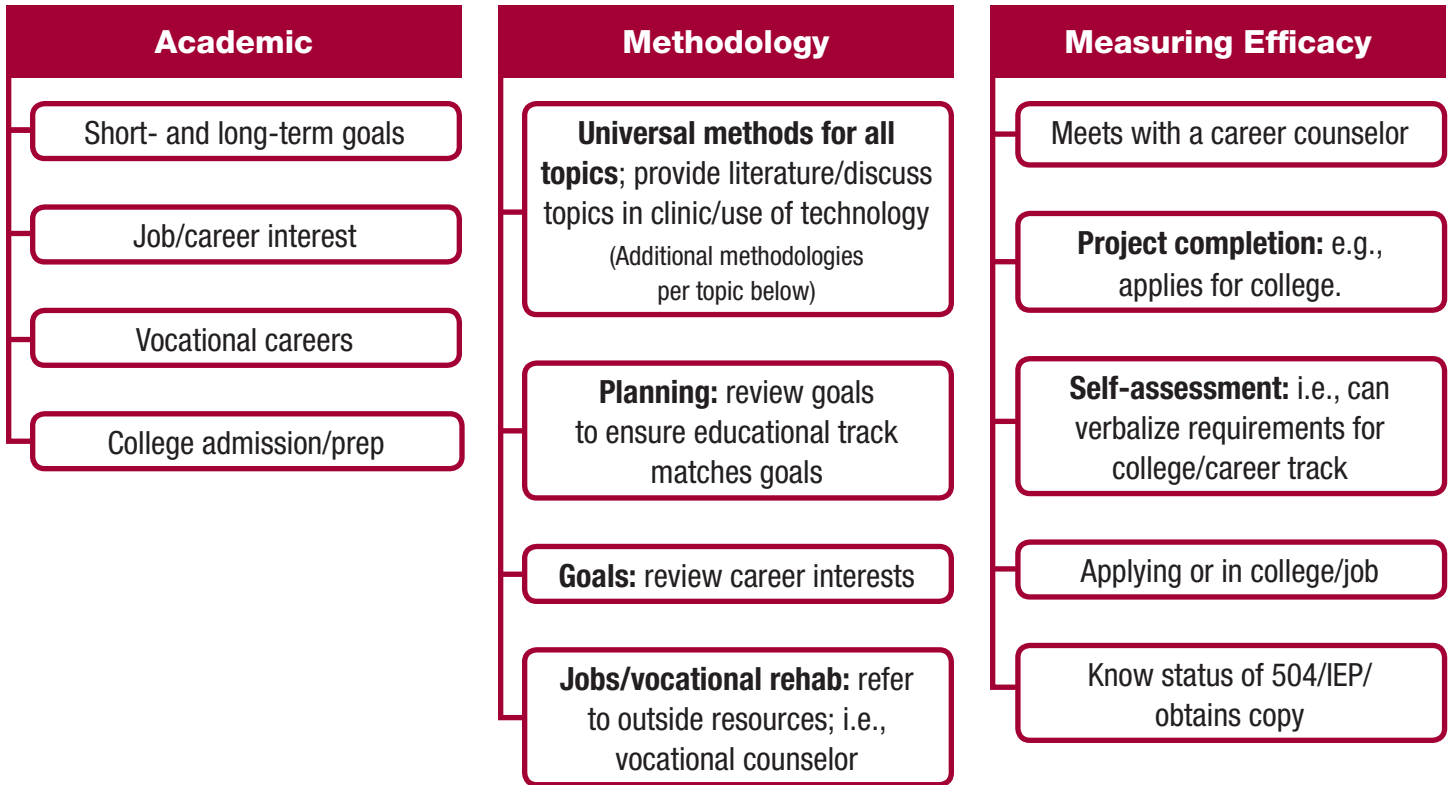
## Medical Domain 18–25 yrs

| Medical Topics  | Methodology  | Measuring Efficacy  |
|---|--|---|
| Knowledge of genotype; genetic counseling   | <p><b>Universal methods for all topics;</b> provide literature and discuss topics in clinic, on-line modules, educational forums<br/>(Additional methodologies per topic below)</p> <p><b>Medications:</b> discuss dose, name, purpose of current meds; explain hydroxyurea if not a current medication</p> <p><b>Pain:</b> review pain triggers/ stress management/relaxation techniques</p> <p><b>Hydration/nutrition:</b> demonstrate visually (with cups/ water bottle) how much daily fluids are required</p> <p><b>Labs:</b> provide copy of lab results with explanation</p> <p><b>Complications:</b> Discuss major complication individualized for consumer history, refer as required for disease complications</p> <p><b>Genotype/pregnancy:</b> Discuss SCD inheritance individualized to consumer and need for high risk OB-GYN for female patient</p> | <p><b>Pre/post tests:</b> for measurement of immediate- and long-term retention</p>   |
| List of medications   |  | <p><b>Self assessment:</b> ask the consumer about knowledge in a particular area; i.e., average Hg level; major disease complications</p> |
| Disease complications: Gallstones, leg ulcers, priapism, AVN, nephropathy, pulmonary and cardiovascular complication, pregnancy |  | <p>Demonstration/teach back</p>   |
| Transfusion indication and risks  |  | <p><b>Project completion:</b> i.e., completion of pain diary and coping mechanisms</p>  |
| Pain triggers/treatment   |  | <p><b>Interactive results:</b> i.e., SCD inheritance risk worksheet</p>   |
| Fever management  |  | <p>*Universal assessment methods for all social topics</p>  |
| Nutrition/hydration/exercise  |  |   |
| Meaning of own laboratory values  |  |   |
| Immunizations: Influenza, meningococcus, pneumococcus   |  |   |
| Risk of illicit drugs/alcohol/ smoking  |  |   |
| Compliance strategies   |  |   |

## Social Domain 18–25 yrs



## Academic Domain 18–25 yrs



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