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DNP Project Proposal: Toolkit for Transition of Young Adults with Autism Spectrum Disorder (YA-ASD) to Primary Care

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**DNP Project Proposal: Toolkit for Transition of Young Adults with Autism Spectrum
Disorder (YA-ASD) to Primary Care**

D B, BSN, RN, DNP Student/Project Lead

A DNP project submitted in partial fulfillment of the requirements for the degree of Doctor of
Nursing Practice

Sacred Heart University Davis & Henley College of Nursing

Dr. M, DNSc, APRN, FNP-BC, EBP-C

+

Approval Page

This is to certify that the DNP Project Final Report by DB, BSN, RN has been approved by the

DNP Project Team on April 10, 2024

for the Doctor of Nursing Practice degree

DNP Project Faculty Advisor: Dr. M, DNSc, APRN, FNP-BC, EBP-C

Project Site Clinical Mentor

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Abstract

Significance and Background: Young adults (YA) with autism spectrum disorder (ASD) transitioning from pediatric to adult care may have more difficulty finding a primary care clinician trained to address their unique medical and mental health needs. Transition resources need to be developed to help these patients and their caregivers while they are still being cared for by their pediatrician.

Purpose: To develop an ASD resource toolkit with resources designed to help YA-ASD and their caregivers with the transition from pediatric care to adult primary care.

Methods: The Model for Healthcare Improvement guided this evidence-based quality improvement project. An evidence review informed the resources that were included in the toolkit. Training on the toolkit and the process for accessing it was delivered by video to all clinicians and nurses in the pediatric practice within a large children's health system. Access to the toolkit was offered to applicable caregivers of YA-ASD during well-child visits.

Results: During the 18-week project, only three caregivers had YA-ASD transitioning. Only one initial survey was accessed but none were filled out. No ASD resource toolkits were distributed.

Conclusion: The next steps must focus on finding the caregivers of YA-ASD transitioning to adult primary care and effective strategies for getting the ASD resource toolkit to caregivers of YA-ASD.

Keywords: *pediatrics, young adults with autism spectrum disorder (YA-ASD), transitions, resources, toolkit, primary care*

Phase 1: Problem Identification and Evidence Review

Description of the Problem

It is estimated that 1 in 44 children in the United States is diagnosed with autism spectrum disorder (ASD) (Christensen et al., 2018). Prevalence rates have increased over time resulting in more adolescent / young adults with autism spectrum disorder (YA-ASD) transitioning to adult primary care (Christensen et al., 2018). It is critical for this patient population to receive uninterrupted quality care throughout their life, because of the frequent range of physical and mental conditions that often accompany autism like gastrointestinal disorders, seizure disorders, attention deficit/hyperactivity disorder, and obsessive-compulsive disorder (Ames et al., 2021; Jones et al, 2016). Patients with these disabilities do not access preventive care as much as their peers without disabilities and utilize the emergency room (ER) for regular healthcare (Verlenden et al., 2021). Consequently, when ER services are used more than primary care it causes an increase in healthcare costs.

Adolescent / YA-ASD transition from a pediatric health care clinician to an adult primary care clinician around the time that typical peers make this transition. Adolescent /YA-ASD may have more difficulty finding an adult primary care clinician trained to address their unique medical and mental health needs (Harris et al., 2021). The lack of a coordinated transition plan may lead to these adolescent /YA-ASD continuing to receive extended care from their pediatric clinicians or have adult primary care clinicians who lack the training to address their health care needs. Efforts are necessary to ensure that the health care transition is seamless, high quality, and tailored to the individual needs of adolescent /YA-ASD and their caregivers.

The local pediatric practice for this project has expressed the need to improve the transition of adolescent /YA-ASD to adult primary care. The current process for transition is

done individually and the opportunity exists to improve this process. The local problem is that the pediatrician office does not have a resource list of adult primary care clinicians that will accept YA-ASD to give to caregivers. The practice understands the need for improvement because they know it is important to direct patients to available adult primary care clinicians who are willing to take patients with ASD. The practice also understands that there are services available for this population that need to be communicated.

Focused Search Question

The focused search question is, in caregivers of adolescents /YA-ASD in the primary care setting (P) does a transitional resource toolkit (I) compared to usual care (C) affect YA-ASD transition to adult primary care (O)? This question will be used to find evidence on resources, tools, and supports to aid the caregiver's planning the transition from pediatric to adult primary care in adolescents /YA-ASD.

Methods for Gathering Evidence, Search Results and Tools used for Appraisal

The following databases were searched; CINAHL, MEDLINE, Nursing & Allied Health Premium, and TRIP. The keywords searched were ASD or autism*, autism spectrum disorder, transition* resource*, primary care or primary health care, "adolescent / young adult" or emerging adult, health care or healthcare transition resource, transition resources, primary care transition. The keywords transitions and ASD narrowed the initial search. Limits for all searches were English language, adolescents (age 13-18), adults (age 18 and over), and published between 2012-2022. Appendix A, Tables A1 through A3 display the search results by database.

The final yield from each database search was 22 articles (CINAHL), 24 articles (MEDLINE), and nine articles (Nursing & Allied Health Premium). A search in TRIP pro using the PICO question function yielded three systematic reviews on adolescent / YA-ASD transition

into adult services with special health needs. The CDC on Autism was contacted for information on the transition to primary care in adolescent/YA-ASD, and this yielded four articles and three websites addressing youth with disabilities transitioning into adult healthcare. There were 62 articles collected and reviewed/skimmed for relevance of the project and level of evidence (LOE). Since the LOE was low due to adolescent /YA-ASD transitioning to primary care being a new phenomenon, articles selected for critical appraisal had a primary focus on improvements for transitioning care from pediatric to adult primary care for adolescent /YA-ASD (n=7 articles).

Evidence Appraisal Summary, Synthesis, and Recommendations

Evidence Appraisal Summary

The seven articles that made the final evaluation underwent rapid critical appraisal (RCA) using Melnyk & Fineout-Overholt's (2019) tools. The individual RCAs for each article are found in Appendix B. Pertinent information from each article was abstracted and entered in an evidence summary table found in Appendix B.

Evidence Synthesis

The LOE synthesis table appears in Appendix C. Transitioning adolescent / YA-ASD is a newer phenomenon, so the overall body of evidence is at a lower level. The highest LOE is IV, a systematic review of experimental and non-experimental studies, and most of the articles in this evidence review have a LOE VI.

Appendix D displays Table Variables of Interest: PICO Question. All seven articles described the problem and identified barriers encountered by adolescent / YA-ASD transitioning to adult primary care. Across the seven articles, 10 improvements were found to facilitate the transition from pediatric to adult primary care. The systematic review gave recommendations for improvements for adolescent / YA-ASD of the articles had a LOE IV, qualitative single study or

meta-synthesis. The LOE IV articles gave other improvements this can be seen in the synthesis table (Appendix D). One was a 25-year longitudinal cohort study at LOE V. Finally, the last study was a quality improvement (QI) project at LOE VIII, which had a new resource, creating a template in the electronic medical record (EMR) described in the synthesis table (Harris et al., 2021) (Appendix D).

Recommendation

In the current evidence searched, appraised, and synthesized (see Appendices B, C, and D), the recommendation is to have a notebook of resources and an adult primary care clinician list for caregivers of adolescent / YA-ASD (Ames et al., 2022; Kuhlthau et al., 2015; Verlenden, et al., Voorheis et al., 2020; Harris et al., 2021). Additional recommendations that are not included in this scope of the project are information sessions for parents and youth, care coordination, adult clinician training, and transition specific appointments (Ames et al., 2022; Jones et al., 2016; Kuhlthau et al., 2015; Verlenden et al., 2021; Voorheis et al., 2020; Harris et al., 2021).

Project Plan

The project team, described later in the project plan, met to review the evidenced based recommendations. The team collaboratively decided to develop a toolkit instead of a notebook to distribute resources to caregivers. Toolkits can help with implementing evidence-based knowledge and treatments into clinical practice (Thoele et al., 2020). Toolkits have information accessible all in one location. Universal precautions for health literacy were implemented in the toolkit development for the ease of accessibility, improved comprehension and to strengthen health literacy (Brega et al., 2015).

Project Goals

1. To develop an ASD transition resource toolkit for English speaking caregivers of adolescent / YA-ASD ages 15-21 and distribute during well visits in a pediatric primary care office.
2. To train clinicians and registered nurses (RNs) on the toolkit and process for caregivers of adolescents/YA-ASD to access the toolkit.
3. To obtain feedback on the toolkit from caregivers of adolescents/YA-ASD.

Framework

The Model for Improvement guided this evidence-based quality improvement (EBQI) project (Institute for Healthcare Improvement, n.d.; Langley et al., 2009). This model was chosen because of the Plan, Do, Study, Act (PDSA) method which is essential to process improvement. Having an essential understanding of EBQI and EBP will impact positive outcomes in healthcare (Milner et al., 2024). PDSA cycles for this project are outlined in Appendix E.

Context: Description of the Setting

The term ‘project setting’ is used to describe the setting for this manuscript. The project setting is a suburban free standing primary care pediatric office. The practice is comprised of four physicians, two nurse practitioners, 13 registered nurses (RN), one licensed practical nurse (LPN), one business manager and six patient service representatives. The office has 7800 active patients and sees approximately 1700-1800 visits per month. The project setting is a part of a large urban academic east coast health system with a level one trauma center. The health system has inpatient, outpatient, research, rehabilitation facilities and alliances with 15 community hospitals.

Description of Participants

The project participants are providers, nurses and caregivers of YA-ASD child ages 15-21 with an ASD diagnosis documented in Epic. They are being seen for a primary care well visit during the project's 18-week time frame. The project setting currently has 63 children aged 12-18 years with ASD. The number of adolescents / YA-ASD who transitioned in 2021 was two. There are four additional ASD patients who turned 18 in 2021 that have extended their care to age 21. The target group will be caregivers of adolescents 15 years of age or older with ASD. Age 12 is the standard age to introduce ASD resources and the idea of transitioning to adult primary care in the future, starting in early adolescence is acceptable for transition guidance due to the variable communication with caregivers (Harris et al., 2021). The importance of early introduction is so the caregiver and patients with ASD can start preparing for transitions. For this project, the practice has decided that the induction age is 15. Previously at the practice, a task list was handed out a year before the patient turned 18. There was not an updated clinician list.

Project Team and Roles

Table 1 displays the project team members and their roles.

Table 1.

Project Team Members and Their Roles

| Team Member | Role |
|-------------|--|
| DB RN, BSN | DNP student, project lead |
| Dr. M | DNP Faculty Project Advisor, evidence-based practice, and quality improvement expert |
| Dr. D. | Project Site Clinical Mentor |

Key Stakeholders, Staff, and Buy-in

Table 2 displays the key stakeholders and strategies to gain their buy-in.

Table 2

Key Stakeholder and Buy-in Strategies

| Stakeholder | Buy-in Strategy |
|---|---|
| Caregivers of YA-ASD* | <ul style="list-style-type: none"> • Transitioning their child to adulthood takes extra steps • Empower the caregivers with critical information that is difficult to find for the public through an easy-to-use toolkit |
| Pediatricians, nurse practitioners, nursing staff | <ul style="list-style-type: none"> • Educate about this problem and project. Specifically, the ASD resource toolkit is intended to help caregivers of adolescents/ YA-ASD with their transition to adult primary care. • To utilize the snack and learn method with staff and listen to their concerns to help overcome barriers. • Develop a script for clinicians so the information will be consistent for each caregiver. • Clinicians will use a script on a laminated flyer and hand out paper flyers. • Provide a training video on how to discuss the project and the process about handing out flyers |

*The term caregiver refers to parent, guardian, or caregiver throughout this project

Description of Practice Change

This practice change aims to improve the process for caregivers of adolescent/ YA-ASD who are transitioning to adult primary care by providing a toolkit with a clinician list and community resources. The ASD resource toolkit will be given to caregivers of adolescents/YA-ASD during a clinic visit. Evaluation of the ASD resource toolkit will be done by asking caregivers of adolescent/YA-ASD for feedback. The specifics of the practice change and the implementation plan are fully described in the next several sections.

Goal #1 Development of the ASD Transition Resource Toolkit

Pre-implementation Plan

Goal # 1, PDSA cycle, develop a toolkit with a current clinician list and community resources. The description of the toolkit is found later in plan under Pre-implementation Creation of Toolkit section.

Implementation Plan

The project team created an ASD transition resource toolkit based on a review of the literature and physician/ clinician feedback see Appendix F. The project team is seeking caregivers of YA-ASD to provide their feedback on the helpfulness of the ASD resource toolkit so that it can be further refined in a meaningful way. Obtaining the caregiver feedback is addressed in goal #3.

Goal #2 Training of Setting's Clinical Staff

Pre-implementation Plan

Goal #2, PSDA cycle, training of four physicians (including the project site clinical mentor), two nurse practitioners and 13 RN staff, had a video recording with a transcript for staff using Vyond.com (2023), Appendix G. The clinicians were introduced to the project process plan during the toolkit meeting. Clinicians (MDs and APPs) at the practice setting will introduce the opportunity to participate in this project to caregivers at the end of their child's clinic visit.

Implementation Plan

To ensure a sound implementation, all clinical staff at the project setting will be asked to watch a project introduction video and attest to completion of this activity. All clinicians' and nurses' emails will be entered into the REDCap survey distribution tool. Automations will be created within REDCap to distribute the instructional video (Appendix G) and include an attestation for staff. The staff will then attest through a unique REDCap survey that they watched the instructional video and understand the scope of the project, "ASD Transition Project Introduction, Staff Attestation," see Appendix H. A setting-specific project email will be set up so staff with questions can communicate with the DNP student/project lead. The DNP student/project lead will be available for questions or concerns and plans to be at the practice at

the project's start. A clear emphasis will be that the DNP student/project lead is implementing a QI project to satisfy her academic requirements and that participation is voluntary

Evaluation Plan

There are four physicians (including the project site clinical mentor), 2 nurse practitioners, and 13 nurses in the setting. Before the project is launched, 100% of the clinicians (MDs and NPs, n=6/6) and 80% of the nurses (n=10/13) will need to attest they watched the project's instructional video and have no further questions regarding the project's implementation plan. REDCap will be used to manage the completed attestations.

Goal #3 Distribution of Toolkit and Creation of Caregiver Feedback Survey

Pre-Implementation Plan

Using Readable.com all interfacing communication with the project's potential caregiver participants was at a fifth-grade reading level to ensure universal precautions accessibility were followed. For Readability reports for all components of the project see Appendix I. A Likert scale for each item in the toolkit was developed with two open ended questions, "Caregiver Feedback" survey, see Appendix J.

Implementation Plan

Presenting the project's introduction to the caregiver will be at the discretion of the clinician or with the clinician in collaboration with the nursing staff at each well visit. The criterion for inclusion in this project is to be a caregiver of a child with ASD between the ages of 15-21 being seen for a well visit. The clinicians will use a laminated introduction flyer with a standard script on the back 'Instructions for Potential Participants ', see Appendix K, and process map for toolkit distribution, see Appendix L. The caregiver will be given a paper flyer to scan in privately. Copies of the flyer will be stored at the nurse's station. If interested, the

potential caregiver participant will scan the QR code on the introduction flyer, which will link to a secure REDCap web-survey, with a welcome page, see Appendix M. Then the welcome page will lead them to “Caregiver Participation” survey, which explains the project to the caregiver and prompts interested participants to enter their email (See Appendix N). Once the caregiver’s email is entered, REDCap will automatically send a toolkit link and a link to the feedback survey, see Appendix O. The caregiver will review the toolkit (Appendix F). After reviewing the toolkit, the caregiver will be asked to take the feedback survey (Appendix J). If the caregiver does not fill out the survey, REDCap will send two reminders 3 days apart to the caregiver’s self-provided email. Caregivers' perceptions will be collected by asking them to report which components of the "The ASD transition resource toolkit " were MOST helpful and which components of the "The ASD transition resource toolkit " were LEAST helpful with a Likert scale for each item in the toolkit “Caregivers Feed Back Survey,” see Appendix J. Combining this feedback with their self-reported demographics will enable the project team to refine the toolkit to meet families' needs.

Post Implementation Plan

Data gathered during the implementation will be evaluated (see Evaluation Plan) and presented to the practice setting. An executive summary of the project results will be prepared for the key stakeholders.

Evaluation Plan

The project will track how many toolkits links were sent out using reporting technology in REDCap. There will be a record of how many paper flyers were made and handed out. The DNP student/project lead will track how many flyers were made and distributed by counting flyers every other week in person in the office. The project site clinical mentor will let the DNP

student/project lead know if more flyers are needed. The DNP student/project lead will identify how many flyers are accepted by caregivers and will record how many flyers are gone every other week along with account of how often Survey 1 “Caregiver Participation” (Appendix N) was accessed. The DNP student/project lead will identify how many surveys were accessed by having a structured query language (SQL) unique identifier placed on each survey by REDCap. The information gathered from the REDCap evaluation survey will be tabulated and displayed in table format as frequencies and percents. This project’s first outcome is a summary description of families’ overall interest in engagement in the project, and caregiver participant completion rates in this project as a proxy measure to determine a need for this type of toolkit/resource.

- A. The DNP student/project lead will work with the project setting to build an Epic query of all encounters at the setting during the project duration period where there was a child seen for a well visit with an ASD diagnosis between 15 and 21 years of age
- B. Number of times the project introduction flyer QR code was scanned by an interested caregiver (structured query language (SQL) placed on each survey by REDCap) divided by A = % of interested caregivers
- C. Number of caregiver interest forms completed in REDCap divided by B = % of interested AND engaged caregivers
- D. Number of caregiver feedback survey responses divided by C = completion rate

This project’s second outcome is a determination of parental perceptions of the toolkit’s overall “helpfulness.” For the purposes of this project, “helpfulness,” is defined as “intent to use, now or in the future.” Helpfulness will be measured by toolkit component sections via a 5-point Likert scale and two questions about the toolkit (See Appendix J). Combining this feedback with

caregivers' self-reported demographics will enable the project team to refine the ASD resource toolkit to meet families' needs.

Barriers to Implementation with Mitigation Plan

The first anticipated barrier is the setting's clinical staff ability or desire to hand out the project introduction flyers with QR codes per protocol. This will be a new practice for the staff. The DNP student/ project lead will create an educational video on how to implement the project and the importance of the population for the staff. The staff would attest to watching the video. With this plan staff can watch the video when it is convenient for them and use it as a reference for the project. One way to overcome this barrier is to initially have a lunch/snack and learn session with staff. In addition, weekly reminders could be placed for staff to give patients the flyers QR code resources. Another prompting could be a weekly email to designated staff as project facilitators. Getting their time through lunches and their support through the understanding of the impact on patients and the depth of the problem would be a critical dual approach.

The second barrier would be the potential caregiver project participants not showing interest in engagement wanting to utilize the flyer with the QR code. There will also be caregivers who are afraid to change or transition. To overcome this barrier, the caregiver could express concerns to the DNP student/project lead. The DNP student/project lead's contact information will be in the flyer.

Sustainment Plan

Once the project is complete, it will be handed over to the project's setting. The evaluations and information from caregivers on what resources were most utilized, this will be including the ASD resource toolkit. The DNP student will work with the project site clinical

mentor and staff to ensure the process is sustainable for future potential caregiver project participants.

