



# Healing children.

## Protecting

# childhood.

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Healthcare Transition at Shriners Hospital

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Shriners Hospitals  
for Children®  
Love to the rescue.™

I have nothing to disclose.

# SHC Approach on Transition

- ♥ For patients to be comfortable and ready to manage their own healthcare and transition to adult care
- ♥ To build independence
- ♥ To identify goals and interests
- ♥ Start the process early
- ♥ Involve patients and parents in discussions
- ♥ Use a multidisciplinary approach



# Multidisciplinary Team

- ♥ Physician
- ♥ Nurse Practitioner
- ♥ Psychologist
- ♥ Physical Therapist
- ♥ Occupational Therapist
- ♥ Recreational Therapist
- ♥ Speech Therapist
- ♥ Nurse Care Manager
- ♥ Social Worker
- ♥ Dietitian



# Topics of Transition

- ♥ Social relationships
- ♥ Hobbies
- ♥ School transition and college planning
- ♥ Independent living
- ♥ Driving
- ♥ Medical management
- ♥ Locating in-network healthcare providers
- ♥ Employment
- ♥ Advocacy
- ♥ Community resources
- ♥ Insurance/Medicaid/Medicare
- ♥ SSI



# Preparing Patients and Families

- ♥ Discussion of interests and goals
- ♥ Education on available resources
- ♥ Organization and planning
- ♥ Toolkit
- ♥ Binder
- ♥ Phone apps (Health app, Walgreens, Mango Health)



# Resources

- ♥ The ARC
- ♥ Center for Independent Living
- ♥ DHS
  - Vocational Rehab
  - Home Services Program
  - PUNS (Prioritization for Urgency of Needs for Services)
- ♥ DSCC/CSHCN
- ♥ Client Assistance Program (CAP)
- ♥ Workshops



# Resources

- ♥ Adaptive Driving <https://www.aded.net>
- ♥ Center for Independent Living listing by state <http://www.ilru.org/>
- ♥ DO-IT (Disabilities, Opportunities, Internetworking, and Technology) at University of Washington <https://www.washington.edu/doit>
- ♥ Education Quest <https://www.educationquest.org>
- ♥ Got Transition <https://www.gottransition.org>
- ♥ Heath Resource Center at George Washington University <https://www.heath.gwu.edu/resources>
- ♥ NHCPAD (National Center on Health, Physical Activity, and Disability) <https://www.nchpad.org>
- ♥ Pacer Center <http://www.pacer.org>
- ♥ The ARC - <https://www.thearc.org/>
- ♥ UIC Specialized Care For Children - <https://dsccl.uic.edu/>
- ♥ US Paralympic Club Directory <https://www.teamusa.org/us-paralympics/find-a-club/club-search>





# Case Study 1

- ♥ 5 year old patient
  - ♥ New diagnosis of spinal cord injury
  - ♥ At time of initial rehab admission he is involved in healthcare discussions
  - ♥ Learning to direct care and participate in catheterization
  - ♥ Dependent on caregivers
  - ♥ Parents and patient met with school. Patient will have an IEP with assistance from an aide.
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- ♥ Now age 8
  - ♥ Independent in cathing. Continues to improve on independence with self-care skills
  - ♥ Increasing knowledge of disability
  - ♥ Able to answer questions and participate at appointments
  - ♥ Independent at school. No longer requiring an aide.
  - ♥ Has adaptive bicycle. Enjoys being outdoors with family and friends.



What are next steps for transition?

# Case Study 2

- ♥ Spinal cord injury at age 8
- ♥ Lives with grandparents
- ♥ Uninsured
- ♥ As a high school student she is managing healthcare needs on her own, however unable to identify needs.
- ♥ Inconsistent in care
- ♥ Starting to discuss transition goals and improve healthcare management

## Age 17

- ♥ Interested in driving
- ♥ Has a job
- ♥ On track to graduate high school. Future plans to attend college.
- ♥ Interested in having own apartment
- ♥ Some improvement in management of medical needs
- ♥ Discussion of voc rehab, CIL, CSHCN, adaptive driving
- ♥ By age 18 looking to have own apartment



What transition goals should we be discussing?

# Case Study 2 continued

## Age 19

- ♥ Living on own
- ♥ Employed
- ♥ High school graduate
- ♥ Looking into resources for adaptive driving
- ♥ Has a primary care physician. Discussing plan for adult care providers.
- ♥ Increased knowledge of diagnosis and healthcare needs
- ♥ Saving money with goal to attend college
- ♥ At follow-up appointments discuss health coverage, assistive technology, adaptive driving, college planning, vocational rehab

## Age 20

- ♥ Driving
- ♥ Employed and interested in college
- ♥ Able to identify a plan for adult care and needs to contact adult care providers.

