Clinical Safety & Effectiveness
Cohort # 22
Team 4
TRANSITION CARE FOR ADOLESCENTS WITH CHRONIC NEEDS at the Pediatric CCC

Educating for Quality Improvement & Patient Safety
The Team

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What We Are Trying to Accomplish?

AIM STATEMENT

To increase percentage of first appointments in adult General Medicine clinic from <1% to 50% of our patients currently aged 18 years to 22 years old, by May 1, 2018.
Background

- Pediatric Comprehensive Care Clinic (Pediatric CCC)
  - Primary care pediatrics office
  - multi-organ involvement, technology dependence
  - Current roster 415 total patients
  - Patients will “graduate” out of pediatric care at age 18 or 21 years.
  - 27 Patients currently aged 18-22 years old
  - 25 Patients currently aged 16-17 years old
  - High rates of healthcare utilization (medications, clinic visits, hospitalization and ER visits, specialists)
Background

- No established consensus on the transition process for a CCC patient going to adult medicine
- Lack of provider knowledge on transition process
- Lack of family knowledge on transition process
- Fear of the unknown
Background

• National Standards
  – “Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to *maximize lifelong functioning and well-being for all youth*, including those who have special health care needs and those who do not.”
PATIENT 1

SD, 18 year old male patient presenting with:

- Lennox Gastaut syndrome (intractable epilepsy)
- severe developmental delay
- Dysphagia
- gastrostomy tube feeding
- cared for by adoptive mom, educated on healthcare system with other medically fragile children she has adopted or cared for in recent years.
- Over the last 2-3 years he has had significant decline in his function due to worsening seizure disorder.
Background/case for change

Since turning 18, SD’s medical records documents:

- recurrent pneumonias, at least 3 episodes required visits to our clinic resulting in antibiotic therapy.
- loss of insurance based on age and complexity of health status.
- Most recently admitted to the hospital for recurrent pneumonia and aspiration that required a 2-week hospital stay.
- No established care with adult specialty providers; does not yet have a new PCP or adult medical home.
- REAL communication barrier between admission to adult medicine and outpatient follow up in pediatric medicine.
Background/Case for Change

PATIENT 2

AO, 20 year old male patient presenting with:

- cerebral palsy, gastrostomy feeding
- admitted to the hospital on the adult medicine service for feeding intolerance with emesis and black stools.
- concern for a GI bleed at that time; discharged after a 1-week stay with recommendation to follow up in adult GI clinic.
- discharged home on an anticoagulant for a catheter-associated DVT
- Family unclear on clinical workup, course of treatment for this medication which is why they wanted ultrasound to ensure no clot present despite absence of DVT symptomology.
Background/Case for Change

PATIENT 2 (continued)

- Family also was unaware of the workup and concern for an enlarged prostate found on an abdominal CT. He has never had clinical symptoms related to this finding.
- Gaps identified: lack of knowledge on primarily “adult” issues during his hospitalization
- Lack of clear instructions on follow up care and medication usage
Texas Data

• 2014 data:
  – Total population: 26 million in Texas census
  – 23-32% in Bexar County aged 22 and younger
  – 13.4% of Texas children with special health care needs

Reference: Maternal Child Health Title V 2015 Needs assessment
Baseline data

• Baseline = 1
  – 1 patient transitioned prior to start of this project
  – 1 patient passed in process of this project (number not included in transition project)
DIFFICULTY

SETTING UP ADULT PCP APPOINTMENT

POLICY

When is the best age to transition?

No info packet

No current policy

Which providers will see them?

Age of DC from specialists and PCP

PARENTAL FEARS

No ambulance transports to appointments.

Who will take care of DME needs?

Where do patients get admitted?

DIFFICULTY

INSURANCE

Who takes both Star KIDS and Star +PLUS

Not all providers are credentialed for both plans.

TRANSPORTATION DIFFICULTIES

Call center doesn’t differentiate between clinics

Distance from home to new PCP

APPOINTMENTS

Who do they call?

Transportation difficulties

DC note can be a barrier

No patient portal for parents

How do providers get in contact

COMMUNICATION

No current policy
Goal Transition Process Flow Map

1. Identify CCC patients 18-22
2. Bring patients into CCC for “transition visit”
3. Provide resources and checklist for families to do prior to next clinic visit
4. Refer to adult specialists (e.g. pulm, neuro, GI) using ACCESSS plus
5. Send Secure Health Message in Sunrise to IM provider (Dr. Montemayor or Dr. Gilbreath)
6. Has family completed tasks/check list?
   - Yes: Follow up with CCC for final “discharge” visit (discharge note generated)
   - No: Pedi RN/SW confirms family aware of new PCP and ensures no further needs
7. General Medicine Clinic staff notifies family of first appointment
Data Measurement

How will we know that change is an improvement?