Timeline

Table 3

Timeline

| Milestone Date | Milestone Description |
|---------------------|---|
| May 2022 | Began asking questions about YA-ASD transitions |
| May 2022 | Developed PICO question and began searching literature and other healthcare systems on how they transition YA-ASD |
| July 2022 | Started onboarding with project setting |
| December 2022 | SHU IRB approval and Project presentation |
| January 2023 | Met with project site mentor and started gathering resources for toolkit |
| June-September 2023 | Worked on flyer, toolkit, instructional video REDCap surveys for IRB submission at project setting site |
| September 2023 | IRB approval at project setting site and started staff training/attestation with video |
| October 2023 | Started project |
| February 2024 | Finished project |
| April 2024 | Present Project Findings |

The timeline was May 2022 through April 2024. See Appendix P for more specific details

Estimated Resources and Budget

The budget will be reviewed and discussed with the practice setting. The material cost will be a copy of the flyers, laminated covers, and Drop Box account cost. Table 4 describes the estimated project resource and budget.

Table 4

Project Resources and Estimated Costs

| Categories of resources | Hours devoted | The number of items | The cost | Total cost |
|--|---------------|---------------------|-----------|------------|
| Human Resources | | | | |
| <u>Student</u> | | | | |
| DNP student/project lead | 100 | | \$50/hour | \$5,000* |
| <u>* Project setting support</u> | | | | |
| Consultation hours | 98 | | | |
| IRB hours | 8 | | | |
| REDCap hours | 15 | | | |
| Ongoing follow-up consultation | 20 | | | |
| Project data review | 3 | | | |
| Final review of dissemination products | 3 | | | |
| Center credentialing | 3 | | | |
| Center IS Support | 5 | | | |
| Staff completing learning/participation | 3 | | | |
| Clinical Project Mentor's time in consultation | 40 | | | |
| Project setting total support hours | 200 | | | |
| Material Resource | | | | |
| Flyers | 20 | 100 | \$0.10 | \$10 |
| Lunch and learns/ snacks for staff | 5 | 2 | \$100 | \$200 |

| | | | | |
|------------------------------------|-------|---|------|------|
| Survey's development with QR code. | 40 | 2 | | |
| Drop Box | 4 | 1 | Free | Free |
| | hours | | | |

Table 5 displays the project dissemination plan. Results will be presented to the practice setting and the Davis and Henley College of Nursing community.

Table 5

Project Dissemination Plan

| Deliverable | Group and Timeframe |
|---------------------|--|
| Executive Summary | Practice setting by spring 2024 |
| Abstract and Poster | Davis & Henley College of Nursing and Sacred Heart University community by spring 2024 Explore abstract submission to local or regional conference winter 2024-2025 |
| Manuscript | Explore developing final DNP project paper into a manuscript and submitting to a practice journal winter 2024-2025 |

Pre-implementation Creation of Toolkit

Design and Accessibility

This section describes the development of the toolkit. The final toolkit is in Appendix F. The toolkit utilized Health Literacy Universal Precautions, meaning all components interfacing with the guardian were at a fifth-grade reading level or less and have 100% reachability in English, (Brega et al., 2015). This was achieved through Readable.com, which gave the Flesher-Kincaid score and readability score, see Appendix I. The toolkit/flyer colors were chosen from an accessible color palette generator from Venngage.com (2023). The vibrant palette, #00B4C5 and #2546F0, color coupling along with black and white text followed the Web Content

Accessibility Guidelines (WCAG) and has a contrast ratio 4.5:1 (Venngage.com, 2023). This means the presentation of the toolkit and flyer will accommodate those with low visual acuity in combination with 16-point text (U.S. General Services Administration, n.d). All graphics were noncopyrighted through stock photos on PowerPoint or from Unsplash.com.

Healthcare and Service Clinician

To identify clinicians accepting new patients and accepting YA-ASD patients see Appendix T, Adult Primary Care Physician contact list. The adult clinician's offices will be surveyed about their willingness to accept adolescent / young adults with chronic diseases like ASD from Gottrasistions.org (2020), see Appendix U. For the current clinician list, the websites google maps, Health Grades and Penn Med websites were used. Adult clinicians in the local area were assessed by phone call. The criteria for barbers and hair salons had to have a Google review rating 4.0 stars or more, have at least 15 reviews, and needed to be in the project setting's regional service area. Barbers and hair salons were asked "Will you take young adults with ASD and accommodate them?"

When surveying clinicians, services and healthcare clinicians that did not answer the phone during regular business hours were not placed on the list, due to accessibility concerns. The recommendation of lawyers and University of West Chester programs were from a mom's group that have already transitioned their children along with a local school program. The school program assists parents/guardians of special needs children.

The ASD Transition Resource Toolkit Components

The included component parts of the ASD transition resource toolkit are all evidence-based and the references appear next to each component. The DNP student/project lead will solicit input for resources from the project setting's site clinical mentor and clinicians at the setting,

Children’s Hospital of Philadelphia’s Center for Autism Research Autism Roadmap™ (<https://www.research.chop.edu/car-autism-roadmap>), and local Kennett Square mom’s group with children with YA-ASD or other disabilities that are transitioning “Questions for Mom’s Group,” see Appendix V.

- Insurance and Financial Help: This section gives links to local Medicaid resources and social security income directions (Kuhlthau et al., 2015; Verlenden et al., 2021; CHOP, 2020c).
- Legal Help: This section will assist caregivers to help decide to obtain guardianship, waivers program to help children stay in their homes and a special needs trust. (Kuhlthau et al., 2015; Harris et al., 2021; CHOP, 2020b & d).
- Educational Help: This section provides a list of services from the state of PA, which help train, obtain, and maintain employment in PA. Resources to get federal aid for living and education, and University of West Chester programs for students with ASD (Kuhlthau et al., 2015; Christensen et al., 2018; CHOP, 2020a).
- Other Programs: This section is a link to Autism Speaks’s Toolkit for transitions and a link to the state of PA’s support of caregivers and people with ASD. (Kuhlthau et al., 2015; Harris et al., 2021; Autism Speaks, 2018).
- A list of local barbers and hair salons: This section is a list of service clinicians willing to take YA-ASD (Kuhlthau et al., 2015; Thoele et al., 2020).
- Eye doctors: This section is a list of local service clinicians willing to take YA-ASD (Kuhlthau et al., 2015; Harris et al., 2021).
- Dentists and orthodontists: This section is a list of local service clinicians willing to take YA-ASD (Kuhlthau et al., 2015; Verlenden et al., 2021; Harris et al., 2021).

- Adult daycare clinicians: This section is a list of local service clinicians willing to take YA-ASD (Kuhlthau et al., 2015; Thoele et al., 2020).
- Lawyers: This section is a list of lawyers who provide legal services for guardianship and special needs trust (Kuhlthau et al., 2015; Harris et al., 2021).
- Adult primary care clinicians: This section is list of local adult primary care clinicians willing to take new YA-ASD patients (Kuhlthau et al., 2015; Harris et al., 2021).

Pre-implementation Ethical Reviews and Approvals

This DNP student has completed the required SHU IRB CITI (see Appendix R) and project setting specific CITI training (see Appendix S). Appendix Q has the completed QI checklist demonstrating that this is an evidence-based QI project. The project was reviewed and given an exempt status by SHU IRB on 12/5/2022 (see Appendix W for email). The project was reviewed and given a determination of non-human subject's research by the project's setting's IRB on 09/12/2023 (see Appendix X for email).

Project Implementation

Description of Actual Project Implementation and Deviation from Project

The DNP student/project lead was present for the staff at the practice setting and started the project on October 11, 2023. The project lasted 18 weeks with the DNP coming to the practice setting bi-weekly to count flyers. The project lead monitored the email box and survey results weekly. The project ended February 9, 2024. The deviation from the project was the extended time requested by the project's setting's center for nursing research and evidence-based practice team. It was the team's hope that there would be more qualified participants.

Evaluation

Results and Interpretation

Process and Outcome Measures

Goal #1 was to develop a transitional toolkit (The ASD resource toolkit) for English-speaking caregivers of adolescent / YA-ASD ages 15-21 and to disseminate this toolkit during well child visits at a pediatric office. The toolkit in Appendix F was completed in September 2023. It took 80 hours to create and edit the toolkit. The toolkit was checked for accessibility and fifth grade reading level.

Goal #2 was to train clinicians and RNs on the toolkit and the process for caregivers of adolescents/YA-ASD to access it. This was done through the REDCap survey tool. An email was sent to all the clinicians and nurses with a link to REDCap. REDCap provided the project education video and an entry for attestation for all the staff. Over a 2-week period, all six (100%) of the clinicians (MDs and APPs) and 85% (n=11/13) RNs viewed the training video and completed attestations. The DNP student/project lead visited the practice setting 9 times (biweekly) over the 18 weeks (about 4 months). During these visits, the DNP student/project lead counted flyers and placed project reminder signs with new colors, and encouraging messages were brought into the staff breakroom along with treats and snacks to keep the project present. At the end of 18 weeks only 5 (5%) of the flyers that described the project and had the QR code to access the toolkit were handed out by staff.

Goal #3 was to distribute the toolkit and obtain feedback from caregivers of adolescent / YA-ASD regarding the toolkit. Queries were every 9 weeks (about 2 months) for the 18 weeks of the project. There were 3 patients/caregivers who qualified during that 18-week period. According to the database report, one caregiver accessed the project introduction and was asked to share their email address if interested in participation, but this potential participant did not complete the form (no interest). No caregivers accessed the toolkit and evaluation survey.

Lessons Learned

Conducting a Project in Health System as a Non-paid Employee

This DNP student gained an appreciation for the challenges a non-employee encounters when trying to carry out a DNP project in a large health system. To ensure compliance with the setting's policies, procedures, and standards, this DNP student needed to gain non-paid employee credentials for the setting. These credentials allow the DNP student/project lead to have access to REDCap, email, and conduct the project in the project setting.

Lack of institutional knowledge (e.g., the process for DNP scholarly project approval within the setting, the setting's data use and access policies, the setting's eIRB approval processes) was a big learning curve resulting in project implementation delays. Without the guidance of the setting's center for nursing research and evidence-based practice, this project would not have been approved.

Small Numbers of YA-ASD Prevented Assessment of Toolkit Impact

The DNP student used the clinician's feedback and their recommendations to initiate the project in a single primary care office setting knowing that the numbers of YA-ASD were low. The thought process that this DNP student agreed with was to test the toolkit in this one setting and adjust based on feedback before offering it to other pediatric primary care practices within the health system. In hindsight, this DNP student realizes that to assess caregivers' perceptions of the helpfulness of the toolkit, more potential participants were needed. This could have been achieved by partnering with the setting to gather data on the number of potentially eligible caregivers meeting project criteria and ensuring that the project implementation plan represented the setting's primary care office(s) with high frequencies.

Access to Data in Real-time

Having access to weekly reports would have been ideal for tracking use of the toolkit. The qualified patient query was run at the 2-month point and at the 4-month point. Three eligible caregivers were identified during the 18-week implementation. The patient population being small was more of an issue than anticipated and more access to data earlier might have sent the project in a different direction. One consideration for the future is to provide the toolkit to all healthcare clinicians in the area or even expand the offering to local schools to ensure maximum impact. However, this could be offset by the cost the clinical site would have to maintain the toolkit.

Addressing a Clinical Issue Versus Problem for a DNP Project

This DNP student/project lead gained an understanding of the difference between a clinical issue and a clinical problem. While clinical issues should not be minimized, it can be challenging to address a clinical issue for a DNP project because the sense of urgency that comes with a clinical problem is not present. In hindsight, there was low frequency of potentially eligible caregivers (n = 3) over the 18-week project period; therefore, this DNP student was unable to assess caregivers' perceptions of this clinical need.

Time it Takes to Create a Quality Toolkit

Designing a universally accessible toolkit was a learning curve for this DNP student. It took time to understand the color palette, font size, and how to write and evaluate a 5th grade reading level. Visual clarity and accessibility were important when making the toolkit to avoid issues with reading the material such as certain color contrast was difficult to read. Learning this new information was invaluable, but it did cause a delay in the project implementation.

Health System Approval and Protecting Patients and Staff Information

Submitting to the setting's IRB for a determination of human subjects research was a new experience for this DNP student. Additional setting-specific CITI training modules had to be completed. This DNP student learned that protecting the setting's patient data was at the forefront of approval processes. The setting's health system's research and evidence-based practice support staff assisted in developing all necessary components for the IRB review, including the development, design, and testing of the data collection and management forms (via the setting's REDCap platform). All project training presentations were done at the pediatric office using the setting's REDCap platform. REDCap is a closed system for data privacy and all information was kept within the setting's network. REDCap is a secure web application commonly used in research for data privacy. All project related information was kept within REDCap and/or a password protected OneDrive site.

Complex Toolkit Distribution

To protect patient data REDCap was used to distribute the toolkit. This distribution was complex and may have been a barrier for the caregiver to access resources. The caregiver had to put down their email to receive a link to the toolkit. Accessing the toolkit took several steps. First scanning the QR code, then filling out their preferred email, then finding the survey/ toolkit in the email, then viewing the toolkit, and finally filling out a caregiver feedback survey. A better design may be to send the toolkit to qualified caregivers. Another possibility is to distribute the toolkit in paper form to caregivers.

Toolkit in Spanish

Nearly a third of the pediatric clinic population was children of Hispanic migrants working in the local mushroom farms. The next steps should include translating the toolkit into Spanish, so this population could access it. Originally the DNP student/project lead wanted the

toolkit in Spanish because of the pediatric patients. The DNP student/project lead was advised not to translate due to the health care system's translation process being time consuming and costly.

What Went Well

This DNP student created an instructional project video with an overview of the project used to educate the setting's staff. The Vyond.com tool was used for making and editing videos. The DNP project student received good feedback on the video and as the project changed the video could be edited easily to accommodate the new modifications. The video made it possible for asynchronous staff education, which fostered a high participation rate of staff watching the video. It was also visually appealing and offered the ability to use images of the material being used, making communication more effective.

Using REDCap for project education to staff was quick and efficient. The educational video viewing and along with staff attestation, REDCap kept a good account of staff completions. This made it easier to obtain the goals of 100% of the clinicians and 80% of the RNs educated for the project. The REDCap tool was useful organizing this part of the project. By using REDCap, the staff could view the video when it was convenient for them.

Lastly, the toolkit itself was very well received by the clinicians. They gave enthusiastic feedback that this would help their patients and their caregivers. The universal precautions evidence-based toolkit was an appreciated concept by the clinicians.

Final Costs of Project and Return of Investment

Table 6 displays the final costs for the project.

Table 6

Actual Project Resources and Costs

| Categories of resources | Original Estimate | Hours devoted | The number of items | The cost | Total cost |
|--|-------------------|---------------|---------------------|-----------|-----------------|
| Human Resources | | | | | |
| DNP student/project lead, Onboarding to completion | 100 hours | 300 hours | | \$50/hour | \$15,000 gratis |
| Project Site Team hours Onboarding to Completion | 200 hours | 250 hours | | | |
| Material Resource | | | | | |
| Flyers | 20 hours | 20 hours | 100 | \$0.75 | \$75 |
| Snack and learns | 5 hours | 5 hours | 2 | \$50 | \$100 |
| Survey's development with QR code. | 40 hours | 80 hours | | | |
| Drop Box (went unused) | 4 hours | 6 hours | 1 | Free | Free |
| Material hours TOTAL | 69 hours | 111 hours | | \$50/hour | \$5,550 gratis |
| Total Costs | | | | | \$20,725 |

ROI was not able to be calculated because of the lack of YA-ASD transitioning to adult PCP. In terms of VOI, this project brought additional attention to the clinical issue of YA-ASD transitioning to adult PCPs and the staff was more knowledgeable after receiving the education. The pediatric clinicians were enthusiastic about the toolkit for their patients because of the vetted services and identifying adult PCPs accepting YA-ASD.

Dissemination

A PowerPoint presentation was done for the health system, the primary care pediatric practice, and the Sacred Heart University community. An executive summary was shared with the health system and pediatric practice (Appendix Y). As part of the DNP program course, the project was presented in poster format for the Davis & Henley College of Nursing faculty and students (Appendix Z).

Sustainability

The ASD transition resource toolkit has already been established and needs to continue distribution. All materials such as flyers and paper examples of the toolkit have been left at the pediatric practice. The REDCap survey is still live for anyone who wants to participate in receiving the toolkit. A designated person or group is needed to respond to the emails and observe the survey participation. Perhaps, a query on all qualified patients/caregivers at the practice and an email sent directly to them telling them about the project. Also, monitoring of the email made for communication of this project needs to be continued.

Going forward to increase the impact, material distribution needs to be dramatically increased. The most logical way to do this would be to consider the following:

- Disseminate the toolkit directly to caregivers and YA-ASD during their visit.
- Expand the scope beyond well visits.
- Distribute the ASD resource toolkit to non-health system practices for their use.
- Distribute the ASD resource toolkit to schools to share with students and caregivers who meet the criteria.

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Appendix A

Table A1

Search Terms and Search Results by Database CINAHL

| Search Terms | Number of hits | Number of title & abstract reviewed | Number of full-text articles reviewed | Number of articles selected for this review without duplicates |
|--|----------------|-------------------------------------|---------------------------------------|--|
| ASD or Autis* | 1,444 | | | |
| ASD or autis*or “autism spectrum disorder” and transition* | 280 | | | |
| “Autism spectrum disorder” or ASD or autis* and transition* and resource* | 26 | 26 | 5 | 17 |
| ASD or Autis*, And transition* and resource* and primary care and primary healthcare or health care | 8 | 8 | 2 | 0 |
| ASD or autis*or “autism spectrum disorder” and transition* and adolescent / young adults or adolescents or teenagers or college students or young person or emerging adult | 141 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and adolescent / young adults or | 23 | 23 | 4 | 4 |

| | | | | |
|---|-----|---|---|---|
| adolescents or teenagers or college students or young person or emerging adult and resource* or tools | | | | |
| Primary care or primary healthcare or primary health care and ASD or autis*or “autism spectrum disorder” | 153 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and adolescent / young adults or adolescents or teenagers or college students or young person or emerging adult and resource* or tool* or service*, Primary care or primary healthcare or primary health care | 2 | 2 | 2 | 2 |

Table A2

Search Results by Medline Database.

| Search Terms | Number of hits | Number of title & abstract reviewed | Number of full-text articles reviewed | Number of articles selected for this review without duplicates |
|--|----------------|-------------------------------------|---------------------------------------|--|
| ASD or Autis* | 5,277 | | | |
| ASD or autis*or “autism spectrum disorder” and transition* | 169 | | | |

| | | | | |
|--|-----|----|---|---|
| “Autism spectrum disorder” or ASD or autis* and transition* and resource* | 13 | 13 | 5 | 5 |
| ASD or Autis*, And transition* and resource* and primary care and primary healthcare or health care | 4 | 4 | 1 | 0 |
| ASD or autis*or “autism spectrum disorder” and transition* and adolescent / young adults or adolescents or teenagers or college students or young person or emerging adult | 169 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and adolescent / young adults or adolescents or teenagers or college students or young person or emerging adult and resource* or tool* | 22 | 22 | 4 | 4 |
| Primary care or primary healthcare or primary health ASD or autis*or “autism spectrum disorder” | 85 | 85 | 9 | 9 |
| ASD or autis*or “autism spectrum disorder” and transitions* and adolescent / young adults or | 17 | 17 | 6 | 6 |

| | | | | |
|--|--|--|--|--|
| adolescents or teenagers or college students or young person or emerging adult and resource* or tools or services, Primary care or primary healthcare or primary health care | | | | |
|--|--|--|--|--|

Search terms and search results by database Medline limiter that would only take one criterion

for age, therefore adolescent / young adult: 19-24years

Table A3

Nursing & Allied Health Premium Database Results

| Search Terms | Number of hits | Number of title & abstract reviewed | Number of full-text articles reviewed | Number of articles selected for this review without duplicates |
|---|----------------|-------------------------------------|---------------------------------------|--|
| ASD or Autis* | 706 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* | 701 | | | |
| “Autism spectrum disorder” or ASD or autis* and “transition” and “Resources” | 262 | | | |
| ASD or Autis*, And transition* and resources* and primary care and primary healthcare and health care | 259 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and | 259 | | | |

| | | | | |
|--|-----|----|---|---|
| “adolescent / young adults” and “adolescent” and “teenagers” and “college students” and “young person” and “emerging adult” | | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and “adolescent / young adults” and “adolescent” and “teenagers” or “college students” and “young person” and “emerging adult” and “resource” and “tool” | 599 | | | |
| ASD or autis*or “autism spectrum disorder” and transitions* and adolescent / young adults or adolescents or teenagers or college students or young person or emerging adult and resource or tools, Primary care or primary healthcare or primary health care | 609 | | | |
| "Adolescent / young adults with ASD" and "autism spectrum disorder" and "healthcare" and "transition" and "resources" and "primary care" | 15 | 15 | 2 | 9 |

Search Terms and Search Results by Nursing & Allied Health Premium, children were excluded from the search and adolescent and adolescent / young adult were included in the search.

