



Providing to Children With Special Needs

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Why?

- ◆ With improving technology, there will be increasing numbers of children of all ages with special needs
- ◆ Childhood interventions may change the functional outcomes of the individual or family
- ◆ Care coordination is economically beneficial for society



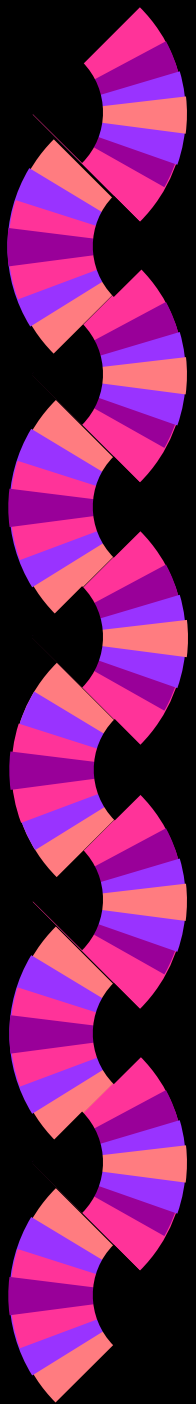
Part I: What needs will need to be met?

- ◆ Example: 4 yo child with HLH s/p
Norwood, Glenn, Fontan



Medical Needs

- ◆ Andrea-future cardiologist will need to address both the acute and chronic cardiac issues that arise from HLH
- ◆ will need to have understanding of associated medical conditions that may or may not be cardiac in origin
- ◆ will need to coordinate care with multiple physicians and ensure that there is a united understanding of medical goals

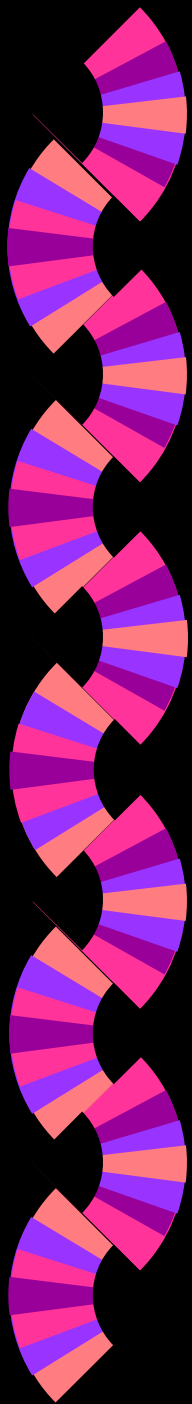


- ◆ Lori-future Urgent Care MD- will need to understand the surgical interventions and medications used in HLH
- ◆ will need to have an understanding of the acute illness
- ◆ will depend on information from both the family and a summary if available regarding the past medical history



Impairment Level Needs

- ◆ Andrea-future cardiologist-will need to understand the needs brought about by poor growth, poor milestone achievement, gross and fine motor impairments, respiratory insufficiency, decreased activity tolerance, and decreased illness tolerance in HLH
- ◆ These impairments bring about a need for home nursing, therapies, home medical equipment, and close medical monitoring
- ◆ An understanding of the family's insurance coverage and financial constraints will be important in addressing these needs



- ◆ Lori-Urgent Care MD-will need to understand what level of impairment is baseline for this child- this will be vital for assessing the degree of illness in the ER
- ◆ Families will often discuss the acute illness in terms of impairments For example,they may say "he has less appetite and takes longer to eat"
- ◆ This understanding will be best gotten from the family



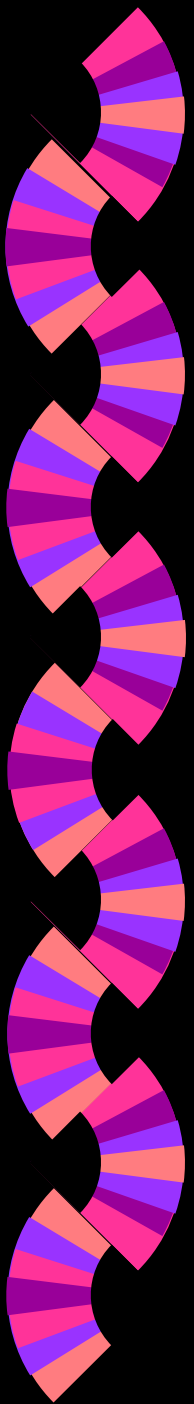
Disability Needs

- ◆ Andrea- will need to assess the need for interventions based on disabilities...in our example, these disabilities would include cognitive delay, inability to participate fully in school, social, and family activities due to functional limitations which may lead to emotional disturbances in family and individual relationships



Environmental Needs

- ◆ Andrea will need to understand that our example patient has needs for adequate transportation and accessibility and an living situation which takes into account the functional limitations of the patient (I.e. for a patient requiring O₂, a ranch house would be preferable)