*Process measures*
- Number of readiness surveys completed
- Number of Educational packets given
- Number of Transition Clinic Visit completed

*Outcome measure*
- Number of first appointment with Gen Med Clinic
Transition Readiness Assessment for Parents

Transition Importance and Confidence
On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for/changes to an adult doctor before age 21?

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How confident do you feel about your ability to prepare for/changes to an adult doctor?

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YOUR CHILD’S HEALTH  Please check the box that applies to you right now. Yes, I know this I need to learn

I understand his/her medical needs.  □  □
I can explain his/her medical needs to others.  □  □
I know his/her symptoms including ones that he/she quickly needs to see a doctor.  □  □
I know what to do in case he/she has a medical emergency.  □  □
I know his/her medicines, what they are for, and when he/she needs to take them.  □  □
My child knows his/her allergies to medicines and medicines he/she should not take.  □  □
I carry important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).  □  □
I understand how health care privacy changes at age 18.  □  □
I can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.  □  □

USING HEALTH CARE

I know or can find his/her doctor’s phone number.  □  □
Before my child’s visit, I think about questions to ask.  □  □
My child has a way to get to his/her doctor’s office.  □  □
I know my child needs to show up 15 minutes before the visit to check in.  □  □
I know where to go to get medical care for my child when the doctor’s office is closed.  □  □
I have a file at home for his/her medical information.  □  □
I have a copy of his/her current plan of care.  □  □
I know how to get referrals to other providers.  □  □
I know where his/her pharmacy is and how to fill his/her medicines.  □  □
I know where to get blood work or x-rays if his/her doctor orders them.  □  □
I have a plan to keep his/her health insurance after ages 18 or older.  □  □
My child and I have discussed his/her ability to make his/her own health care decisions at age 18.  □  □
My child and I have discussed a plan for supported decision-making, if needed.  □  □
Transition from Childhood to Adulthood

What Goes Into Transition Planning?
A transition plan isn’t a single plan. It’s a set of plans that cover all the areas of transition: plans about transitioning out of school, transitioning doctors, applying for services, or looking toward a career. It helps if you and your child have a clear vision of what your child wants for their future.

Per the STAR Kids Managed Care Contract, all STAR Kids members begin transition services when they are 15 years of age and periodically meet with a transition specialist to plan their transition to adulthood.
(Source: https://hhs.texas.gov/book/export/html/80616 Section 1110)

Knowledge of Health Care Needs
For patients who are able to understand and process the information, it is time to begin explaining the patients’ health care needs, including the disease process and progression specific to the patient’s active diagnosis. It is recommended the parent or legal representative be able to know at what level of understanding the patient has and be able to provide.

Educate the patient on health and wellness to assist the member with self-management.

Alternative caregiver identified and a written back-up plan in place in the event the primary caregiver is unable to care for the member.

Promote independence and social skills by discussing available programs, such as camps.

Guardianship and Power of Attorney
Guardianship provides for the person’s care and management of his or her money while preserving the person’s independence and right to make decisions affecting his or her life. Guardianship removes certain rights and privileges from an incapacitated person. An incapacitated person can be a minor or an adult. At times, because guardianship takes away a person’s rights, the Texas courts will look for less restrictive before granting guardianship.

Power of Attorney (POA)—the document is executed by an adult who has the capacity authorizing another person to act on his or her behalf. The power can be either specific or general.
Supported decision-making—empowers people with a disability who want supported decision-making

There are several options to assist you with legal documents to protect your child’s rights:
Catholic Charities; The Arc of Texas; Texas Guardianship Reform and Supported Decision Making.
*Please note that this will take time to happen, start the process early so your child is not at risk*

Education
If there is a transition plan (school) in place for the member with an Individualized Education Program (IEP), if no transition plan is in place, urge the member to reach out to the school to have a transition plan developed. If desired by the member or the member’s LAR, coordinate with the member’s school and IEP to ensure consistency of goals and include any 504 plans, if applicable.
Your child may decide to continue attending public school until age 21.
Explore opportunities for higher education, such as college or technical school.