Appendix B

Evidence Synthesis Table and Rapid Critical Appraisals

PICO question: The focused search question is, in caregivers of adolescents /YA-ASD in the primary care setting (P) does a transitional resource toolkit (I) compared to usual care (C) affect YA-ASD transition to adult primary care (O)? This question will be used to find evidence on resources, tools, and supports to aid the caregiver's planning the transition from pediatric to adult primary care in adolescents /YA-ASD.

Table B1

Evidence Synthesis Table

| Citation | Conceptual Framework | Evidence Type/ Design/ Method | Sample/ Setting | Major Variables Studied and Their Definitions | Outcome Measurement | Data Analysis | Findings | Level of Evidence /Quality | Quality of Evidence: Critical Worth to Practice |
|--|-----------------------------|-------------------------------|--|---|--|-----------------|--|----------------------------|--|
| Author Year Title County Funding | Theoretical basis for study | | Number Characteristics Exclusion criteria | Independent variables IV1 = IV2 = | What scales used - reliability info (alphas) | What stats used | Statistical findings or qualitative findings | Level = | Strengths Limitations Risk or harm if implemented Feasibility of use in your practice |

| | | | Attrition | Dependent variables | | | | | |
|---|---|--------|---|---------------------|--------------------|--|---|---|---|
| Article 1 | | | | | | | | | |
| Ames 2021 Transitioning youth with autism spectrum disorders and other special health care needs into adult primary care: A clinician survey USA Funded by Autism Speaks and the Working for Inclusive and Transformative Healthcare | To find information on transition readiness for adolescent / young adults with ASD and healthcare clinician | survey | Online Voluntary to Northern California adolescent / young adults with ASD or SHCN and clinicians | none | Information tables | Chi-square Compared pediatric to adult clinicians | Adolescent / young adults with ASD and healthcare clinicians are not transition ready | 5 | To look at the need for resources to help transition with care for both the clinician, adolescent / young adults with ASD and their parents/guardians |

| | | | | | | | | | |
|---|--|-----------------------------------|--|------|--|---|--|---|--|
| (WITH) Foundation | | | | | | | | | |
| Article 2 | | | | | | | | | |
| Kuhlthau 2015 perspectives on the transition to adult health care for youth with autism spectrum disorder: Current strategies and promising new directions. | To find transition improve ments for youth with ASD | Qualit ative interv iews | ASD pediatri c specialt y ASD clincia ns in clinics | none | improve ments for ASD transitio n suggeste d | Num ber of sugg estio ns | suggestions for improveme nts for adolescent / young adults with ASD transitionin g into primary care | 6 | this article had many suggestions for improvements to help adolescent / young adults with ASD transitions into primary care a) trainings for adult clinicians; (b) systematic medical summaries; (c) information sessions for parents/guardians and youth; (d) transition folders; (e) a transition center; (f) care coordination; (g) systematic lists of adult clinicians who are open |

| | | | | | | | | | |
|--|---|--|---|------|--------------------|-----------------|---|---|---|
| | | | | | | | | | for patients, willing to care for individuals with ASD, and knowledgeable; and (h) a transition-point person. Transition specific appointments, pediatrician communicates with adult primary care Community resource list |
| Article 3 | | | | | | | | | |
| Voorhies 2020 Rapid Synthesis: Identifying Features of Approaches to Supporting Transitions from Child to Adult Care for | To conduct a systematic review on qualitative studies | systematic review on qualitative studies | Adolescent / young adults with disabilities | none | Information tables | recommendations | Evidence and recommendations for transition of care | 4 | Look at barriers, improvements, and recommendations for adolescent / young adults with disabilities in Canada. Current evidence Building relationships in transition improvements was established through |

| | | | | | | | | | |
|--|-------------------------------------|---------------------------|-------------------------------|------------------------------------|--------------------|--------------------------|--|----------|---|
| <p>Young People with Special Healthcare Needs-- McMaster Forum</p> | | | | | | | | | <p>fostering patient-clinician interactions and patient-peer connections</p> <p>giving tours of adult care facilities, introducing patients to adult clinicians, organizing informal luncheons, and scheduling introductory appointments with adult clinicians</p> <p>A platform to text and follow up with patients</p> <p>Transition center</p> <p>Barriers identified child health system to adults—not equal services</p> |
| <p>Article 4</p> | | | | | | | | | |
| <p>(Verlenden, J. V., 2021) Healthcare Access and</p> | <p>Identify barriers and health</p> | <p>Meta analysis of a</p> | <p>unweighted n =15,710)</p> | <p>health care utilization for</p> | <p>differences</p> | <p>Chi-square, using</p> | <p>Those with disabilities were more likely to</p> | <p>6</p> | <p>Those with disabilities were more likely to use the emergency room as their usual place of care</p> |

| | | | | | | | | | |
|---|---|---------------|--|--|--|--|---|--|---|
| <p>Utilization for Adolescent / young adults with Disability: U.S., 2014e2018</p> | <p>care utilization for young people (18-30) with or without disabilities</p> | <p>survey</p> | <p>18–30-year-old adults with/without disabilities</p> | <p>young people (18-30) with or without disabilities</p> | | <p>pairwise comparisons via bivariate logistic regression s. Compared nondisabled to disabled adults</p> | <p>use the emergency room as their usual place of care (5.3% vs. 1.8%). A greater percentage of adolescent / young adults with disabilities delayed medical care due to cost (19.1% vs. 8.9%) and reported an unmet medical need (21% vs. 10.2%).</p> | | <p>(5.3% vs. 1.8%). A greater percentage of adolescent / young adults with disabilities delayed medical care due to cost (19.1% vs. 8.9%) and reported an unmet medical need (21% vs. 10.2%).</p> |
| <p>Article 5</p> | | | | | | | | | |

| | | | | | | | | | |
|---|---|--|------------------------|--|--------------------------------|--|--|---|--|
| (Jones et al, 2016) A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study | Identify what kind of health conditions of ASD adolescent / young adult- adult In Utah | Cohort 25year longitudinal study | N = 92 N=11 died | description of illnesses | information tables | descriptive statistics Fisher's exact test Mann Whitney U test | obesity seizures GI neurological GI neurological ear nose and throat sleep disturbances and Constipation | 5 | obesity seizures GI neurological ear nose and throat sleep disturbances and Constipation |
| Article 6 | | | | | | | | | |
| Lee et al, 2022 The Role of Acceptance in the Transition to Adulthood: A Multi-Informant Comparison of Practitioners | Thematic study adds adolescent / young adults with autism parents and | qualitative study | N=6 N=7 N=11 | describe feelings of adolescent / young adults with autism | discussion on thematic results | thematic analysis | This study used multiple stakeholder groups of autistic youth, parents, and practitioner | 6 | Autistic youth highlighted the lack of understanding of sensory needs and parents underscored the lack of understanding by medical professionals. In contrast, practitioners highlighted the |

| | | | | | | | |
|--|---------------|--|--|---|--|---|---|
| , Parents/guardians, and Youth with Autism | practitioners | | | their parents' concerns and practitioner's viewpoints | | s in sharing their experience of the transition process. As part of a broader study, results reported in this study represented the four unique themes on acceptance. Autistic youth discussed Self-Advocacy and Self-Acceptance as a salient theme, speaking | presence of Community Openness in the sense of welcoming autistic adolescents / young adults to work and the need to provide accommodation to address deficits. Both practitioners and parents discussed Finding Personal Support through Acceptance. Although the importance of self-acceptance and acceptance was conveyed, there needs to continue advocating for the true sentiment and actions of acceptance for autistic adolescent / young adults and parents/guardians to achieve well-being. |
|--|---------------|--|--|---|--|---|---|

| | | | | | | | | | |
|------------------|--|--|--|--|--|--|---|--|--|
| | | | | | | | on the importance of not only focusing on the formal transition service process but also the developmental experience of transitions. Both youth and parents discussed the next theme, Lack of Understanding and Acceptance . | | |
| Article 7 | | | | | | | | | |

| | | | | | | | | | |
|--|--|-----------|--------------|-----------|-----------|---|--|----------|---|
| <p>Harris et al, 2021 Development and implementation of health care transition resources for youth with autism spectrum disorders within a primary care medical home</p> | | <p>QI</p> | <p>N=199</p> | <p>NA</p> | <p>NA</p> | <p>Yes 199/484</p> <p>Where transition improvement occurred</p> | <p>Need to think of other ways for transition to be talked about not just by physicians and need to involve adult primary care physicians/clinicians</p> | <p>8</p> | <p>Resource notebook transition template created for EMR workshop seminar for parents/guardians and patients physician and staff education on transitioning</p> |
|--|--|-----------|--------------|-----------|-----------|---|--|----------|---|

Rapid Critical Appraisals

Rapid Critical Appraisal of a Descriptive Study

Project Title: Transitioning youth with autism spectrum disorders and other special health care needs into adult primary care: A provider survey

Date: 2021

PICO Question: In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article citation (APA): Ames, J. L., Massolo, M. L., Davignon, M. N., Qian, Y., & Croen, L. A. (2021).

Healthcare service utilization and cost among transition-age youth with autism spectrum disorder and other special healthcare needs. *Autism*, 25(3), 705–718. <https://doi.org/10.1177/1362361320931268>

Indicate the level of the study you are appraising: 8: survey for information gathering

Recommendation for article inclusion in the body of evidence to answer your question: This article starts the information collecting process. There is a know needs of transitioning young adults with ASD, however, how to do that is the unknown.

Overview

- Purpose of study, including research question(s) or hypotheses:** To gather information
- Design/Method:** ON-line survey
- Sample:** 354 pediatric (43% response rate) and 715 adult providers (30% response rate) from Kaiser Permanente Northern California-- voluntary participants
- Setting:** on-line

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Rapid Critical Appraisal of a Descriptive Study

Comments: [Click here to enter text.](#)

6. **Were outcomes clearly described?** Yes No Unknown

Comments: [Click here to enter text.](#)

7. **Was sampling clearly described?** Yes No Unknown

Comments: volunteers

8. **Were all participants accounted for throughout the duration of the study?** Yes No Unknown

- What was the rate attrition? [Click here to enter text.](#)
- What reason were given to explain why subjects did not complete study? [Click here to enter text.](#)

9. **Was there freedom from conflict of interest?** Yes No Unknown

- Sponsorship/funding agency
- Investigator

Comments: [Click here to enter text.](#)

10. **Was the date range of the cited literature current?** Yes No Unknown

- What date ranges were included? 1993 to 2018
 - If older literature was included, why was it included? 1993 was to describe the "service cliff" that occurs when young adults transition out of pediatric care and school services, can have a profound impact on the quality of life for special needs individuals and their families.

Reliability: Are these valid study results important?

11. **What were the results?** Explained the need to have a transition policy

12. **Was measurement of the intervention(s) appropriate?** Yes No Unknown

Comments: survey

13. **Was measurement of the intervention(s) clearly defined?**

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Rapid Critical Appraisal of a Descriptive Study

5. **Data Collection:** We designed separate surveys for pediatric and adult providers (Supplementary Figure 1). The pediatric provider survey had 20 questions and the adult provider survey had 15 questions. Nine questions were identical or complementarily phrased across the two surveys and formatted using either Likert-type scale (n=5) or multiple choice (n=4). Questions unique to the pediatric survey addressed practices in assisting with medical documentation for educational and vocational programs and in helping families identify an adult provider and plan the optimal timing of the transition.

Quality of the Study

Validity: Are the results of this study valid?

1. **Were the study/survey methods appropriate for the question?** Yes No Unknown

Comments: [Click here to enter text.](#)

2. **Were the study/survey methods clearly described?** Yes No Unknown

Comments: [Click here to enter text.](#)

3. **Were instruments used to measure the outcomes valid and reliable?** Yes No Unknown

- Were the instruments tested to be valid and reliable? Yes No
- What statistic was reported and what was the finding? (Cronbach's alpha/other)? chi-square tests and cronbach alpha

4. **Were all appropriate variable and interventions clearly described?** Yes No Unknown

Comments: Just information

5. **Were outcome appropriate for the question?** Yes No Unknown

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Rapid Critical Appraisal of a Descriptive Study

Unknown Yes No Unknown

Comments: [Click here to enter text.](#)

14. **Was the measurement of the outcome(s) appropriate?** Yes No Unknown

Comments: [Click here to enter text.](#)

15. **Was measurements of the outcome(s) clearly defined?** Yes No Unknown

Comments: [Click here to enter text.](#)

16. **Did the study have a sufficient sample size?** Yes No Unknown

- Was a power analysis conducted? Yes No
- Did the sample size achieve or exceed the power analysis requirement? Yes No
- Did each subgroup also have sufficient sample size? Yes No

Comments: survey

17. **What were the main results of the case control study?**

- Statistical significance (p value): [Click here to enter text.](#)
- Confidence interval and/or Standard deviation: [Click here to enter text.](#)
- How precise was the intervention/treatment?
 - Narrow? Wide: [Click here to enter text.](#)
- Effect size: [Click here to enter text.](#)

18. **Were the results clinically significant?** Yes No Unknown

- a. **Were the following reported:** NNH (number needed to harm), NNT (number needed to treat), OR (odds ratio), RR (relative risk)? [Click here to enter text.](#)

Comments: [Click here to enter text.](#)

19. **Were the potential confounders identified?** Yes No Unknown

Comments: [Click here to enter text.](#)

20. **Were safety concerns including risks/benefits identified?**

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Rapid Critical Appraisal of a Descriptive Study

Yes No

Unknown:

Comments: [Click here to enter text.](#)

Applicability/Generalizability: Can I apply these valid, important study results?

21. Can the results be applied to my population of interest? Yes No Unknown

a. Is the treatment feasible in my care setting? Yes

No

b. Do the outcomes apply to my population of interest? Yes No

c. Are the likely benefits worth the potential harm and costs? Yes No

d. Are the subjects/participants in this study similar to my population of interest?

Yes No

e. Were all clinically important outcomes considered? Yes

No

Comments: [Click here to enter text.](#)

22. Will you use the study/article in your practice to make a difference in outcomes?

Yes No Unknown

f. If yes, why would you do this & how? [Help develop a resource packet](#)

g. If no, why would you not include the results to make a difference? [Click here to](#)

[enter text.](#)

Strength of Study

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Rapid Critical Appraisal of a Descriptive Study

Level of study: I II III IV V VI VII

Quality of Study: High Medium Low

Strength = Level + Quality

What is the strength of this study? 5, descriptive informational study

What is your recommendation for article inclusion in the body of evidence to answer your question?

Include this article in the body of evidence (place article on evaluation and synthesis table)

Do NOT include this article in the body of evidence

Additional comments: [Click here to enter text.](#)

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Rated Critical Appraisal Questions for EBP Implementation or Quality Improvement Projects

Indicate the extent to which the item is met in the published report of the EBP or QI project.

| Validity of Evidence Synthesis (i.e., good methodology) | 1= No | 2= A Little | 3= Somewhat | 4= Quite a bit | 5= Very much | Data to support rating |
|---|-------|-------------|-------------|----------------|--------------|--|
| 1. The title of the publication identifies the report project as an evidence-based practice implementation or quality improvement project. | | | | | X | Development and implementation of health care transition resources for youth with autism spectrum disorders within a primary care medical home. |
| 2. The project report provides a structured summary that includes, as applicable: data to establish the existence and background of the clinical issue, the research evidence on (a) the success of evidence, evidence synthesis, effectiveness and testing of the EBP or QI project, project limitations, results/outcomes, recommendations and implications for policy. | | | | | X | Practice from studies in adult health care systems presents unique challenges for adolescents with autism spectrum disorder who often have complex medical and mental health needs, without a coordinated care plan, available providers often continue to provide care to young adults with autism spectrum disorder throughout their lives. This study provides young adults with autism spectrum disorder. The study is a retrospective review of the health care transition from a pediatric health care provider to a primary care provider who |
| 3. Report includes existing external evidence to describe the clinical issue. | | | | | X | |
| 4. Provides an explicit statement of the question being addressed with reference to participant or population, intervention/comparison/outcome (PICO). | | | | | X | Identify the population with the diagnosis of autism spectrum disorder (ASD) and requires communication to help them with transition. While the supports helped improve the amount and quality of data patients and families received, medical transition remains a challenging process for patients and providers with ASD transitioning from pediatric to adult health care systems. |
| 5. Explicitly describes the search method, inclusion and exclusion criteria, and rationale for search strategy limits. | | | | | X | ED, Ger Transition, multiple authors in multiple studies |
| 6. Describes multiple information sources (e.g., databases, contact with study authors to identify additional studies, or any other additional search strategies) included in the search strategy, and date. | | | | | X | Does not describe the process, or studies just uses them as a support for her QI. |
| 7. States the process for title, abstract, and article screening for relevance/quality. | | | | | X | She obtained the information from Ger Transition and other projects. |
| 8. Describes the method of data extraction (e.g., independently or process for validating data from multiple reviewers). | | | | | no | |
| 9. Includes conceptual and operational definitions for all variables for which data were abstracted (e.g., define blood pressure as systolic blood pressure, diastolic blood pressure, ambulatory blood pressure, morning cuff blood pressure or actual blood pressure). | | | | | X | |
| 10. Describes methods used for assessing risk of bias of individual studies (including application of whether bias was done at the study or outcome level). | X | | | | no | |
| 11. States the principal summary measures (e.g., risk ratio, difference in means). | | | | | X | Multiple measures were captured to determine the "best" state of the practice and potential of emerging practice innovations, models. |

| Validity of Evidence Synthesis (i.e., good methodology) | 1= No | 2= A Little | 3= Somewhat | 4= Quite a bit | 5= Very much | Data to support rating |
|--|-------|-------------|-------------|----------------|--------------|---|
| 12. Describe the method of combining results of studies including quality, quantity, and consistency of evidence. | | | | | X | Large quantity of evidence and quality of evidence. |
| 13. Specific measurement of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | | | | | X | she did not talk about bias. |
| 14. Describe appraisal procedure and conflict resolution. | | | | | X | do not talk about conflict resolution. |
| 15. Provide number of studies assessed, assessed for eligibility, and included in the review, with reasons for exclusion at each stage, ideally with a flow diagram. | | | | | X | she talked about eligibility being 12 or 21 years of age with being diagnosed with ASD. |
| 16. For each study, present characteristics for which data were extracted (e.g., study size, design, method, follow-up period) and provides a citation. | | | | | X | There was one study and intervention. |
| 17. Present data on risk of bias of each study and, if available, any other method assessment. | | | | | X | doctors met following up with transition conversation. |
| 18. For all outcomes considered (benefits or harms), include a table with summary data for each intervention group, effect estimates, and confidence intervals, ideally with a forest plot. | | | | | no | |
| 19. Summarize the main findings including the strength of evidence for each main outcome, considering their relevance to key groups (i.e., health care providers, users, and policy makers). | | | | | X | It was hard to get everyone on board with the process intervention. |
| 20. Discusses limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias). | | | | | X | Yes. Physicians found it difficult to discuss transition while doing medical exams and primary care, they suggested that other meetings and number provide the education. |
| 21. Provides a general interpretation of the results in the context of other evidence, and implications for further research, practice or policy changes. | | | | | X | suggest increasing relationships with adult providers on young adults with ASD. |
| Validity of Implementation (i.e., well-done project) | | | | | X | |
| 22. Statement of focus: Does their evidence synthesis | | | | | X | patients doctors and their families. |
| 23. Stakeholders (active & passive) are identified and communication with them is described. | | | | | X | yes |
| 24. Implementation process is consistent with evidence synthesis (fidelity of the intervention). | | | | | X | yes, they had a notebook of transition materials. |
| 25. Implementation process is not fully detailed to provide for replication across project participants. | | | | | X | they also provided a workshop for patients and families. |
| 26. Evaluation of project participants and other stakeholders is clearly detailed. | | | | | X | the physician did increase their discussion with family and patient about transition. |
| 27. Outcomes are measured with measures supported in the evidence synthesis. | | | | | X | |

| Validity of Evidence Synthesis (i.e., good methodology) | 1= No | 2= A Little | 3= Somewhat | 4= Quite a bit | 5= Very much | Data to support rating |
|--|-------|-------------|-------------|----------------|--------------|--|
| Reliability of Implementation Project (i.e., I can learn from an implementation project results) | | | | | X | |
| 1. Data are collected with sufficient rigor to be dependable for like process to those participants of the project. | | | | | X | No, I did not see that. |
| 2. Results of evidence implementation are clinically meaningful (outcomes are interpreted as such). | | | | | X | |
| Application of Implementation (i.e., this project is useful for my patients) | | | | | X | |
| 1. How feasible is the project process? | | | | | X | She provided a notebook, seminar, education/presentations. |
| 2. Have the project managers considered/distributed all outcomes that are important to my work? | | | | | X | Yes, people benefited and knew to the transition seminar. |
| 3. Is implementing the project safe (i.e., low risk of harm)? | | | | | X | no |
| Summary Score | | | | | 40 | |
| Recommendations with consideration of the type of level IV interventional evidence: | | | | | | |
| <ul style="list-style-type: none"> 32-40: consider evidence with extreme caution 41-49: consider evidence with caution 50-60: consider evidence with confidence | | | | | | |

