Adult Down Syndrome Clinic

Faculty

Cindy Blackburn, RN, MSN
Clinical Care Coordinator
Adult Down Syndrome Clinic
University of Alabama at Birmingham

ADSC History

- Started in 2007
- Started by PADS
  - Parent Advocates Down Syndrome

ADSC History

- Obstacles to starting and maintaining the clinic
  - Billing and reimbursement issues
  - Funding
  - Marketing vs. scheduling

ADSC Today

- Using a multidisciplinary team of care providers, individuals age 12 and over, with Down Syndrome, are evaluated by:
  - Medical director / geneticist
  - Family practitioner
  - Psychologist

ADSC Today

  - Audiologist
  - Occupational therapist
  - Speech therapist
  - Physical therapist
  - Nutritionist

Dr. Eddy Lose, Medical Director

- Medical care needs
- Role in transition
- Liaison between UAB and ADSC

Medical Care Needs

- Medical advice prior to clinic visit
- Verify adherence of recommendations
  - Lab results, other test results
- Provide the “big picture” over the lifespan of an individual having a genetic variation

Medical Care Needs

- Brings latest research into the picture so that patients and families have accurate goals and expectations

Role in Transition

- Knowledge of pediatric needs and normal expectations for our younger patients
- Access to and knowledge of providers within the Children’s Health System

Liaison Between UAB and the Clinic

- Allows patients to have access to more coordinated care
- Allows us to provide appropriate referrals to specialists
- Provides access to electronic medical records between our clinic and the specialists to whom we refer

Liaison Between UAB and the Clinic

- Provides opportunities for research protocols and clinical trials
  - Educates medical students and residents
- Gives the clinic access to the many resources at UAB
  - Sparks Clinic

Liaison Between UAB and the Clinic

- Providers at Sparks
  - PT, OT, Speech, Audiology, Nutrition
- Education for providers
- Health care collaboration

Dr. Vicki Moore, MD Family Practitioner

- Medical management
- Emotional support

Medical Management

- Identifies and initiates treatment of abnormal results
  - Including labs and other diagnostic tests

Common Medical Problems

- Accelerated aging process
- Obesity
- Congenital heart failure
- Celiac disease
- Thyroid dysfunction

Common Medical Problems

- Skeletal problems
- Skin disorders
- Sleep apnea

Medical Management

- Identifies medical needs from patient's history and records
  - Differentiates psychosocial needs from physiologic needs
    - Mania / depression vs. thyroid
    - Sleep issues / depression vs. dementia

Medical Management

- Behavioral programs desperately needed won't work if underlying medical condition is untreated
- Referrals to specialists
- Referrals for procedures
  - Sleep studies, EEG, etc.

Medical Management

- Provides information to families about what medical findings are normal or abnormal for individuals with DS
- Prescriptions
- Familiar with proper dosage of medications for depression, behavioral problems

Medical Management

- Able to initiate other medications as needed which are then followed by patient's PCP

Emotional Support

- Uniquely able to comfort patients and families because is a parent of an individual with DS
- Provides genuine empathy to struggling caregivers
  - All of them struggle in some way

Emotional Support

- Opens door for parents / caregivers to express fears and questions they have about their loved one
- Encourages tough love, which is frequently needed

Dr. Christine Le Psychologist

- Psychological consultation

Psychological Consultation

- Mental health challenges
  - Depression
    - Often two years after finishing high school
  - Anxiety
    - Panic attacks, separation anxiety

Psychological Consultation

- Declining skills
  - Speech, self-care
- Aggression
  - Hitting, lashing out, throwing / punching objects
- Speech
  - Not talking, not talking clearly

Psychological Consultation

- School
  - IEP: goals, safety
- Work
  - Developing skills
- Family
  - Isolation

Psychological Consultation

- Placement
  - Exceptional Foundation, UCP, Rainbow Omega, Glenwood, Workshops Unlimited, Mitchell's Place, ARC of Shelby County, ARC of Jefferson County, Hoover Recreational Center

Psychological Consultation

- Dementia
  - Assess other possible causes for decline
- Physical health
  - Weight gain, restricting soda intake

Psychological Consultation

- Psychosis
  - Seeing or hearing things
- Asthma
  - Dual diagnosis
- Death and dying
  - Grief counseling / preparing family

Psychological Consultation

- Communication challenges
  - Nonverbal
  - Self-talk
  - IQ

Psychological Consultation

- Communication challenges tools
  - Visual schedule
  - Prompting
  - PECS
  - Technological applications
    - i.e. Grace

Psychological Consultation

- Medical challenges
  - Dementia
  - Accelerated aging process
- Tools: Grief counseling for family, family therapy, support for placement

Cindy Blackburn, RN, MSN Clinical Care Coordinator

- Medical coordinator
  - Initial contact with patients and families
  - Triage patient visits
    - Initial and follow-up

Cindy Blackburn, RN, MSN Clinical Care Coordinator

- Schedule patient / coordinate with Sparks providers
- Conduct clinic every Monday morning
- Coordinate plan of care outlined at clinic visit

Cindy Blackburn, RN, MSN Clinical Care Coordinator

- Collaborates with PCP, specialists, hospitals, community resources, and insurance companies

Clinical Coordination

- Communication coordination
  - With PCP or referring physician
  - Receiving medical records / lab results / interpret results

Clinical Coordination

- Referral coordination
  - Medical subspecialists
  - Day program
  - Residential program
  - Work / volunteer opportunities

Clinical Coordination

- Research coordination
  - Current study comparing prevalence of diabetes compared to general population

Clinical Coordination

- Community liaison
  - Educate general public, healthcare providers, and families regarding the ADSC

ADSC Transition Needs

- Developing career goals
- Defining and developing work skills
- Community placement

ADSC Transition Tools

- Alabama Planning for Transition Handbook
  - The ARC of Shelby County and Susan Ellis
- Steps in Transition
  - From The Down Syndrome Transition Handbook by Jo Ann Simons, M.S.W.