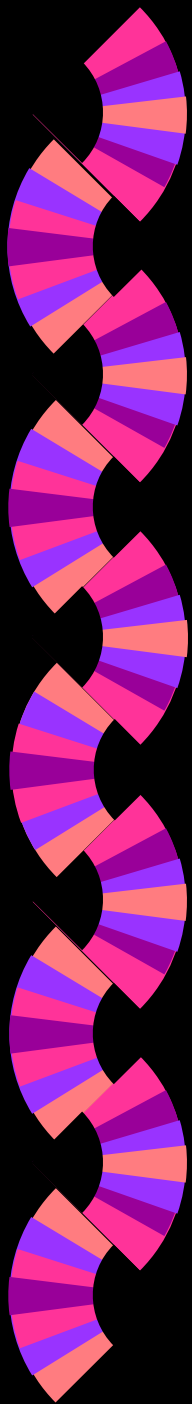


- ◆ Lori-will need to understand the need for transportation services and physical access barriers which should be addressed by the Urgent Care

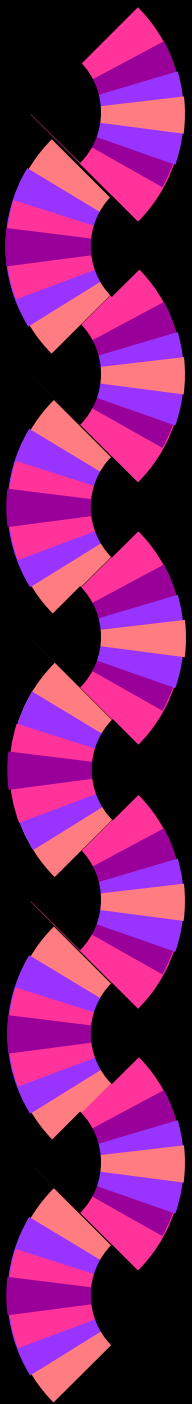


How to Accommodate These Needs

- ◆ As previously mentioned, there must be an understanding that these kids have different needs than other patients
- ◆ Each practitioner also must understand the availability of resources and programs in the state in which they practice because there are wide variations between states



- ◆ There must also be a realization made by the practitioner that these needs will change over time and the family needs good anticipatory guidance
- ◆ There should be every effort made to have the family participate in the decisions regarding how to meet these special needs
- ◆ The practitioner must also recognize that the family may have extra needs



- ◆ These include the needs for financial support, home medical supplies, respite care and emotional support



Physical Barriers to Accommodation

- ◆ The individual will need appropriate accessibility and transportation to attend medical appointments and other activities
- ◆ If he has too many appointments, he may have to choose between those and other activities
- ◆ The home and school must be set up in a way conducive to the function of the individual



Physical Barriers to Accommodation

- ◆ The **FAMILY** may also have time constraints and may have to choose between activities
- ◆ They may not have the physical stamina and/or health to provide on-going cares for the patient



Physical Barriers to Accommodation

- ◆ The physician will need to have an accessible office space
- ◆ The physician will have time constraints



Social Barriers to Accommodation

- ◆ The individual may not want to feel different than other children and may resist therapies-this may be especially true of adolescents



Social Barriers to Accommodation

- ◆ The family may have cultural and language barriers
- ◆ There may also be educational barriers which could impact the family's understanding of the condition
- ◆ The family may feel isolated



Social Barriers to Accommodation

- ◆ The MD will have their own cultural and other beliefs-this may impact communication with the family



Emotional Barriers to Accommodation

- ◆ The individual will be dealing with a disease process that impacts his/her social function which can impact emotional health
- ◆ There may also be feelings of grief and questions about why this happened to them
- ◆ There may also be feelings of guilt if they sense that family members have had to change their lifestyles to provide for them



Emotional Barriers to Accommodation

- ◆ The family may experience burnout after caring for the child for a long time
- ◆ There may also be feelings of guilt and even resentment because the entire family's life is impacted by the individual's needs-this may be especially true of other children in the family



Emotional Barriers to Accommodation

- ◆ The MD may also have feelings of burnout and subsequent guilt
- ◆ The MD can even experience resentment since increased medical needs of patient mean increased phone calls and increased time away from their own family



Financial Barriers to Accommodation

- ◆ The family will need to have insurance that will cover as much of the medical and therapy needs as possible
- ◆ There may be increased out of pocket expenses for items insurance doesn't cover
- ◆ The parents may not be able to work as much because of the need to take care of the child which further complicates finances



Financial Barriers to Accommodation

- ◆ The MD will also have financial constraints since they may not be reimbursed for a significant amount of time spent with special needs children
- ◆ This will impact the amount of children they are able to follow who have special needs



Important Points

- ◆ Must recognize needs beyond medical model of child and family
- ◆ Family should be included in all decision making
- ◆ There should be a coordination of care and integration of resources