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Quality Rating for Organizational Experiences (Quality improvement, program or financial evaluation) (Dearholt & Dang, 2018):

A High quality: Clear aims and objectives, consistent results across multiple settings, formal quality improvement or financial evaluation methods used, defensible conclusions, consistent recommendations with thorough reference to scientific evidence.

B Good quality: Clear aims and objectives, formal quality improvement or financial evaluation methods used; consistent results in a single setting; consistent recommendations with some reference to scientific evidence.

C Low quality or major flaws: Unclear or missing aims and objectives; inconsistent results; poorly defined quality improvement/financial analysis method; recommendations cannot be made.

Dearholt, S., & Dang, D. (2018). *Johns Hopkins Nursing Evidence-Based Practice: Models and Guidelines* (3rd ed.). Indianapolis, IN: Sigma Theta Tau.

RAPID CRITICAL APPRAISAL OF A COHORT STUDY

Project Title: A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study

Date: 92

Appraiser's Name: Dawn Boal

PICO(T) Question: 1 In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article Citation (in APA 6th ed format) Jones, K. B., Cottie, K., Bakian, A., Farley, M., Bilder, D., Coon, H., & McVahon, W. M. (2016). A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study. *Autism, 20*(5), 551–561. <https://doi.org/10.1177/1362361315594798>

Indicate the level of the study you are appraising: observational studies cohort

GENERAL DESCRIPTION OF STUDY

- Purpose of study, including research question(s) or hypotheses:** This study describes medical conditions experienced by a population-based cohort of adults with autism spectrum disorder whose significant developmental concerns were apparent during childhood. As part of a 25-year outcome study of autism spectrum disorder in adulthood, medical histories were collected on 92 participants who were first ascertained as children in the mid-1980s, 11 of whom were deceased at the time of follow-up.
- Design/Method:** Longitude study of children growing into adults with ASD and assessing their medical conditions
- Sample:** 92
- Setting:** Utah

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Comments: [Click here to enter text.](#)

- Were all appropriate predictor variables (predictive confounders/exposures) and interventions clearly described? Yes No Unknown

Comments: [Click here to enter text.](#)

- Were objective and unbiased outcomes criteria used? Yes No Unknown

Comments: [Click here to enter text.](#)

- Were outcomes clearly described? Yes No Unknown

Comments: [Click here to enter text.](#)

- Was the follow up process described and complete Yes No Unknown
 - Was the follow up long enough to fully study the effects of the intervention: Yes No

- What was the rate of attrition (how many of the original participants were lost)?

(NOTE: If greater than 20% of the original participants are lost, then bias is a greater concern): [Click here to enter text.](#)

Comments: 11 people died

- Was there freedom from conflict of interest? Yes No Unknown

Comments: [Click here to enter text.](#)

- Was the date range of the cited literature current? Yes No Unknown

What was the date range? 1980 to 2014
(NOTE: If older literature was included, why was it included?) Dx of mental disorders

Comments: [Click here to enter text.](#)

RELIABILITY: Are the study results important?

- Did the study have a sufficiently large sample size? Yes No Unknown
 - Was a power analysis conducted? Yes No Unknown
 - IF YES to question A: Did the sample size meet or exceed the needed power analysis requirement? Yes No Unknown
 - Did each subgroup also have sufficient sample size? Yes No Unknown

Comments: [Click here to enter text.](#)

- What were the main results of the cohort study? [Click here to enter text.](#)
 - Were the results statistically significant ($p < 0.05$)? Yes No
 - Was the Confidence Interval and/or Standard Deviation reported? Yes No

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5. Data Collection methods: questionnaires

Indicate the level of evidence of the study you are appraising: V

Recommendation for article inclusion in your body of evidence to answer your question: queried medical symptoms, disorders, hospitalizations, surgeries, and medication use. Median age at follow-up was 36 years (range: 23.5-50.5 years), and intellectual disability co-occurred in 62%. The most common medical conditions were seizures, obesity, insomnia, and constipation. The median number of medical conditions per person was 11. Increased medical comorbidity was associated with female gender ($p = 0.01$) and obesity ($p = 0.03$), but not intellectual disability ($p = 0.79$). Adults in this cohort of autism spectrum disorder first ascertained in the 1980s experience a high number of chronic medical conditions, regardless of intellectual ability. Understanding of these conditions commonly experienced should direct community-based and medical primary care for this population.

QUALITY OF STUDY

These questions will help you determine the VALIDITY of the study; whether or not the results of the study factually sound.

- Were the study methods appropriate for the question? Yes No Unknown
 - Were the study methods clearly described (i.e. sample, setting, etc) Yes No
 - Were the instruments clearly described? Yes No
 - Were the interventions clearly described? Yes No

Comments: [Click here to enter text.](#)

- Was there a representative and well defined sample population at a similar point in the course of the disease, event, etc? Yes No Unknown

Comments: [Click here to enter text.](#)

- Were the instruments used to measure the outcomes valid and reliable? Yes No Unknown

*What statistic was reported and what were the findings (Cronbach's Alpha/other)? Fisher's exact tests were used in cases where cell frequencies were less than five. Mann-Whitney U tests were used to test for differences among variables measured on the interval or ratio scale such as psychotropic medication use frequency between participants with and without cardiovascular risk factors (i.e. hypertension, hyperlipidemia, and diabetes).

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- Was the effect size reported? Yes No Unknown
 - IF YES, what was the effect size? Small (0.2) Medium (0.5) Large (0.8)

Comments: [Click here to enter text.](#)

- Were the results clinically significant? Yes No Unknown

a. Were the following reported: NNH (number needed to harm), NNT (number needed to treat), OR (odds ratio), RR (relative risk)? [Click here to enter text.](#)

Comments: [Click here to enter text.](#)

- Were the potential confounders identified? Yes No Unknown

Comments: [Click here to enter text.](#)

- Were adverse events identified? Yes No Unknown

Comments: [Click here to enter text.](#)

- Were safety concerns including risks/benefits identified? Yes No Unknown

Comments: [Click here to enter text.](#)

APPLICABILITY/TRANSFERABILITY: "Can I apply these valid, important study results?"

- Can the results be applied to my population of interest? Yes No Unknown
 - Is the treatment feasible in my care setting? Yes No
 - Do the outcomes apply to my population of interest? Yes No
 - Are the likely benefits worth the potential harm and costs? Yes No
 - Were the subjects/participants in this study similar to my population of interest? Yes No

*Were all clinically important outcomes considered? Yes No

Comments: [Click here to enter text.](#)

- Will you include this article/study in your practice decision to make a difference in outcomes? Yes No Unknown

*If yes, why would you do this? Specific with outcomes

*If no, why would you not include the results to make a difference? [Click here to enter text.](#)

Comments: [Click here to enter text.](#)

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STRENGTH OF STUDYLevel of Study: I II III IV V VI VIIQuality of study: High Medium Low**STRENGTH = LEVEL + QUALITY**What is the strength of the study? [Click here to enter text.](#)What is your recommendation for article inclusion in the body of evidence to answer your question? [Click here to enter text.](#) Include this article in the body of evidence (place this article's information on the evaluation & synthesis tables) Do NOT include this article in the body of evidenceAdditional comments: [Click here to enter text.](#)

Rapid Critical Appraisal of a Descriptive Study

Project Title: Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: Current strategies and promising new directions

Date: 06/20/2022

PICOT Question: 1. In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article citation (APA): Kuhlthau, K. A., Warfield, M. E., Hurson, J., Delahaye, J., & Crossman, M. K. (2015). Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: Current strategies and promising new directions. *Autism, 19*(3), 262–271. <https://doi.org/10.1177/1362361313518125>

Indicate the level of the study you are appraising: level 6 Qualitative single study

Recommendation for article inclusion in the body of evidence to answer your question: 8 suggestions or recommendations to help transition young adults with ASD into primary care

Overview

1. Purpose of study, including research question(s) or hypotheses: . What are the current strategies or interventions taking place in ASD-specific pediatric settings to facilitate successful transition from pediatric to adult health care for youth with ASD?
2. What strategies or interventions are needed or would be most helpful in facilitating the transition from pediatric to adult health care for youth with ASD?

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Rapid Critical Appraisal of a Descriptive Study

2. **Design/Method:** Surveyed and interviewed pediatric providers/clinic for ASD in the USA and Canada
3. **Sample:** 13/17 clinics participated
4. **Setting:** ASD clinics and phone interviews
5. **Data Collection:** Surveys and interviews

Quality of the Study

Validity: Are the results of this study valid?

1. Were the study/survey methods appropriate for the question? Yes No Unknown
Comments: Click here to enter text.
2. Were the study/survey methods clearly described? Yes No Unknown
Comments: Click here to enter text.
3. Were instruments used to measure the outcomes valid and reliable? Yes No Unknown
 - Were the instruments tested to be valid and reliable? Yes No
 - What statistic was reported and what was the finding? (Cronbach's alpha/other)? no
4. Were all appropriate variable and interventions clearly described? Yes No Unknown
Comments: Click here to enter text.
5. Were outcome appropriate for the question? Yes No Unknown
Comments: Click here to enter text.
6. Were outcomes clearly described? Yes No Unknown

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Rapid Critical Appraisal of a Descriptive Study

Comments: Click here to enter text.

7. Was sampling clearly described? Yes No Unknown
Comments: Click here to enter text.
8. Were all participants accounted for throughout the duration of the study? Yes No Unknown
 - What was the rate attrition? Low, greater than 76% participated no attrition
 - What reason were given to explain why subjects did not complete study?
Comments: Click here to enter text.
9. Was there freedom from conflict of interest? Yes No Unknown
 - Sponsorship/funding agency
 - Investigator

Comments: No COI Click here to enter text.
10. Was the date range of the cited literature current? Yes No Unknown
 - What date ranges were included? 1989 to 2013
 - o If older literature was included, why was it included? Click here to enter text. Previous studies done on autism transitions again service cliff was sited 1993 and 1989 was on transforming qualitative data

Reliability: Are these valid study results important?

11. What were the results? Click here to enter text.
12. Was measurement of the intervention(s) appropriate Yes No Unknown
Comments: Click here to enter text.
13. Was measurement of the intervention(s) clearly defined? Yes No Unknown
Comments: questions
14. Was the measurement of the outcome(s) appropriate?

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Rapid Critical Appraisal of a Descriptive Study

Yes No Unknown

Comments: Click here to enter text.

15. Was measurements of the outcome(s) clearly defined? Yes No Unknown
Comments: Click here to enter text.
16. Did the study have a sufficient sample size? Yes No Unknown
 - Was a power analysis conducted? Yes No
 - Did the sample size achieve or exceed the power analysis requirement? Yes No
 - Did each subgroup also have sufficient sample size? Yes No

Comments: Click here to enter text.
17. What were the main results of the case control study?
 - Statistical significance (p value): Click here to enter text.
 - Confidence Interval and/or Standard deviation: Click here to enter text.
 - How precise was the intervention/treatment?
 - o Narrow? Wide: Click here to enter text.
 - Effect size: Click here to enter text.
18. Were the results clinically significant? Yes No Unknown
 - a. Were the following reported: NNH (number needed to harm), NNT (number needed to treat), OR (odds ratio), RR (relative risk)? Click here to enter text.

Comments: Click here to enter text.
19. Were the potential confounders identified? Yes No Unknown
Comments: Click here to enter text.
20. Were safety concerns including risks/benefits identified? Yes No Unknown
Comments: Click here to enter text.

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Rapid Critical Appraisal of a Descriptive Study

Applicability/Generalizability: Can I apply these valid, important study results?

21. Can the results be applied to my population of interest? Yes No Unknown
- a. Is the treatment feasible in my care setting? Yes No
- b. Do the outcomes apply to my population of interest? Yes No
- c. Are the likely benefits worth the potential harm and costs? Yes No
- d. Are the subjects/participants in this study similar to my population of interest? Yes No
- e. Were all clinically important outcomes considered? Yes No
- Comments: [Click here to enter text.](#)

22. Will you use the study/article in your practice to make a difference in outcomes? Yes No Unknown
- f. If yes, why would you do this & how? Apply their interventions
- g. If no, why would you not include the results to make a difference? [Click here to enter text.](#)

Strength of Study

Level of study: I II III IV V VI VII

Quality of Study: High Medium Low

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Rapid Critical Appraisal of a Descriptive Study

Strength = Level + Quality

What is the strength of this study? 6+

What is your recommendation for article inclusion in the body of evidence to answer your question?

Include this article in the body of evidence (place article on evaluation and synthesis table)

Do NOT include this article in the body of evidence

Additional comments: [Click here to enter text.](#)

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Rapid Critical Appraisal of a Descriptive Study

Project Title: The Role of Acceptance in the Transition to Adulthood: A Multi-Informant Comparison of Practitioners, Families, and Youth with Autism

Date: June 26, 2022

PICOT Question: 1 In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article citation (APA): Lee, G. K., Curtiss, S. L., Kuo, H. J., Chun, J., Lee, H., & Nimako, D. D. (2022). The role of acceptance in the transition to adulthood: A multi-informant comparison of practitioners, families, and youth with autism. *Journal of Autism and Developmental Disorders*, 52(4), 1444–1457. <https://doi.org/10.1007/s10803-021-05037-1>

Indicate the level of the study you are appraising: VI qualitative single study

Recommendation for article inclusion in the body of evidence to answer your question: YES

Overview

- Purpose of study, including research question(s) or hypotheses:** This study investigated the role of acceptance during the transition process among autistic young adults, parents, and practitioners
- Design/Method:** six focus groups were run and thematic analysis was used to identify 4 themes
- Sample:** six focus groups
- Setting:** Midwestern University

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Rapid Critical Appraisal of a Descriptive Study

- Yes No Unknown
- What was the rate attrition? none
 - What reason were given to explain why subjects did not complete study?
- Comments: Click here to enter text.
9. Was there freedom from conflict of interest? Yes No Unknown
- Unknown:
- Sponsorship/funding agency
 - Investigator
- Comments: Click here to enter text.
10. Was the date range of the cited literature current? Yes No Unknown
- Unknown:
- What date ranges were included? 2005 to 2019
 - If older literature was included, why was it included? Reference book on qualitative studies in special education
- Reliability: Are these valid study results important?**
11. What were the results? This study used multiple stakeholder groups of autistic youth, parents, and practitioners in sharing their experience of the transition process. As part of a broader study, results reported in this study represented the four unique themes on acceptance. Autistic youth discussed Self-Advocacy and Self-Acceptance as a salient theme, speaking on the importance of not only focus on the formal transition service process but also the developmental experience of transitions. Both youth and parents discussed the next theme, Lack of Understanding and Acceptance.
12. Was measurement of the intervention(s) appropriate? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
13. Was measurement of the intervention(s) clearly defined? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
14. Was the measurement of the outcome(s) appropriate? Yes No Unknown

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Rapid Critical Appraisal of a Descriptive Study

5. **Data Collection:** Click here to enter text.

Quality of the Study

Validity: Are the results of this study valid?

1. Were the study/survey methods appropriate for the question? Yes No Unknown
- Comments: Click here to enter text.
2. Were the study/survey methods clearly described? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
3. Were instruments used to measure the outcomes valid and reliable? Yes No Unknown
- Unknown:
- Were the instruments tested to be valid and reliable? Yes No
 - What statistic was reported and what was the finding? (Cronbach's alpha/other)? thematic analysis
4. Were all appropriate variable and interventions clearly described? Yes No Unknown
- Comments: Click here to enter text.
5. Were outcome appropriate for the question? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
6. Were outcomes clearly described? Yes No Unknown
- Comments: Click here to enter text.
7. Was sampling clearly described? Yes No Unknown
- Comments: Click here to enter text.
8. Were all participants accounted for throughout the duration of the study?