ADSC Transition Tools

- Various community resources
  - Exceptional Foundation
  - Hoover Recreation Center
  - Mitchell's Place
  - UCP
  - Others

Transition Process

- Hand off care
  - Multiple possible players
    - School: IEP
    - Social worker: State, case worker / DHR
    - Caregivers: their own research and motivation

Transition Process

- PCP
- Pediatric DS Clinic (PDSC)

Transition Process

- Process is gradual if we have luxury of seeing in teen years
- Presently PDSC sees gaps between age 3-5 and over age 12
  - Age of transition begins when we see each patient, which is age 12 and older, but most frequently over age 21

Transition Process

- We help get the pieces in place
  - i.e. communication, transportation, vocational rehab, community resources, Medicaid waiver, etc.

Transition Process

- We encourage participation of the teen in the process, and this looks like encouraging the caregiver to ask the teen questions
  - Person-centered plan, making connections in community

Transition Process

- Requires:
  - Caregivers’ role explanation
  - Assertiveness by caregivers and / or teen

Transition Process

- Transition checklist
  - Alabama Planning for Transition Workbook, Steps in Transition
    - From The Down Syndrome Transition Handbook by Jo Ann Simons, MSW

Transition Process

- Information sharing
  - A copy of the clinic visit summary is sent to the patient’s PCP and / referring physician

Transition Process

- Obstacles to transition
  - Lack of funding
    - Could merge with PDSC
    - Market / fund more clinic hours as needed as result of marketing
    - Down Syndrome Center

Transition Process

- School system
  - IEP not individualized
- Starting too late
  - Start in elementary school

Transition Process

- Ideas for transition
  - Peer helper gets “double” service hours for helping an atypical student obtain their own service hours
  - Take transition handbook list to IEP in order to implement realistic goals

Transition Process

- Most important community partners
  - Social workers
  - ARC
  - Primary care physicians
  - Day programs

Transition Process

- Keys to success
  - Start early
  - Motivated caregivers and individuals
  - Pay attention to individual’s gifts, desires, connections
  - Advocates keep the big picture in mind, looking forward

Changing Lives

- Presenting complaint: psychosis (female in 20’s)
  - Patient’s physician prescribed antipsychotic medicine
    - Side effects: Obesity, diabetes, sedation (risk of increased isolation from family), cardiac problems, movement

Changing Lives

- Psychosis
  - Antipsychotic medicine vs. normal self-talk
    - Amazing visual memory, act out scenes from her favorite TV show
    - Zach and Cody party

Changing Lives

- Family could understand her world, join her in it, common point of sharing

Changing Lives

- Presenting complaint: Speech (male, age 18) poor articulation, couldn’t be understood by anyone outside of family, spoke two words every three days
  - School was always doing speech therapy to improve articulation

Changing Lives

- Speech therapy vs. picture communication using iPad and iPod Touch
  - Immediately began communicating
    - Changed IEP goals
      - Will be able to communicate in day program in three years

Future Goals of ADSC

- Increase number of patients seen
- Increase number of younger teens seen
- Increase awareness of ADSC in community
- Add more enrichment, educational, and social activities

L's Story

- 16-year-old girl
- Referred by pediatrician for behavior problems
  - Throwing tantrums
- Has hyper-coagulable disease, ODD
- Weighs almost 300 pounds

L's Story

- Was uncooperative in getting ready for school
  - Came to clinic and threw a tantrum while in clinic
  - Gave recommendations for adding medication and behavior plan, asking school for aide to help before school

L's Story

- After clinic visit Cindy contacted:
  - Insurance company
  - CRS
  - County Mental Health Center / Case Manager
  - Respite care
  - Alabama Parent Education Center

L's Story

- After clinic visit Mom contacted:
  - Social Security
  - Medicaid
  - Psychiatrist
- Cindy contacted Mom every week or two via phone / email

L’s Story

- ADSC doctors tweaked meds and behavior plan multiple times
- Patient regressed to the point she would not go to school or even get out of bed
- Mom came for clinic visit without patient

L’s Story

- ADSC team recommended hospitalization to try medication changes and check possible medical causes of behavior problems
- Patient was admitted to UAB Adolescent Psychiatric Unit
- Adjusted behavior medications

L’s Story

- Conducted tests (ultrasounds) which ruled out physiological problems
- ADSC team had close contact with physicians caring for patient in hospital

L’s Story

- ADSC team played a key role in allowing patient to remain an inpatient for time sufficient to address her needs
- Patient was discharged from hospital and mom came to clinic again without patient

L’s Story

- ADSC team collaborated with Mom about how to follow through with goals made during hospitalization
- ADSC team made recommendations to patient’s IEP team to receive assistance every morning from aide to facilitate patient to get ready and ride bus to school

L’s Story

- ADSC team recommended Mom take a strong representative with her to IEP meeting
- Cindy and patient’s mom will continue to pursue patients’ case manager, CRS, and multi-needs council for services