Employment/Training
What age will the member no longer receive educational services and when should career planning, such as: Coordination with the Texas Workforce Commission to help identify future employment and employment training opportunities

PDN and MDCP Current Eligible Children
This topic is only for individuals who receive Private Duty Nursing (PDN) and/or Medically Dependent Children Program (MDCP) services.
Children’s services, such as PDN and MDCP, are not available to adults. For individuals receiving PDN, the STAR-PLUS Home and Community Based Services (HCBS) program or an intellectual developmental disability (IDD) waiver will need to cover medically necessary nursing services that are not intermittent or part-time at age 21, which may not be the same level of nursing they receive through STAR Kids. To be eligible for the STAR-PLUS HCBS program or an IDD waiver, the individual’s health and safety must be ensured under the cost limit for the waiver program.

Career planning
DARS (Department of Assistive and Rehabilitative Services); Easter Seals; Goodwill Industries and Texas Workforce Commission

Social service agencies (e.g., area agencies on aging, residential support agencies, independent living centers, supported employment agencies, etc.);

Community resources
ARC-SA; AACOG; Alamo Local Authority; Texas Department of Assistive and Rehabilitative Services

Insurance changes
Star KIDS coverage for eligible children continues until the last day of their birth month of their 21st birthday. (For example, if your child’s birthday is November 10th, his/her coverage would continue until November 31st. Beginning December 1st, the child’s coverage should change to Star-PLUS).

Social Security
Verify eligibility for Supplemental Security Income (SSI) with patient, parent or legal guardian the month of the member’s 18th birthday. If the member does not have SSI, on behalf of the patient contact the Social Security Administration.
The age-18 redetermination will review your eligibility for continued SSI benefits based on disability rules for adults, including nonmedical eligibility rules.

Changes to waivers
Waivers such as MDCP and CLASS are different for older children and/or adults. Please be sure to place your child’s name on as many wantlists as they qualify for to help with their transition.
Independent living
Data Measurement

• Readiness Survey
  – Weekly phone calls to patients or during clinic visit

• Transition clinic visit
  – Documentation in CCC visit note of “Transition Planning” (ICD10 Code: Z71.89 – Counseling for transition from pediatric to adult care provider)

• Providing Educational packets at clinic visits

• Patient registry tracking each task completed
To increase percentage of first appointments in adult General Medicine clinic from <1% to 50% of our patients currently aged 18 years to 22 years old, by May 1, 2018.

**AIM**

**PRIMARY DRIVERS**

- Create a policy
  - Meet with CCC Drs (RS1)
  - Create a Registry
  - Establish process with CCC team (RS1)

- Inform Providers
  - Meet with Gen Med DRs
  - SHM Gen Med providers to set up 1st appointment

- Communicate with family
  - Call families for clinic visit and educate on policy (RS2)
  - Families access Gen Med clinic to verify appointment

- Verify insurance gaps
  - Families educated to apply for waivers and verify insurance
  - Utilize insurance provided transition coordinators (RS2)

**INTERVENTION**

**MEASURE/DATES**

- CCC providers/Jan
- SW/Jan
- Wu and pedi SW/Feb 9
- Registry CCC providers/May
- Readiness survey SW – April 1
- All providers/May
- Registry CCC providers and SW
Interventions

• Created a registry to track our patients
• Surveyed families and patients to identify gaps of knowledge
• Provided education on transition process with a clinic visit
• Created “Transition Checklist and Information” packet for the family
• Met and identified adult providers
Results

Resource Packet and Checklist Given
(g-chart for "rare" events)

Days Between Events

UCL=32.61
CL=2.55
LCL=0

Date of Birth
Results
Results

CCC Transition Visit
(g-chart for "rare" events)

Days Between Events vs. Date of Birth

- UCL = 34.21
- CL = 2.71
- LCL = 0
Results

Transitional to PCP
(g-chart for "rare" events)

Date of Birth

Days Between Events

UCL=626.7
CL=64.8
LCL=0
Return on Investment

• Without access to primary care, our patients will frequent the ER and risk hospitalization.

• Cost of an ER visit: $515
  – Respiratory
  – GI complications
  – Seizures

• Cost of hospitalization: $1600/day

If we meet our AIM of transitioning 50% of our adult patients, we will save the health system approximately $6,695 in the first year alone.
What’s Next

- Continue our registry and updating patients as they turn 18
- Outreach to identify more adult providers comfortable with this population
- Start educating at an earlier age (Ideally begin at age 14)
- Create criteria for “urgent care” or emergency care
- Educate other pediatric providers on appropriate transition processes
Conclusions

Lessons Learned
- Identified patient needs
- Identified gaps in patient knowledge
- Not a linear process
- Learned multiple steps and time involved

Future Benefits
- Lessen fear of providers in adult and pediatric providers
- Improve access to care
- Streamline cost and overutilization of resources
Thank you!

Educating for Quality Improvement & Patient Safety