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Rapid Critical Appraisal of a Descriptive Study

- Comments: Click here to enter text.
15. Was measurements of the outcome(s) clearly defined? Yes No Unknown
- Comments: Click here to enter text.
16. Did the study have a sufficient sample size? Yes No Unknown
- Unknown:
- Was a power analysis conducted? Yes No
 - Did the sample size achieve or exceed the power analysis requirement? Yes No
 - Did each subgroup also have sufficient sample size? Yes No
- Comments: Click here to enter text.
17. What were the main results of the case control study?
- Statistical significance (p value): Click here to enter text.
 - Confidence interval and/or Standard deviation: Click here to enter text.
 - How precise was the intervention/treatment?
 - Narrow? Wide: Click here to enter text.
 - Effect size: Click here to enter text.
18. Were the results clinically significant? Yes No Unknown
- Unknown:
- Were the following reported: NNH (number needed to harm), NNT (number needed to treat), OR (odds ratio), RR (relative risk)? Click here to enter text.
- Comments: Click here to enter text.
19. Were the potential confounders identified? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
20. Were safety concerns including risks/benefits identified? Yes No Unknown
- Unknown:
- Comments: Click here to enter text.
- Applicability/Generalizability: Can I apply these valid, important study results?**

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Rapid Critical Appraisal of a Descriptive Study

21. Can the results be applied to my population of interest? Yes No Unknown

a. Is the treatment feasible in my care setting? Yes
 No

b. Do the outcomes apply to my population of interest? Yes No

c. Are the likely benefits worth the potential harm and costs? Yes No

d. Are the subjects/participants in this study similar to my population of interest?
 Yes No

e. Were all clinically important outcomes considered? Yes
 No

Comments: [Click here to enter text.](#)

22. Will you use the study/article in your practice to make a difference in outcomes?

Yes No Unknown

f. If yes, why would you do this & how? [Click here to enter text.](#)

g. If no, why would you not include the results to make a difference? [Click here to enter text.](#)

Strength of Study

Level of study: I II III IV V VI VII

Quality of Study: High Medium Low

Strength = Level + Quality

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Rapid Critical Appraisal of a Descriptive Study

What is the strength of this study? Medium

What is your recommendation for article inclusion in the body of evidence to answer your question?

Include this article in the body of evidence (place article on evaluation and synthesis table)

Do NOT include this article in the body of evidence

Additional comments: [Click here to enter text.](#)

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Rapid Critical Appraisal of a Descriptive Study

Project Title: Healthcare Access and Utilization for Young Adults with Disability: U.S., 2014-2018

Date: 06/26/2022 By Dawn Boal

PICOT Question: 1 In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article citation (APA): Verlenden, J. V., Zablotsky, B., Yeargin-Allsopp, M., & Peacock, G. (2022).

Healthcare access and utilization for young adults with disability: U. S., 2014–2018. *Journal of Adolescent Health*, 70(2), 241–248. <https://doi.org/10.1016/j.jadohealth.2021.08.023>

Indicate the level of the study you are appraising: Level 6 meta-synthesis

Recommendation for article inclusion in the body of evidence to answer your question: Yes, show problem, barriers, and suggestions

Overview

- Purpose of study, including research question(s) or hypotheses:** Young adults with disability experience barriers to healthcare access and are at risk for not receiving needed services as they transition from pediatric to adult health systems. This study examined patterns of healthcare utilization for young adults with disability and potential barriers to receipt of care.
- Design/Method:** meta-synthesis 2014 to 2018 National Health Interview Survey
- Sample:** (unweighted n =15,710) 18-30 year old adults with/without disabilities
- Setting:** National survey
- Data Collection:** Interview

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Rapid Critical Appraisal of a Descriptive Study

- What was the rate attrition? NA
- What reason were given to explain why subjects did not complete study?

Comments: Click here to enter text.

9. Was there freedom from conflict of interest? Yes No Unknown

- Sponsorship/funding agency
- Investigator

Comments: Click here to enter text.

10. Was the date range of the cited literature current? Yes No Unknown

- What date ranges were included? 2000 to 2020
 - If older literature was included, why was it included? Click here to enter text.

Reliability: Are these valid study results important?

11. What were the results? Significant difference between young adults with disabilities and young adults without disabilities, among young adults with disabilities 19.1% report having had to delay medical care due to cost and 11.9 reported not receiving medical care due to costs, significantly more than young adults without disabilities and 21.2% of young adults with disabilities had unmet medical care needs compared to just 10.2% without disabilities. Those with disability were more likely to use the emergency room as their usual place of care (5.3% vs. 1.8%). A greater percentage of young adults with disability delayed medical care due to cost (19.1% vs. 8.9%) and reported an unmet medical need (21% vs. 10.2%).

12. Was measurement of the intervention(s) appropriate? Yes No Unknown

Comments: Click here to enter text.

13. Was measurement of the intervention(s) clearly defined? Yes No Unknown

Comments: Click here to enter text.

14. Was the measurement of the outcome(s) appropriate?

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Rapid Critical Appraisal of a Descriptive Study

Quality of the Study

Validity: Are the results of this study valid?

1. Were the study/survey methods appropriate for the question? Yes No Unknown

Comments: Click here to enter text.

2. Were the study/survey methods clearly described? Yes No Unknown

Comments: Click here to enter text.

3. Were instruments used to measure the outcomes valid and reliable? Yes No Unknown

- Were the instruments tested to be valid and reliable? Yes No
- What statistic was reported and what was the finding? (Cronbach's alpha/other)? Chi-square, using pairwise comparisons via bivariate logistic regressions. Compared non-disabled to disabled adults

4. Were all appropriate variable and interventions clearly described? Yes No Unknown

Comments: Click here to enter text.

5. Were outcome appropriate for the question? Yes No Unknown

Comments: Click here to enter text.

6. Were outcomes clearly described? Yes No Unknown

Comments: Click here to enter text.

7. Was sampling clearly described? Yes No Unknown

Comments: unweighted

8. Were all participants accounted for throughout the duration of the study? Yes No Unknown

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Rapid Critical Appraisal of a Descriptive Study

15. Was measurements of the outcome(s) clearly defined? Yes No Unknown

Comments: Click here to enter text.

16. Did the study have a sufficient sample size? Yes No Unknown

Comments: Click here to enter text.

17. What were the main results of the case control study? Yes No Unknown

- Was a power analysis conducted? Yes No
- Did the sample size achieve or exceed the power analysis requirement? Yes No
- Did each subgroup also have sufficient sample size? Yes No

Comments: Click here to enter text.

18. Were the results clinically significant? Yes No Unknown
- Statistical significance (p value): < .001
 - Confidence Interval and/or Standard deviation: CI: 1.68-3.12, p < .001
 - How precise was the intervention/treatment?
 - Narrow? Wide: Click here to enter text.
 - Effect size: Click here to enter text.

19. Were the results clinically significant? Yes No Unknown
- Were the following reported: NNH (number needed to harm), NNT (number needed to treat), OR (odds ratio), RR (relative risk)? Click here to enter text.

Comments: Click here to enter text.

20. Were the potential confounders identified? Yes No Unknown

Comments: Click here to enter text.

21. Were safety concerns including risks/benefits identified? Yes No Unknown

Comments: Click here to enter text.

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Rapid Critical Appraisal of a Descriptive Study

Applicability/Generalizability: Can I apply these valid, important study results?21. Can the results be applied to my population of interest? Yes No Unknowna. Is the treatment feasible in my care setting? Yes Nob. Do the outcomes apply to my population of interest? Yes Noc. Are the likely benefits worth the potential harm and costs? Yes No

d. Are the subjects/participants in this study similar to my population of interest?

 Yes Noe. Were all clinically important outcomes considered? Yes NoComments: [Click here to enter text.](#)

22. Will you use the study/article in your practice to make a difference in outcomes?

 Yes No Unknown

f. If yes, why would you do this & how? The disparities of health care for disabled young adults

g. If no, why would you not include the results to make a difference? [Click here to](#)[enter text.](#)**Strength of Study**Level of study: I II III IV V VI VII

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Rapid Critical Appraisal of a Descriptive Study

Quality of Study: High Medium Low**Strength = Level + Quality**

What is the strength of this study? high

What is your recommendation for article inclusion in the body of evidence to answer your question?

 Include this article in the body of evidence (place article on evaluation and synthesis table) Do NOT include this article in the body of evidenceAdditional comments: [Click here to enter text.](#)

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

Project Title: Rapid Synthesis: Identifying Features of Approaches to Supporting Transitions from Child to Adult Care for Young People with Special Healthcare Needs–McMaster Forum

Date: March 27, 2020

PICOT Question: PICO Question #1 In young adults with ASD (P) does health care transition resources (I) compared to usual care (C) affect their transition to primary care (O)? I obtained three systematic reviews on young adults with ASD transition into adult services with special health needs.

Article citation (APA): Voorheis P, Wilson MG, Scallan E. (2020). Rapid synthesis: Identifying features of novel approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada. Hamilton: McMaster Health Forum. [Identifying Features of Approaches to Supporting Transitions from Child to Adult Care for Young People with Special Healthcare Needs](#) ([mcmasterforum.org](#))

Indicate the level of the study you are appraising: Level 4: Systematic review of mixed experimental and non-experimental

Recommendation for article inclusion in the body of evidence to answer your question: It gave recommendations for resources for transition and explained barriers

Overview

1. **Purpose of study, including research question(s) or hypotheses:** What are the features of novel approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada?

2. **Design/Method:** Systematic review of mixed experimental and non-experimental

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

g. Double-blind? Yes No

Comments: [Click here to enter text.](#)

4. Did the systematic review/meta-analysis include non-RCTs? Yes No Unknown

a. Was criteria used to select articles for inclusion? Yes No

b. What were the criteria for inclusion? Transitioning young adults with special needs

c. Analyzed in assigned groups? Yes No

d. Complete follow-up of subjects? Yes No

e. Blind? Yes No

f. Double-blind? Yes No

5. Were the included studies appraised to be highly quality by the authors? Yes No Unknown

Comments: high- medium quality

6. Were the methods consistent from study to study? Yes No Unknown

a. Were the populations in the included studies comparable? Yes No

b. Were the outcomes, interventions, and exposures measured the same way in the groups being compared in the included studies? Yes No

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

3. **Sample:** Canada health system

4. **Setting:** Canada

Quality of the Study

Validity: Are the results of this study valid?

1. Did the systematic review/meta-analysis address a focused clinical question? Yes No Unknown

a. What was the focused clinical question? What are the features of novel approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada?

2. Was the search for relevant studies detailed and exhaustive? Yes No Unknown

Comment: [Click here to enter text.](#)

3. Did the systematic review/meta-analysis include RCTs? Yes No

a. Was criteria used to select articles for inclusion? Yes No

b. What were the criteria for inclusion? Yes No

c. Random assignment to treatment groups? Yes No

d. Analyzed in assigned groups? Yes No

e. Complete follow-up of subjects? Yes No

f. Blind? Yes No

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

Comments: [Click here to enter text.](#)

7. Were the results consistent across the included studies? Yes No Unknown

Comments: Charts included for intervention

8. Was there freedom from conflict of interest? Yes No Unknown

Unknown

- Sponsorship/funding agency

- Investigators

Comments: Funding: Scotiabank Chair in Child Health Research held by Dr. Jan Willem

Gorter. The McMaster Health Forum receives both financial and in-kind support from McMaster University.

9. Was the date range of the cited literature current? Yes No Unknown

a. What date ranges were included? 2006 to 2020

b. If older literature was included, why? [Click here to enter text.](#)

Comments: [Click here to enter text.](#)

Reliability: Are these valid study results important?

10. What were the main results of the systematic review/meta-analysis?

a. For each individual study:

i. Statistical Significance (p value): no meta analysis

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

- ii. **Confidence Interval and/or Standard Deviations:** [Click here to enter text.](#)
- iii. **How precise was the intervention/treatment?** [Click here to enter text.](#)
- Narrow/wide?** [Click here to enter text.](#)
- b. **For the summary statistic?**
- Statistical significance (z statistic):** [Click here to enter text.](#)
 - Were the studies heterogeneous?** Yes No
 - Confidence interval:** [Click here to enter text.](#)
 - Effect size:** [Click here to enter text.](#)
 - Did it favor the intervention?** Yes No
 - Did it favor the control?** Yes No
- Comments:** [Click here to enter text.](#)
11. **Were the results clinically significant?** Yes No Unknown
- Were the following reported: NNT, NNH, OR, RR? Yes No
- Comments:** [Click here to enter text.](#)
12. **Were potential confounders identified?** Yes No Unknown
- Were the potential confounders discussed in the relationship to the results?** Yes No
- Comments:** [Click here to enter text.](#)
13. **Were adverse events identified?** Yes No Unknown

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

Quality of Study: High Medium Low

Strength = Level + Quality

What is the strength of this study? Medium

What is your recommendation for article inclusion in the body of evidence to answer your question?

- Include this article in the body of evidence (place article on evaluation and synthesis table)
- Do NOT include this article in the body of evidence

Additional comments: [Click here to enter text.](#)

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Rapid Critical Appraisal of a Systematic Review/Meta Analysis of Quantitative Studies

Comments: [Click here to enter text.](#)

Applicability/Generalizability: Can I apply these valid, important study results?

14. **Can the results be applied to my population of interest?** Yes No Unknown
- Is the treatment feasible in my care setting?** Yes No
 - Do the outcomes apply to my population of interest?** Yes No
 - Are the likely benefits worth the potential harm and costs?** Yes No
 - Are the subjects/participants in this study similar to my population of interest?** Yes No
 - Were all clinically important outcomes considered?** Yes No
15. **Will you use the study/article in your practice to make a difference in outcomes?** Yes No Unknown
- If yes, why would you do this & how?** It explores all aspects of transition and barriers
 - If no, why would you not include the results to make a difference?** [Click here to enter text.](#)

Strength of Study

Level of study: I II III IV V VI VII

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Appendix C

Level of Evidence Table for PICO Question

Level of Evidence Table for PICO

| Levels of Evidence | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|---|
| Level I: Systematic review or meta-analysis of RCTs | | | | | | | |
| Level II: Randomized controlled trial | | | | | | | |
| Level III: Systematic review with or without metanalysis of mixed experimental study design | | | | | | | |
| Level IV: Systematic Review of experimental and non-experimental study design | | | x | | | | |
| Level V: Observational studies (cohort, case-control, cross-sectional) | | | | | x | | |
| Level VI: Qualitative single study or meta-synthesis | x | x | | x | | x | |
| Level VII: Peer reviewed Professional and organizational standards with clinical studies to support recommendations | | | | | | | |
| Level VIII: expert opinion or literature review or peer reviewed professional and organizational standards without clinical studies to support recommendations, or quality improvement study or evident evidence-based practice project | | | | | | | x |
| Level IX manufacturers' recommendations | | | | | | | |

LEGEND

1= Ames et al., 2022, 2= Kuhlthau et al., 2015. 3= Voorhies et al., 2020. 4= Verlenden,et al., 2021. 5= Jones et al., 2016, 6= Lee et al., 2022,7=Harris et al, 2018.

Appendix D

Table 1

Variables of Interest: PICO Question

| P Variables in Articles | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|----------|----------|----------|----------|----------|----------|----------|
| Describes the Problem | P | P | P | P | P | P | P |
| Describes Barriers to Transition | P | P | P | P | P | P | P |
| Trainings for adult clinicians | P | P | P | | P | | P |
| Systematic medical summaries | | P | | | | | P |
| Information sessions for parents/guardians and youth | P | P | P | P | | | P |
| Transition notebooks | P | P | P | | | | P |
| Care coordination | P | P | P | | | | P |
| Systematic lists of adult clinicians willing to care for individuals with ASD and knowledgeable about their care needs | P | P | P | | | | P |
| Transition-point person | P | P | P | | | | |
| Transition specific appointments, pediatrician communicates with adult primary care | P | P | P | | | | P |
| Community resource list | P | P | P | P | | | P |
| EMR transition documentation | P | | P | | | | P |

SYMBOL KEY **P** That it is present in the report

LEGEND **1**= Ames et al., 2022, **2**= Kuhlthau et al., 2015. **3**= Voorhies et al., 2020. **4**= Verlenden, et al., 2021. **5**= Jones et al., 2016, **6**= Lee et al., 2022, **7**= Harris et al, 2018.

Appendix E

Figure 1. Implementation of PDSA Cycle

| PDSA CYCLES | | | | TIME OF IMPLEMENTATION | | | | |
|--|--|-------|--|------------------------|-----|------|------|---------------|
| PDSA | Description Activity | PDSA | Description | April | May | June | July | August & Sept |
| 1ST PDSA CYCLE May 2022- May 2023 preparation | | | | | | | | |
| PLAN | Develop and create a Transitional Tool kit for Caregivers with YA-ASD | | | | x | x | x | x |
| PLAN | Gather information on what resources are valuable for transition | | | x | | | | |
| DO | Call providers in the area on who are accepting new patients and will accept YA-ASD | | | x | | | | |
| DO | <i>"The lead investigator (D. Boal) will assemble a list of providers accepting new YA-ASD patient"</i> | | | | | | | |
| DO | Activity/intervention A Complete provider list | STUDY | Once all the numbers on the original provider list have been called and survey taken with Got transition questions 1 &3 asked | | | | | |
| DO | Activity/intervention B Met with Dr. D | STUDY | Discussed what resources need to go into tool kit | | | | | |
| DO | Activity/intervention C Connected with local Mom's group | STUDY | Read emails about caregivers' transitional stories and input | | | | | |
| DO | | STUDY | | | | | | |
| DO | Tool kit Assembly | | | | x | x | x | x |
| DO | <i>"The lead investigator (D. Boal) will assemble Toolkit and upload it to REDcap"</i> | | | | | | | |
| DO | Activity/intervention A Test links of resources | STUDY | How will you determine/measure if activity A is an effective intervention activity? What are your outcomes and measurements? To see if the links work | | | | | |
| DO | Activity/intervention B Place provider list/ resources | STUDY | To see if the provider list and resources are an easy-to-read list for caregivers in using readable.com and are at 5 th grade reading level | | | | | |
| DO | Obtain Feedback on Toolkit | | | | x | | | |
| DO | Will ask for feedback From Clinical expert, Project mentor and project advisor and Providers from the practice setting | STUDY | Listen to feedback and adjust toolkits and resources | | | | | |
| ACT & PLAN | If our goal is not met, and using the data collected from PDSA cycle #1, the lead investigator (D. Boal) will determine what she will do differently in PDSA cycle # 2 | | | | | x | | |
| PDSA CYCLE QR code/ REDcap caregiver survey to evaluate tool kit | | | | | | | | |
| All next steps of the PDSA cycle will be dependent on the findings from the 1 st PDSA cycle | | | | | | | | |
| PLAN | Working with the team, the lead investigator (D. Boal) will develop a survey for caregivers to evaluate the transitional tool kit. | | | | | | x | |
| DO | Activity/intervention: Ask questions to clinical specialist | STUDY | The design is to have a Likert scale that will evaluate each section of the toolkit. There will, also be two questions for feedback. | | | | | |
| DO | Activity/intervention B Learn REDcap | STUDY | REDcap can capture the survey response so the data can be analyzed. Test surveys to make sure they are working correctly | | | | | |
| DO | Obtain Feedback on final survey questions | | | | x | | | |
| DO | Will ask feedback for change in process From Clinical expert, and project advisor | STUDY | Check if QR Code survey links are working by testing input. Then see if the tool kit needs to be improved base on survey response. | | | | | |

| ACT & PLAN | If our goal is not met, and using the data collected from PDSA cycle #1, the lead investigator (D. Boal) will determine what she will do differently in PDSA cycle # 2 | | | | | X | | X |
|---|--|-------|---|------------------------|-----|------|------|---------------|
| PDSA CYCLES | | | | TIME OF IMPLEMENTATION | | | | |
| PDSA | Description Activity | PDSA | Description | April | May | June | July | August & Sept |
| PDSA CYCLE- May 2023 implementation plan | | | | | | | | |
| PLAN | To train clinicians & collaborating RNs about the process and need for project | | | | X | X | X | X |
| PLAN | Develop and create a script, flyer, describing project and QR code link to REDcap survey to store and use caregivers' personal information | | | | X | X | X | X |
| DO | <i>"The lead investigator (D. Boal) will develop a video explaining the project and the role for the clinicians and collaborating RNs in the project.</i> | | | | X | X | X | X |
| DO | <i>"The lead investigator (D. Boal) will create a script for on the flyer to ensure the same information is given to everyone consistently</i> | | | | | | | |
| DO | Activity/intervention A Develop flyer with script on it explaining project | STUDY | Look at the flyer and think about the most effective and efficient way to explain project for script. For flyer, convey what resources are important and the necessity of the information in the toolkit | | | | | |
| DO | Activity/intervention B Have a laminated flyer for the clinicians | STUDY | The clinicians and RNs will have a laminated flyer for the project and will give a regular flyer to caregivers who want to receive the toolkit. | | | | | |
| DO | Activity/intervention C Have a QR code explaining who the project manager is and capture caregiver's information | STUDY | The lead investigator will have to learn how to capture this on REDcap via QR Code on flyer and make sure all information in QR code is correct. | | | | | |
| DO | Make sure the automated Redcap survey and toolkit are sent to caregivers | STUDY | Once contact data has been captured on REDcap, Redcap will automatically send the toolkit to the Caregiver via email with the feedback survey. Test Redcap Surveys to make sure they work with smart phones and computers. | | | | | |
| DO | Project management and continuation of project | | | | X | X | X | X |
| DO | <i>"The lead investigator (D. Boal) will visit as often as requested for the beginning of project implementation and at least once every other week throughout the project. follow up/ nudge emails will be sent to encourage and remind designated project advocates. if project manager could not be there, Emails from Kennett Square office will be addressed daily.</i> | | | | | | | |
| DO | Activity/intervention A & B Script on flyer | STUDY | How will you determine/measure if activity A is an effective intervention activity? <u>What are your outcomes and measurements?</u> That clinicians can offer the project with ease and will demonstrate understanding of the video by filling out the attestation in REDcap. | | | | | |
| DO | Activity/intervention C | STUDY | This will be assessed by the caregiver giving out contact information in the QRcode link to REDcap survey, receiving the toolkit and can access all links without difficulty | | | | | |
| DO | Obtain Feedback on Toolkit distribution process | | | | X | X | X | X |
| DO | Will ask for feedback, from clinicians and nurses | STUDY | Listen to feedback and adjust project process as needed | | | | | |
| ACT & PLAN | If our goal is not met, and using the data collected from PDSA cycle #1, the lead investigator (D. Boal) will determine what she will do differently in PDSA cycle # 2 | | | | | X | | X |

Appendix F

ASD Resource Toolkit



Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care

Quality Improvement Project
by Dawn Boal BSN, RN
ASDtransitions@xxx.edu
Doctor of Nursing Practice
Student - Sacred Heart
University
Project Site Clinical Mentor
Dr. Kerry A. Milner, DNsc,
APRN, EBP-CH
Faculty Advisor










Purpose of the Toolkit

This tool kit is to help caregivers of children with autism spectrum disorder. It is for the County area. It has key links to helpful resources.

Did you know that some service providers won't take new customers or new patients with ASD? Our lists show providers who will take them!

This toolkit is a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty Advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxx.edu

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-  [7 Dentists / Orthodontists](#)
-  [8 Adult Day Care](#)
-  [9 Lawyers](#)
- [10 Adult Providers](#)
- [11 Survey \(Please help me by taking this\)](#)

This toolkit is a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty Advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxx.edu

1. Insurance and Financial Help

Local Medicaid resource link

- In Pennsylvania: <https://www.compass.state.pa.us>
- In Delaware: www.dhss.delaware.gov/dss/medicaid.html

Your child could qualify them for support income. This link gives directions on how to meet them and what to bring.
<https://www.research.chop.edu/car-autism-roadmap/supplemental-security-income-for-children-with-disabilities>

Last Updated:
June 10th, 2023



This toolkit is a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty Advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxx.edu

Last Updated:
June 10th, 2023

2. Legal Help

Here are options for when your child needs to decide. This link helps you and your child of 18 years or older to make decisions when they are an adult.

<https://www.research.chop.edu/car-autism-roadmap/turning-18-options-for-when-your-child-needs-decision-making-help>

Waivers are programs that are to help someone stay in their home.

Some kids move to an institution because of a need for care.

<https://www.research.chop.edu/car-autism-roadmap/waivers>

Special needs trust are a way to help your child have money. This link explains what is a special needs trust.

<https://www.research.chop.edu/car-autism-roadmap/special-needs-trusts>



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3. Educational Help

Services from the state of PA. This link is to services which help train, obtain, and maintain employment in PA.

<https://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx>

This link informs you how your child can get federal aid for school. Help for living and academics are also a part of this program.

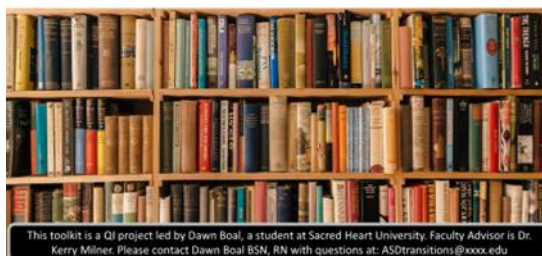
<https://www.research.chop.edu/car-autism-roadmap/higher-education-opportunity-act-of-2008>

This link is to a local college that has a program designed for students with ASD.

<https://www.wcupa.edu/deputy-provost/dcap/>

This link is to a program to assess readiness for college at West Chester University

<https://www.wcupa.edu/deputy-provost/dcap/carr.aspx>



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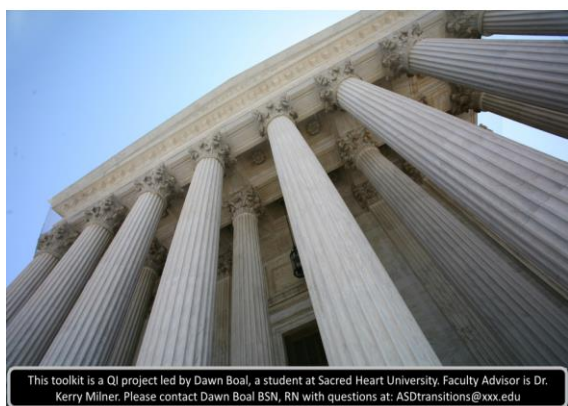
4. Other Programs

This link is to the Autism Speaks toolkit for transitions, which covers general topics.

<https://www.autismspeaks.org/tool-kit/transition-tool-kit>

This link is for a program offered by the state of PA. It is to support caregivers of and people with ASD.

<https://www.dhs.pa.gov/contact/DHS-Offices/Pages/ODP-Bureau%20of%20Autism%20Services.aspx>



5. Barbers and Hair Salons

Last Updated:
June 10th, 2023

- Blue 52 Barber Shop 610-612-9361
331 State St, Kennett Square, PA 19348
- Burton's Barber Shop 610-444-9964
105 W State St # A, Kennett Square, PA 19348
- B&B Barber Lounge 484-732-7951
116 S Union St, Kennett Square, PA 19348
- Pepe's Barbershop 610-492-2244
1153 Newark Rd, Toughkenamon, PA 19374
- Holiday Hair 610-444-9997
350 Scarlet Rd suite 25-b, Kennett Square, PA 19348
- Supercuts Kennett Square 484-732-8053
817 E Baltimore Pike, Kennett Square, PA 19348
- Flips Barber Shop 610-467-1670
10 S 3rd St, Oxford, PA 19363
- SmartStyle Hair Salon 610-998-1483
800 Commons Dr, Oxford, PA 19363
- Top-Notch Barbershop 610-806-5412
11 Exchange Pl, West Grove, PA 19390
- Great Clips 610-444-6510
144 Onix Dr, Kennett Square, PA 19348
- Salon Secrets Spa- Kennett Square 610-444-0605
829 E Baltimore Pike, Kennett Square, PA 19348
- Linda's Hair Techniques 610-268-3221
911 Gap Newport Pike, Avondale, PA 19311
- Shear Satisfaction 610-268-8917
1120 Newark Rd, Toughkenamon, PA 19374
- Jillian Grace Salon 610-869-4114
2050 Newark Rd, Lincoln University, PA 19352

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Last Updated:
June 10th, 2023

6. Eye Doctors

- Ganly Vision Care 484-770-8132
402 Bayard Rd #200, Kennett Square, PA 19348
- MyEyeDr. - Kennett 610-444-5252
841 E Baltimore Pike, Kennett Square, PA 19348
- Kennett Square Eye Care 610-444-5522
216 S Mill Rd Ste 112, Kennett Square, PA 19348
- Chester County Eye Care Associates 610-696-1230
455 W Woodview Rd #125, West Grove, PA 19390
- Miller Eye Care 610-869-4200
57 Jenners Vlg Ctr, West Grove, PA 19390
- MyEyeDr. - Oxford 610-932-9356
49 S 2nd St, Oxford, PA 19363



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Last Updated:
June 10th, 2023

7a. Dentists

- Leardi Family Dentistry 610-571-2520
690 Unionville Rd, Kennett Square, PA 19348
- Albert J Schmitt DMD 610-444-6300
413 McFarlan Rd, Kennett Square, PA 19348
- Jay W. Dorgan DDS 610-925-3222
127 W Street Rd #301, Kennett Square, PA 19348
- C Christian Franck Family Dental 610-444-3212
721 E Baltimore Pike # 301, Kennett Square, PA 19348
- Dental Health Associates 610-444-0750
687 Unionville Rd, Kennett Square, PA 19348
- Kennett Dental 610-444-4033
402 McFarlan Rd #303, Kennett Square, PA 19348

7b. Orthodontists

- The Orthodontic Group of Chester County 484-218-0088
400 McFarlan Rd STE 200, Kennett Square, PA 19348
- McCormick Orthodontics 888-333-3757
900 W Baltimore Pike #201, West Grove, PA 19390



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8. Adult Day Care

- Chester County Department of Mental Health/ Intellectual & Developmental Disabilities (MH/IDD) 610-344-6265
www.chesco.org/mhidd
(Can help with free adult day care)
- Active Day of Kennett Square 610-388-1166
500 Old Forge Ln, Kennett Square, PA 19348
- Kennett Area YMCA 610-444-9622
101 Race St, Kennett Square, PA 19348

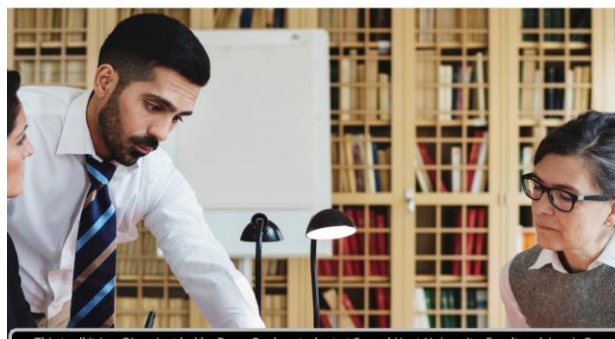


This toolkit is a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty Advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxx.edu

Last Updated:
June 10th, 2023

9. Lawyers

- Randy Hope Steen, Esq 215-570-0047
600 Eagleview Blvd, Exton, PA 19341
- Stephan D. Potts, Esq 610-254-0114
138 West Gay St, West Chester, PA 19380



This toolkit is a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxedu

10. Adult Providers for 18 years olds+

Your child's provider will continue to work with them. Even when your child becomes an adult and moves into adult care.

Last Updated:
June 10th, 2023

[Dr. Cheryl Hlavac, MD](#)

- 402 McFarlan Rd Ste 102, Kennett Square, PA 19348
- 610-444-5678
- Practice Name: Penn Family Medicine Kennett

[Megan M. Gaskill, MD](#)

- 402 McFarlan Rd Ste 102 Kennett Square, PA 19348
- 610-444-5678
- Practice Name: Penn Family Medicine Kennett

[Dr. Deepika Suri MD](#)

- 404 McFarlan Road, Suite 101, Kennett Square, PA 19348
- 610-925-3835
- Practice Name: Penn Family and Internal Medicine Longwood

[Melissa Hubley, DO](#)

- 620 Spear Street, Oxford, PA 19363
- 610-932-9300
- Practice Name: LG Health Physicians Family Medicine Oxford

[Spencer S. Hoffman, DO](#)

- 620 Spear Street, Oxford, PA 19363
- 610-932-9300
- Practice Name: LG Health Physicians Family Medicine Oxford

[Dr. Karl Zimmerman, MD](#)

- 127 W Street Rd Ste 101 Kennett Square, PA 19348
- 610-444-1212
- Practice Name: Willowdale Internal Medicine Associates



This toolkit is part of a QI project led by Dawn Boal, a student at Sacred Heart University. Faculty Advisor is Dr. Kerry Milner. Please contact Dawn Boal BSN, RN with questions at: ASDtransitions@xxx.edu

Appendix G

Link to clinician instruction video and Transcript

<https://youtu.be/fY27cgIjZg>

Hi, I am a Doctor of Nursing practice student at an University. I'm here to talk about my project, a toolkit to help transitioning young adults with autism spectrum disorder move to primary care. This is a quality improvement project. The purpose of this project is to provide a The ASD transition resource toolkit that presents numerous important resources and lists of supportive local service clinicians with a criterion that includes caregivers of adolescents and young adults with autism spectrum disorder ages 15-21. We have an additional goal to get the caregiver's feedback on how to improve the toolkit.

When the caregiver comes in for a well office visit that meets the criteria, it is up to the discretion of the clinician to present the quality improvement project to the caregiver. Nurses in collaboration with the clinician may also present the project to the caregiver.

There will be a laminated flyer with a script on the back, for the clinician or nurse to present the project to the caregiver, The script would need to be followed exactly. If possible, please present this at the end of the visit.

Remember we are not trying to transition everyone out of pediatric care, this project is to get feedback on the toolkit and its contents. This project attempts to prepare the caregiver and what the next steps are when their child becomes an adult with A.S.D.

If the caregiver chooses to participate, there will be flyers to give to them. This process allows them to scan the QR code without pressure, I will need to keep an account of the flyers, so please do not make extra copies without letting me know. I will keep extra copies in the office.

When Caregivers scan the QR code, a welcome page will be presented. The caregiver will enter their email address to participate; once entered the caregiver survey will be presented and upon completion the tool kit will automatically be emailed to the caregiver.

This email will include the tool kit and a link to the survey for evaluation. This email and toolkit can be accessed as many times as the caregiver needs.

Thank you for helping me with my quality improvement project.

I also want to recognize and acknowledge...

My Faculty Advisor,

My Project Site Clinical Mentor,

For any questions email at ASDtransitions@xxedu

Appendix H

ASD Transition Project Introduction, Staff Attestation

Thank you for your participation in this project, "Toolkit for Transition of Young Adults with Autism Spectrum Disorder (YA-ASD) to Primary Care." Ensuring all of the team members at Project Setting are aware of the project, understand the impact of the project to the staff, our patients, and their families, and have the opportunity to ask questions or give feedback is a priority for the project team.

This project has been supported by Project Settings Center for Pediatric Nursing Research & Evidence-Based Practice and has been reviewed by Project Setting's IRB and determined to be non-human subjects research.

The project lead is DNP Student/Project Lead, xxx@xxx.edu, and the project's co-investigator is Project Site Clinical Mentor, xxx@xxx.edu. The project team has a shared inbox that is continuously monitored, and questions or comments can be directed here at any time: ASDtransitions@xxx.edu.

To ensure all of the team at the Project Site have completed the needed preparation for the project, we are asking everyone to complete the following attestation. Once you have watched the introduction video, please complete the form below. Thank you!

Please watch the attached video and then fill out the following

1) What is your name? _____

2) What is your Project Site email address? _____

3) What is your role at the Project Site?

- clinical nurse
 nurse practitioner
 medical doctor
 other

4) I attest that I have reviewed and understood the video explaining the implementation process for the project "Toolkit for Transition of Young Adults with Autism Spectrum Disorder (YA-ASD) to Primary Care

YES

(If you have not yet finished the project's introductory video, please save and close this form. REDCap will provide instruction as to how to return to it AFTER you have watched the video. Thank you!)

5) If you have any questions or comments, please share them below and DNP Student/project lead, will be in touch soon!

(required so that the DNP Student/project lead can follow up with staff as needed)

Appendix I

Readable.com Reports for Project Interface with Caregiver



Text readability report generated on 2023-06-22 03:31.

| Readability Grade Levels | | ReadablePro Rating | | Text Quality | |
|----------------------------|-------|--------------------|--|--------------|--|
| Flesch-Kincaid Grade Level | 5.14 | A | | | |
| Gunning Fog Index | 5.01 | | | | |
| Coleman-Liau Index | 10.36 | | | | |
| SMOG Index | 7.39 | | | | |
| Readability Scores | | | | | |
| Flesch Reading Ease | 78.78 | | | | |
| CEFR Level | B2 | | | | |
| IELTS Level | 5-6 | | | | |
| Spache Score | 4.34 | | | | |
| New Dale-Chall Score | 5.58 | | | | |
| Lix Readability | 32.71 | | | | |
| Lensear Write | 85.58 | | | | |
| Text Quality | | | | | |
| Spelling Issues | 0 | 0% | | | |
| Grammar Issues | 2 | 22% | | | |
| Sentences > 30 Syllables | 0 | 0% | | | |
| Sentences > 20 Syllables | 1 | 11% | | | |
| Words > 4 Syllables | 0 | 0% | | | |
| Words > 12 Letters | 0 | 0% | | | |
| Writing Style | | | | | |
| Passive Voice Count | 0 | 0% | | | |
| Adverb Count | 0 | 0% | | | |
| Cliché Count | 0 | 0% | | | |



Text readability report generated on 2023-08-16 06:07.

| Readability Grade Levels | | ReadablePro Rating | | Text Quality | |
|----------------------------|-------|--------------------|--|--------------|--|
| Flesch-Kincaid Grade Level | 5.70 | A | | | |
| Gunning Fog Index | 5.91 | | | | |
| Coleman-Liau Index | 7.78 | | | | |
| SMOG Index | 8.59 | | | | |
| Readability Scores | | | | | |
| Flesch Reading Ease | 74.18 | | | | |
| CEFR Level | B2 | | | | |
| IELTS Level | 5-6 | | | | |
| Spache Score | 3.73 | | | | |
| New Dale-Chall Score | 5.79 | | | | |
| Lix Readability | 31.61 | | | | |
| Lensear Write | 87.24 | | | | |
| Text Quality | | | | | |
| Spelling Issues | 3 | 1% | | | |
| Grammar Issues | 5 | 14% | | | |
| Sentences > 30 Syllables | 1 | 3% | | | |
| Sentences > 20 Syllables | 8 | 23% | | | |
| Words > 4 Syllables | 2 | 1% | | | |
| Words > 12 Letters | 2 | 1% | | | |
| Writing Style | | | | | |
| Passive Voice Count | 3 | 2% | | | |
| Adverb Count | 3 | 1% | | | |
| Cliché Count | 0 | 0% | | | |

Caregiver Feedback 1 week reminder

Automated Bridge with Toolkit and Survey link



Text readability report generated on 2023-06-22 03:07.

| Readability Grade Levels | | ReadablePro Rating | | Text Quality | |
|----------------------------|--------|--------------------|--|--------------|--|
| Flesch-Kincaid Grade Level | 4.62 | A | | | |
| Gunning Fog Index | 3.16 | | | | |
| Coleman-Liau Index | 9.57 | | | | |
| SMOG Index | 7.90 | | | | |
| Readability Scores | | | | | |
| Flesch Reading Ease | 71.63 | | | | |
| CEFR Level | C2 | | | | |
| IELTS Level | 8+ | | | | |
| Spache Score | 3.39 | | | | |
| New Dale-Chall Score | 7.06 | | | | |
| Lix Readability | 31.19 | | | | |
| Lensear Write | 116.31 | | | | |
| Text Quality | | | | | |
| Spelling Issues | 35 | 4% | | | |
| Grammar Issues | 45 | 29% | | | |
| Sentences > 30 Syllables | 0 | 0% | | | |
| Sentences > 20 Syllables | 10 | 6% | | | |
| Words > 4 Syllables | 9 | 1% | | | |
| Words > 12 Letters | 1 | 0% | | | |
| Writing Style | | | | | |
| Passive Voice Count | 0 | 0% | | | |
| Adverb Count | 3 | 0% | | | |
| Cliché Count | 0 | 0% | | | |



Text readability report generated on 2023-06-22 02:43.

| Readability Grade Levels | | ReadablePro Rating | | Text Quality | |
|----------------------------|-------|--------------------|--|--------------|--|
| Flesch-Kincaid Grade Level | 5.30 | A | | | |
| Gunning Fog Index | 7.05 | | | | |
| Coleman-Liau Index | 7.24 | | | | |
| SMOG Index | 8.42 | | | | |
| Readability Scores | | | | | |
| Flesch Reading Ease | 78.72 | | | | |
| CEFR Level | B2 | | | | |
| IELTS Level | 5-6 | | | | |
| Spache Score | 3.80 | | | | |
| New Dale-Chall Score | 4.44 | | | | |
| Lix Readability | 29.40 | | | | |
| Lensear Write | 90.59 | | | | |
| Text Quality | | | | | |
| Spelling Issues | 0 | 0% | | | |
| Grammar Issues | 3 | 14% | | | |
| Sentences > 30 Syllables | 0 | 0% | | | |
| Sentences > 20 Syllables | 6 | 29% | | | |
| Words > 4 Syllables | 0 | 0% | | | |
| Words > 12 Letters | 0 | 0% | | | |
| Writing Style | | | | | |
| Passive Voice Count | 0 | 0% | | | |
| Adverb Count | 3 | 1% | | | |
| Cliché Count | 0 | 0% | | | |

Report for Toolkit v9

Report for Flyer and Script



Text readability report generated on 2023-06-20 18:30.

| Readability Grade Levels | ReadablePro Rating | Text Quality |
|------------------------------|--------------------|------------------------------|
| Flesch-Kincaid Grade Level | - | Spelling Issues - - |
| Gunning Fog Index | - | Grammar Issues - - |
| Coleman-Liau Index | - | Sentences > 30 Syllables - - |
| SMOG Index | - | Sentences > 20 Syllables - - |
| Automated Readability Index | - | Words > 4 Syllables - - |
| FORCAST Grade Level | - | Words > 12 Letters - - |
| Powers Sumner Kearsley Grade | - | Writing Style |
| Rix Readability | - | Passive Voice Count - - |
| Raygor Readability | - | Adverb Count - - |
| Fry Readability | - | Cliché Count - - |



Text readability report generated on 2023-06-09 22:25.

| Readability Grade Levels | ReadablePro Rating | Text Quality |
|------------------------------|--------------------|--------------------------------|
| Flesch-Kincaid Grade Level | 4.19 | Spelling Issues 0 0% |
| Gunning Fog Index | 5.02 | Grammar Issues 6 16% |
| Coleman-Liau Index | 7.63 | Sentences > 30 Syllables 1 3% |
| SMOG Index | 7.43 | Sentences > 20 Syllables 6 16% |
| Automated Readability Index | 4.45 | Words > 4 Syllables 1 0% |
| FORCAST Grade Level | 9.32 | Words > 12 Letters 0 0% |
| Powers Sumner Kearsley Grade | 4.21 | Writing Style |
| Rix Readability | 6.00 | Passive Voice Count 2 1% |
| Raygor Readability | 0.00 | Adverb Count 1 0% |
| Fry Readability | 4.00 | Cliché Count 0 0% |

Survey Welcome Page

Caregiver intertest, survey 1 (participation)



Text readability report generated on 2023-06-11 19:22.

| Readability Grade Levels | ReadablePro Rating | Text Quality |
|------------------------------|--------------------|--------------------------------|
| Flesch-Kincaid Grade Level | 4.83 | Spelling Issues 0 0% |
| Gunning Fog Index | 5.61 | Grammar Issues 9 24% |
| Coleman-Liau Index | 8.57 | Sentences > 30 Syllables 0 0% |
| SMOG Index | 8.19 | Sentences > 20 Syllables 5 14% |
| Automated Readability Index | 5.00 | Words > 4 Syllables 1 0% |
| FORCAST Grade Level | 10.58 | Words > 12 Letters 1 0% |
| Powers Sumner Kearsley Grade | 4.38 | Writing Style |
| Rix Readability | 5.00 | Passive Voice Count 2 2% |
| Raygor Readability | 0.00 | Adverb Count 8 3% |
| Fry Readability | 0.00 | Cliché Count 0 0% |

Appendix J

Caregiver Feedback Survey

It is now time for you to provide your feedback on the RESOURCE TOOLKIT, "Toolkit for Caregivers of young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care"

This online survey will take no more than 5 minutes of your time.

Questions? Please email the DNP Student / project lead at ASDtransitions@xxx.edu

Thank You for reviewing the "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care."

Thank you! You have now had time using our newly designed "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care. Please let us know which parts of the "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care" you found MOST and LEAST helpful by answering the questions below:

Please let us know if you agree or disagree, if the resources are helpful now or in the future.

| | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
|---------------------------------|-------------------|----------|----------------------------|-------|----------------|
| 1) Insurance and Financial Help | ___ | ___ | ___ | ___ | ___ |
| 2) Legal Help | ___ | ___ | ___ | ___ | ___ |
| 3) Educational Help | ___ | ___ | ___ | ___ | ___ |
| 4) Other Programs | ___ | ___ | ___ | ___ | ___ |
| 5) Barbers & Hair Salons | ___ | ___ | ___ | ___ | ___ |
| 6) Eye Doctors | ___ | ___ | ___ | ___ | ___ |
| 7) Dentists/Orthodontists | ___ | ___ | ___ | ___ | ___ |
| 8) Adult Day Care | ___ | ___ | ___ | ___ | ___ |
| 9) Lawyers | ___ | ___ | ___ | ___ | ___ |
| 10) Adult Providers | ___ | ___ | ___ | ___ | ___ |

Do you have any suggestions on how to make the "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care" better?

Do you have any comments on things the "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care" does well?

Have you already attempted to transfer the care of your child with ASD from a pediatric primary care provider to an adult primary care provider or practice?

Yes ___ No ___

Appendix K

Flyer and Script

Now Entering Adult Health Care

Moving Your Child with Autism Spectrum Disorder (ASD) to Adult Care

When a child turns 18, they are an adult by law.

1. When they are an adult, they are responsible for their own health care.
2. Parents may not be able to see their child's health records.
3. The adult child must sign a waiver allowing parents to have access to health information.
4. Parents must follow the legal process to become guardian of their adult child with ASD.



Aim your smartphone camera at the QR code, click the link that appears, and sign up to get the toolkit.

There are many free benefits that your child with ASD is eligible for as an adult!

Once you sign up, we will give you a toolkit. The toolkit will have many links. This will help you get information for your child. Review the toolkit and give us your feedback through a survey.

Toolkit for Transitioning Young Adults with Autism Spectrum Disorder to Primary Care
 A quality improvement project led by Dawn Boal, BSN, RN & Sacred Heart Doctor of Nursing Practice Student at Sacred Heart University with Dr. Kerry A. Milner, DNSc, APRN, EBP-CH as Faculty Advisor. Email: ASDtransitions@xxx.edu

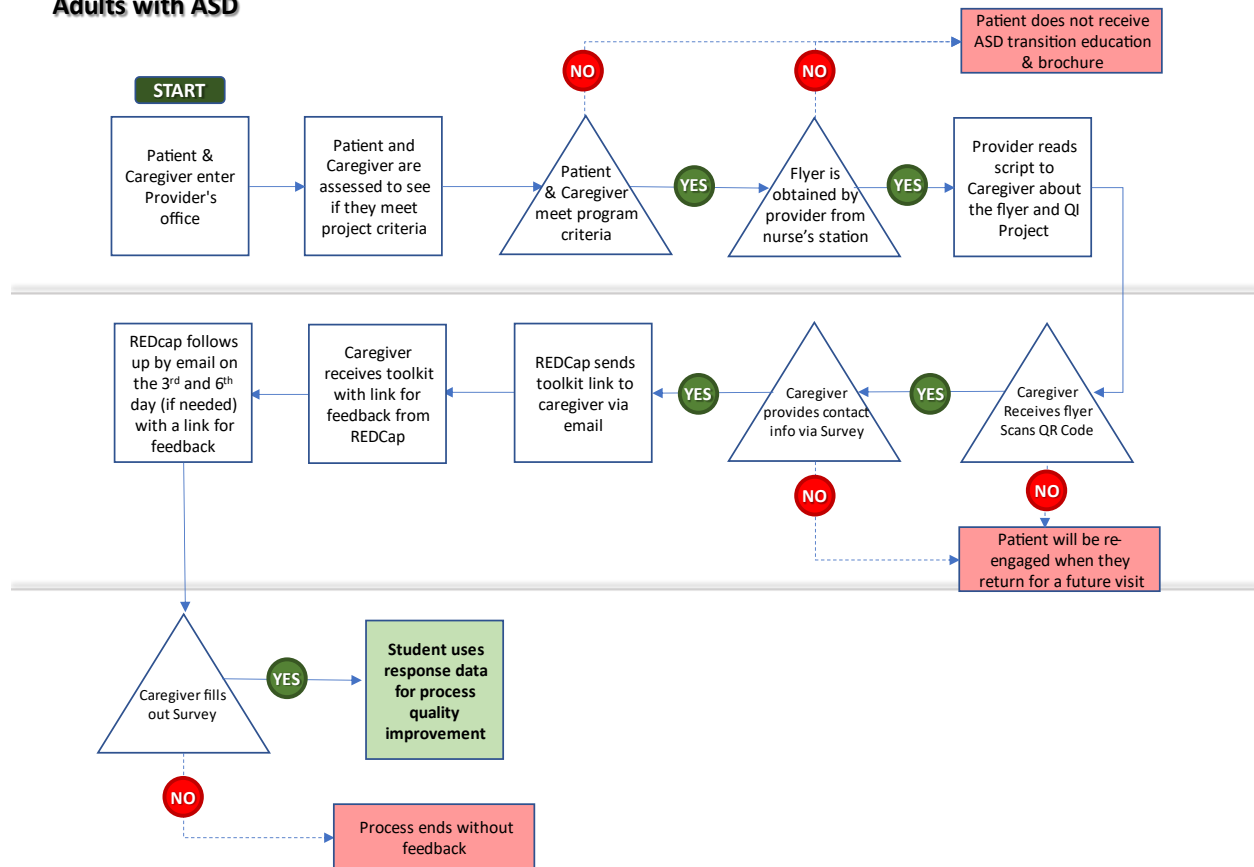
Instructions for Potential Participants

Thank you again for coming in today. Before you leave, I wanted to let you know that our practice is working with a nursing student named Dawn Boal. She is leading a project focused on helping families with children that have Autism Spectrum Disorder (ASD). She will give you tools to help your child move into adulthood. She will also ask for your feedback on her toolkit. If you would like to do this, here's a flyer for you to take with you. Please know you are not required to do this. We are offering this project to caregivers of children with ASD.

Appendix L

Process Map

Process for Distribution of Toolkits and Gathering Feedback From Caregivers of Young Adults with ASD



Appendix M

Welcome Page to Surveys

Welcome Page

Please complete the survey below.

Thank you!

Thank you for your interest in our Resource Toolkit for Caregivers of Young People with Autism Spectrum Disorder! This project is led by DNP Student/ Project Lead, a doctoral student at xxx University (faculty advisor is Faculty Advisor) in partnership with Project Site Clinical Mentor and the team at the Practice Setting primary care office. Any questions you have can be sent via email to ASDtransitions@xxx.edu

Please press "Continue" to submit your information to participate in this project

Appendix N

Caregiver Participation Survey

Thank you for your interest in our project!

Thank you for your interest in providing feedback on our resource toolkit, "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care."

WHAT IS THIS PROJECT ABOUT?

We would like feedback from caregivers of children with ASD this toolkit. The toolkit has resources that can help your child.

WHY PARTICIPATE?

If you would like to give feedback as a caregiver of a child with ASD, here's what this project will mean for you: The RESOURCE TOOLKIT will be provided to you, free of charge.

You will use the RESOURCE TOOLKIT how you see best!

You will complete 1 survey to let us know which parts of the RESOURCE TOOLKIT you find most and least helpful.

TO QUALIFY FOR THIS PROJECT, YOU MUST

Be a parent or caregiver of a child with ASD and Your child with ASD is a patient at CHOP's Kennett Square Practice Your child with ASD is between the ages of 15-21 years old

I WANT TO HELP! WHAT CAN I DO?

Please complete the form below with your name and email, then you will receive a resource toolkit and a follow up survey to provide your feedback.

WHO CAN I CONTACT IF I HAVE QUESTIONS?

E-mail the project team at ASDtransitions@xxx.edu

This project is led by a DNP student/Project Lead in partnership with Project Site Clinical Mentor and Practice Setting Primary Care Practice's leadership team. DNP student/Project Lead is a student in a doctorate of nursing practice program at xxx University with xxx as Faculty Advisor. The DNP student/Project Lead is a parent of a child with ASD.

This project is focused on feedback from parents or legal guardians of children with ASD

How old is your child with ASD that was seen for primary care at Practice Setting Primary Care Practice?

- Less than Age 15
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- Greater than Age 21

What is your full name?

Thank you! From your responses, you qualify to participate in this project.

The "Toolkit for Caregivers of Young People with Autism Spectrum Disorder moving to Adult Primary Care" will be sent to interested caregivers via email.

NOTE: If you do not see the toolkit in your email inbox, please look in your junk or spam folder. All project-related communications will be sent from ASDtransitions@xxx.edu

Please enter your preferred email address here _____

Appendix O

REDCap Automated Link to Toolkit and Caregiver feedback Survey

Thank you for your interest in our toolkit, "Toolkit for Caregivers of Young People with Autism Spectrum Disorder (ASD) Moving to Adult Primary Care."

WHAT IS THIS PROJECT ABOUT?

We would like feedback from caregivers of children with ASD about this toolkit. The toolkit has resources that can help your child move into adulthood. This is an ongoing quality improvement (QI) project.

WHY PARTICIPATE?

If you would like to give feedback as a caregiver of a child with ASD, here's what this project will mean for you:

The RESOURCE TOOLKIT will be provided to you, free of charge.

You will use the RESOURCE TOOLKIT to see how useful it is!

You can view the toolkit now or later. Click the link to the toolkit below.

[Link to the ASD resource toolkit was here](#)

You will have access to the RESOURCE TOOLKIT. You can also copy and paste the link into your web browser.

After you review the RESOURCE TOOLKIT:

You will complete 1 survey to let us know what parts of the toolkit you find most and least helpful. You can complete the survey now or later. When you are ready to take the survey:

- You can view the survey after clicking the survey link down below
- If the survey remains incomplete, 2 reminders will be emailed

TO QUALIFY FOR THIS PROJECT, YOU MUST

- Be a parent or caregiver of a child with ASD and
- your child with ASD is a patient at CHOP's Kennett Square Practice
- your child with ASD is between the ages of 15 - 21 years old

WHO CAN I CONTACT IF I HAVE QUESTIONS?

E-mail DNP Student/Project Lead at ASDtransitions@chop@xxx.edu

This project is led by DNP Student/Project Lead in partnership with Practice Setting's Primary Care Practice's leadership team. DNP Student/Project Lead is a student in a Doctor of Nursing practice program at xxx University. DNP Student/Project Lead is also a parent of a child with ASD.

Toolkit for Transitioning Young Adults with Autism Spectrum Disorder to Primary Care Led by DNP Student/Project Lead at xxx University with Faculty Advisor and Project Site Clinical Mentor.

You may open the survey in your web browser by clicking the link below: [survey-link]

If the link above does not work, try copying the link below into your web browser: [survey-url]

This link is unique to you and should not be forwarded to others.

Appendix P

Summarized Action Plan

Summarized Action Plan

| Project Director DB | | | | | |
|---|--|---------------------------|--------------------------------------|-----------------------------|---|
| Dr. M will be advising when needed throughout the project. | | | | | |
| Project purpose To gather caregivers' perceptions of the usefulness/helpfulness of an evidence-based ASD transitions toolkit to enable the transition from pediatric to adult care provider services | | | | | |
| Key step or objective | Specific activities to meet objective | Person responsible | Materials or resources needed | Timeline | Evaluation |
| Talk to project setting's clinical project site clinical mentor on overcoming barriers of transitionin g of ASD adolescent / young adults | To gain knowledge on how my pediatrician, oversees adolescent / young adults ASD transition | Dawn | Appointment with children | May 10 th , 2022 | Discussed my son's transitioning to primary care |
| Background information on Strategies for improving primary care for adolescent / young adults with autism transitionin g from pediatric services | Searching literature, calling health systems -John Hopkin's -Georgetown -University of Pittsburg -Nemours-DuPont | Dawn | Phone | | 5/25 - Children's Hospital, called back E. M. explained they have a transition program for ages 17, 18, 19 only and emailed list of state agencies for resource |

| | | | | | |
|---|---|-------------|---|-----------------------------|---|
| Called setting's Autism Center | To ask how they transition from pediatric to adolescent / young adult with ASD | D | Phone | May 24 th , 2022 | Referred to affiliated university's behavioral health program |
| PICO question to Dr. M | | D | email | 5/25 | |
| Resource librarian | Went over how to search for resources using PICO question | D& Geoffrey | zoom | 5/26 | I learned a lot and Geoffrey recorded the session for me. Met three times with librarians |
| Evidence searches | Finding evidence for PICO question | Dawn | School on-line library | 5/27-28 | |
| Project setting's clinical project site clinical mentor | about site for project | Dawn | Various modalities (Back and forth communication) | 6/3 started | 7/8 Project setting's clinical project site clinical mentor to do project |
| Emailed Dr. P, CDC's Autism task force | Ask about transition of adolescent / young adults with autism into primary care resources | Dawn | email | 6/7 | 6/8 Dr. P wrote back with resources and contacts/experts |
| Start going over literature and evidence search using RCA tools | | Dawn | | 6/8 | |
| Worked on evidence | | Dawn | | 6/17-6/21 | |

| | | | | | |
|--|---|--|-------------------------|------------------|--|
| search plan, evidence evaluation, and evidence summary table | | | | | |
| Dr V from the CDC | Information on resource transition | Dand Dr V | Video call | 6/17 | Obtained more contact information on organization and individuals who could help, discussed her research study |
| Successfully contacted setting's nursing professional development specialist | To find out next steps to start at project setting and obtain non-traditional employee credentials (non-paid) | Dawn | Call/email | 7/8/22 | Email stated she will give direction of next steps, the week of 7/11 |
| Corrections and Started project proposal paper with evaluations | | Dawn | Emailed Dr. B and Dr. M | 7/10/22 | For feedback 11/20 On version 7 of project proposal |
| Project setting and SHU And DNP student/project lead | Onboarding at project setting for project | Dawn, SHU & project setting's Faculty and Administration | Email | Started 7/14/22 | Continues until application for the IRB Is approved |
| SHU project presentation | | Dawn | | | 12/14 |
| SHU IRB | | Dand Dr. M | | Approved 12/5/22 | |

| | | | | | |
|--|--|--|---|-------------------------------------|---------------------------------------|
| Completing Information for the project setting's center for nursing research and evidence-based practice | | Dawn | -access to project setting as non-traditional employee (non-paid) | 12/16/22 | 12/16/22 |
| Start project | | Dawn | | | Estimate July 28 th , 2023 |
| Call local primary Care clinicians | To assess if taking new patients and ASD patients. For resource for patients | Dawn | Phone call/ Website email | | Estimate 1/09/2023 March & April 2023 |
| Discuss with Dr D Contents for resource folder/ toolkit | Resources to go in the folder | Dawn Dr. D | In person or video call | | 01/09/2023 |
| Finish: Toolkit Flyer Instruction video Check a components of project meeting universal precautions | | Dawn | | | June 2023 Recheck August 2023 |
| Have staff meeting-lunch and learn | To educate staff on project/ toolkits and taking pt.'s | Dawn with support from project setting's | In person Email reminder | Attempted May 25 th 2023 | June 1 zoom meeting. 2023 |

| | | | | | |
|--|--|---------------------------------------|--|------------------------|---|
| | contact information sheet 1 | clinical project site clinical mentor | | | |
| Create a Project instructional video for Clinicians and Staff | To educate staff on project/ toolkits and taking pt.'s contact information | Dawn | Vyond.com | Final draft on YouTube | August 2023 |
| Wait time for project to clear IRB at project setting | | Dawn | Email | | IRB determined project to be non-human subjects research on 9/12/2023 |
| Completion of staff training | Send REDCap with video and attestation to staff | Dawn | REDCap web-survey tool | Estimate Sept 25th | |
| Start distribution of toolkits | | Staff & D | | | c October 2023 |
| Every other week office visits and weekly follow ups Monitor on- line input | check-ins (one more lunch and learn beginning of) | Dawn | In person & Emails | Estimate Start 2023 | Project started October 11 th , 2023 |
| Monitor on- line input | Check REDCap surveys | Dawn | Access to project setting's secure network | | Sept 2023 |
| Start data collection on project | Start taking surveys of, patient, and parents/guardians, | Dawn | Access to project setting's secure network | | Oct 2023 – Feb 2024 |

| | | | | | |
|---|---|------|----------------------------|--|---------------|
| | Compile on-line surveys and QR code access. | | Setting's REDCap | | |
| Evaluation of data | Begin to start report of findings of QI project | D | Computer | | February 2024 |
| Prepare project presentation | Dissemination | Dawn | Computer PowerPoint Poster | | March 2024 |
| Present project for setting's health system | | Dawn | virtually | | April 2024 |
| Present project for project setting's primary care office | | | | | April 2024 |

Appendix Q

Differentiating Quality Improvement and Research Activities Tool

| Question | Yes | No |
|---|-----|----|
| Is the project designed to bring about immediate improvement in patient care? | X | |
| Is the purpose of the project to bring new knowledge to daily practice? | | X |
| Is the project designed to sustain the improvement? | X | |
| Is the purpose to measure the effect of a process change on delivery of care? | X | |
| Are findings specific to this pediatric clinic? | X | |
| Are all patients who participate in the project expected to benefit? | X | |
| Is the improvement at least as safe as routine care? | X | |
| Will all participants receive at least usual care? | X | |
| Do you intend to gather just enough data to learn and complete the cycle? | X | |
| Do you intend to limit the time for data collection to accelerate the rate of improvement? | X | |
| Is the project intended to test a novel hypothesis or replicate one? | | X |
| Does the project involve withholding any usual care? | | X |
| Does the project involve testing improvements/practices that are not usual or standard of care? | | X |
| Will any of the 18 identifiers according to the HIPAA Privacy Rule be included? | | X |

Adapted from Foster, J. (2013). Differentiating quality improvement and research activities.

Clinical Nurse Specialist, 27(1), 10–3. <https://doi.org/10.1097/NUR.0b013e3182776db>

Appendix R

CITI Training

  Completion Date: 25-Jun-2022
Expiration Date: 24-Jun-2025
Record ID: 49790972

This is to certify that:

Dawn Boal

Has completed the following CITI Program course:

Social & Behavioral Research - Basic/Refresher
(Curriculum Group)
Social & Behavioral Research - Basic/Refresher
(Course Learner Group)
1 - Basic Course
(Stage)



Under requirements set by:

Sacred Heart University, Inc.


Collaborative Institutional Training Initiative

Not valid for renewal of certification through CME.

Verify at www.citiprogram.org/verify/7w83305b77-43bd-4595-a023-6121926e05cf-49790972

  Completion Date: 24-Jun-2022
Expiration Date: 23-Jun-2026
Record ID: 49790975

This is to certify that:


Dawn Boal

Has completed the following CITI Program course:

Conflict of Interest mini-course
(Curriculum Group)
Conflict of Interest
(Course Learner Group)
1 - Stage 1
(Stage)



Under requirements set by:

Sacred Heart University, Inc.


Collaborative Institutional Training Initiative

Not valid for renewal of certification through CME.

Verify at www.citiprogram.org/verify/7wef19f5a4-9a16-4333-bab3-d1ab4f120815-49790975

  Completion Date: 25-Jun-2022
Expiration Date: 24-Jun-2025
Record ID: 49790974

This is to certify that:


Dawn Boal

Has completed the following CITI Program course:

Responsible Conduct of Research (RCR)
(Curriculum Group)
Responsible Conduct of Research (RCR)
(Course Learner Group)
1 - RCR
(Stage)

Under requirements set by:

Sacred Heart University, Inc.


Collaborative Institutional Training Initiative

Not valid for renewal of certification through CME.

Verify at www.citiprogram.org/verify/7wfb725271-01d7-46e6-98bd-5e470cabd388-49790974

Appendix S

Project Site Specific CITI Training

Course Completion for DB

Congratulations on your recent course completion!

Name: **DB** (ID: 11287912)

Institution: **[xxxx]**

Course: **Group 2: Social-Behavioral-Educational Researchers**

Stage: **1 - Basic Course**

Completion Date: **20 Dec 2022**

Expiration Date: **20 Dec 2025**

Completion Record ID: **53243804**

Appendix T

List of potential primary care clinicians, other health care clinicians and barbers/hairstylists

| Table No. Patients w/AD/2 | Willing to Participate? | Adult Primary Care Provider | Address | Phone | Practice Name | Affiliation | Profile Page |
|---------------------------|-------------------------|-------------------------------------|--|--------------|---|-------------|---|
| | | Mary-Anne Ost, MD | (West Grove) | 610-869-0311 | Office of Mary-Anne Ost, MD, Ltd | Independent | https://www.penmedicine.org/providers/profile/mary-anne-ost-7aff-pennmedicine&keyword=family%20medicine |
| | | Dr. Raymond McLaughlin, MD | 701 E Baltimore Pike Kennett Square, PA 19348 | 610-444-4060 | Office of Ray McLaughlin MD | Independent | https://www.penmedicine.org/providers/profile/ramondmclaughlin-7aff-pennmedicine&keyword=family%20medicine |
| x | x | Dr. Cheryl Hlavac, MD | 402 McFarlan Rd Ste 102 Kennett Square, PA 19348 | 610-444-5678 | Penn Family Medicine Kennett | Penn Med | https://www.penmedicine.org/providers/profile/cheryl-hlavac-7aff-pennmedicine&keyword=family%20medicine |
| | | Martha Lynn Brinsfield, MD | 402 McFarlan Rd Ste 102 Kennett Square, PA 19348 | 610-444-5678 | Penn Family Medicine Kennett | Penn Med | https://www.penmedicine.org/providers/profile/martha-lynn-brinsfield-7aff-pennmedicine&keyword=family%20medicine |
| x | x | Megan M. Gaskill, MD | 402 McFarlan Rd Ste 102 Kennett Square, PA 19348 | 610-444-5678 | Penn Family Medicine Kennett | Penn Med | https://www.penmedicine.org/providers/profile/megan-gaskill-7aff-pennmedicine&keyword=family%20medicine |
| | | Dr. Steven Ginsburg, DO | 402 McFarlan Rd Ste 102 Kennett Square, PA 19348 | 610-444-5678 | Penn Family Medicine Kennett | Penn Med | https://www.penmedicine.org/providers/profile/mark-barman-7aff-pennmedicine&keyword=family%20medicine |
| | | Max J. Bateman, MPAS-PA-C | 402 McFarlan Rd Ste 102 Kennett Square, PA 19348 | 610-444-5678 | Penn Family Medicine Kennett | Penn Med | https://www.penmedicine.org/providers/profile/thomas-santamaria-7aff-pennmedicine&keyword=family%20medicine |
| | | Dr. Thomas Santamaria, MD | 830 W Cypress St Kennett Square, PA 19348 | 610-444-8084 | Kennett Primary Care | Penn Med | https://www.penmedicine.org/providers/profile/pedro-rooney-7aff-pennmedicine&keyword=family%20medicine |
| | | Pedro M. Solanet, MD | 830 W Cypress St Kennett Square, PA 19348 | 610-444-8084 | Kennett Primary Care | Penn Med | https://www.penmedicine.org/providers/profile/pedro-rooney-7aff-pennmedicine&keyword=family%20medicine |
| x | | Dr. Deepika Suri MD | Matthew Pagano, DO 404 McFarlan Road, Suite 101, Kennett Square, PA 19348 | 610-625-3835 | Penn Family and Internal Medicine Longwood | Penn Med | https://www.penmedicine.org/providers/profile/matthew-pagano-do-profile-1-pennmedicine.org |
| | | David G. Rooney, MD | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/david-rooney-7aff-pennmedicine&keyword=family%20medicine |
| | | Theresa Metanichuk, DO | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/theresa-metanichuk-7aff-pennmedicine&keyword=family%20medicine |
| | | Michael D Kirk, MD | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/michael-kirk-7aff-pennmedicine&keyword=family%20medicine |
| | | Stephen Naylor, DO | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/stephen-naylor-7aff-pennmedicine&keyword=family%20medicine |
| | | John N. Dagher, MD | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/john-dagher-7aff-pennmedicine&keyword=family%20medicine |
| | | Debra Ditzonzi Wright, CRNP, MSN | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/debra-wright-7aff-pennmedicine&keyword=family%20medicine |
| | | Judith Gawlikowski, CRNP | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/judith-gawlikowski-7aff-pennmedicine&keyword=family%20medicine |
| | | Sophia Sabo-Gesmundt, CRNP | 455 Woodlawn Road, Suite 100, West Grove, PA 19390 | 610-345-1900 | Penn Medicine Southern Chester County | Penn Med | https://www.penmedicine.org/providers/profile/sophia-sabo-gesmundt-7aff-pennmedicine&keyword=family%20medicine |
| | | Michael K. Robinson, II, MD | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/michael-k-robinson-7aff-pennmedicine&keyword=family%20medicine |
| x | x | Missisa Huley, DO | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/missisa-huley-7aff-pennmedicine&keyword=family%20medicine |
| x | x | Spencer S. Hoffman, DO | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/spencer-hoffman-7aff-pennmedicine&keyword=family%20medicine |
| | | Ashley Ailes, CRNP | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/ashley-ailes-7aff-pennmedicine&keyword=family%20medicine |
| | | Sarah N. Keser, CRNP | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/sarah-n-keser-7aff-pennmedicine&keyword=family%20medicine |
| | | Susan M. Wolf, CRNP | 620 Spear Street, Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Penn Med | https://www.penmedicine.org/providers/profile/susan-m-wolf-7aff-pennmedicine&keyword=family%20medicine |
| | | Mary-Anne Ost, MD (See above in KS) | 1 Commerce Blvd Ste 203 West Grove, PA 19390 | 610-860-2199 | Office of Mary-Anne Ost, MD, Ltd | Independent | |
| | | Dr. Marylou Checchia-Romano, DO | 1660 E Street Rd Kennett Square, PA 19348 | 610-388-5634 | | | |
| x | x | Dr. Karl Zimmerman, MD | 127 W Street Rd Ste 101 Kennett Square, PA 19348 | 610-444-1212 | | | |
| | | Dr. Julia Eickoff-Vangen, MD | 200 Old Forge Ln Ste 203 Kennett Square, PA 19348 | 484-628-0797 | | | |
| | | Dr. Stefane Steiner, DO | (West Grove) | 484-628-0797 | Also at Family Practice Associates WG | | |
| | | Kathryn Mitchell, FNP-C | 200 Old Forge Ln Ste 203 Kennett Square, PA 19348 | 484-628-0797 | | | |
| | | Dr. Peter Baddick II, DO | 300 Old Forge Ln Ste 302 Kennett Square, PA 19348 | 484-778-8000 | Tower Health | | |
| | | Dr. Paul Chwiecko, MD | 300 Old Forge Ln Ste 302 Kennett Square, PA 19348 | 484-778-8000 | Tower Health | | |
| | | Dr. Zaid Osman, MD | 300 Old Forge Ln Ste 302 Kennett Square, PA 19348 | 484-778-8000 | Tower Health | | |
| | | Dr. Robert McKinstry, MD | 548 SCHOOL HOUSE RD Kennett Square, PA 19348 | 484-770-8558 | | | |
| | | Dr. Shannon Lieb, DO | 404 McFarlan Rd Ste 101 Kennett Square, PA 19348 | 610-625-3835 | | | |
| | | Dr. Ulzma Qurashi, MD | 701 E Baltimore Pike Ste C Kennett Square, PA 19348 | 610-444-5630 | Brandywine Internal Medicine PC | | |
| | | Dr. Faye Meyers, MD | 731 W Cypress St Kennett Square, PA 19348 | 610-444-0070 | | | |
| | | Dr. Elaine Richiowar, MD | 731 W Cypress St Kennett Square, PA 19348 | 610-444-0070 | | | |
| | | Dr. David Hoffman, MD | 203 McKeister Blvd # 100 Landenberg, PA 19350 | 610-320-2373 | | | |
| | | Dr. Richard Strachicko, DO | 620 SPEAR ST Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Not listed | |
| | | Dr. Patrick Anderson, DO | 620 SPEAR ST Oxford, PA 19363 | 610-932-9300 | LG Health Physicians Family Medicine Oxford | Not listed | |
| | | Dr. Daniel Duran, MD | 900 W Baltimore Pike Ste 200 West Grove, PA 19390 | 610-869-4627 | Family Practice Associates WG | | |
| | | Dr. Michael Barkasy Jr., MD | 900 W Baltimore Pike Ste 200 West Grove, PA 19390 | 610-869-4627 | Family Practice Associates WG | | |
| | | (KS) | 900 W Baltimore Pike Ste 200 West Grove, PA 19390 | 610-869-4627 | Family Practice Associates WG | | |
| | | Dr. Steven Breslow, DO | 390 Vinograd Way Ste 501 West Grove, PA 19390 | 484-628-9156 | Group | | |
| | | Dr. Neah Bass, DO | 1015 W Baltimore Pike West Grove, PA 19380 | 610-869-4648 | | | |
| | | Dr. Sony Jahn, MD | 404 McFarlan Rd Ste 101 Kennett Square, PA 19348 | 610-625-3835 | Allied Diagnostics Pklyg Onstret | | |
| | | Dr. Paula Barry, MD | 404 McFarlan Rd Ste 101 Kennett Square, PA 19348 | 610-625-3835 | | | |
| | | Lindsay Calio, MMS, PAC | 404 McFarlan Rd Ste 101 Kennett Square, PA 19348 | 610-625-3835 | | | |

| Service | Y/N | Provider Name | Phone Number | Provider Address | Website |
|----------------------|-----|---|------------------------------|--|---|
| Barber / Hairdresser | y | Blue 52 Barber Shop | 610-612-9361 | 331 State St, Kennett Square, PA 19348 | https://www.vagaro.com/blue52barbershop |
| Barber / Hairdresser | y | Burton's Barber Shop | 610-444-9964 | 105 W State St # A, Kennett Square, PA 19348 | NA |
| Barber / Hairdresser | n | KSQ Barber Lounge | 484-731-4189 | 106 Sycamore Alley, Kennett Square, PA 19348 | http://www.vagaro.com/ksqbarberlounge |
| Barber / Hairdresser | y | B&B Barber Lounge | 484-732-7951 | 116 S Union St, Kennett Square, PA 19348 | https://bb-barber-lounge.business.site/?utm_source=gmb&utm_medium=referral |
| Barber / Hairdresser | y | Pepe's Barbershop | 610-492-2244 | 1153 Newark Rd, Toughkenamon, PA 19374 | https://www.vagaro.com/pepesbarbershop |
| Barber / Hairdresser | y | Holiday Hair | 610-446-9997 610-764-0584 | 350 Scarlet Rd suite 25- Kennett Square, PA 19348 | https://www.sjgnstunstyle.com/locations/pa/kennett-square/holiday-hair-new-garden-town-square-haircuts-19293.html |
| Barber / Hairdresser | n | Rivera's Barber Shop | 610-268-5545 | 88 Pennsylvania Ave, Avondale, PA 19311 | NA |
| Barber / Hairdresser | y | Supercuts Kennett Square | 484-732-8053 | 817 E Baltimore Pike, Kennett Square, PA 19348 | https://www.supercuts.com/checkin/82817 |
| Barber / Hairdresser | y | Flips Barber Shop | 610-467-1670 | 10 S 3rd St, Oxford, PA 19363 | https://flips-barber-shop.edan.io/ |
| Barber / Hairdresser | y | SmartStyle Hair Salon | 610-998-1483 | 800 Commons Dr, Oxford, PA 19363 | https://www.smartstyle.com/checkin/18798 |
| Barber / Hairdresser | n | 3rd Street Parlor | 484-746-0055 | 3 S 3rd St, Oxford, PA 19363 | https://3rdstreetparlorbarbershop.com/ |
| Barber / Hairdresser | yes | Top-Notch Barbershop | 610-806-5412 | 11 Exchange Pl, West Grove, PA 19390 | http://linktr.ee/TopNotchBarbershopInc |
| Barber / Hairdresser | no | Ruffini's Barber Shop | 610-869-3002 | 104 Rosehill Ave, West Grove, PA 19390 | NA |
| Barber / Hairdresser | yes | Great Clips | 610-444-5510 | 144 Onix Dr, Kennett Square, PA 19348 | https://salons.greatclips.com/us/pa/kennett-square/144-onix-dr?utm_source=google&utm_medium=organic&utm_campaign=gmb |
| Barber / Hairdresser | yes | Salon Secrets Spa- Kennett Square | 610-444-0605 | 829 E Baltimore Pike, Kennett Square, PA 19348 | http://www.salonsecretspa.com/ |
| Barber / Hairdresser | yes | Linda's Hair Techniques | 610-268-3221 | 911 Gap Newport Pike, Avondale, PA 19311 | http://www.lindahairtechniques.com/ |
| Barber / Hairdresser | yes | Shear Satisfaction | 610-268-8917 | 1120 Newark Rd, Toughkenamon, PA 19374 | http://www.shearsatisfaction.com/ |
| Barber / Hairdresser | no | Fa Shears By Aimee | 610-444-1430 | 910 E Baltimore Pike, Kennett Square, PA 19348 | http://www.fashears.com/?y_source=1_MiAxNzA0QDEtNzE1LWxvY2F0aWUudmNpGkU3D |
| Barber / Hairdresser | yes | Jillian Grace Salon | 610-869-4114 | 2050 Newark Rd, Lincoln University, PA 19352 | http://jgsalon.com/ |
| Eye Doctor | yes | Ganly Vision Care | 484-770-8132 | 402 Bayard Rd #200, Kennett Square, PA 19348 | http://www.ganlyvisioncare.com/ |
| Eye Doctor | yes | MyEyeDr. - Kennett | 610-444-5252 | 841 E Baltimore Pike, Kennett Square, PA 19348 | https://locations.myeedr.com/pa/kennett-square/841-e-baltimore-pike?utm_source=google&utm_medium=organic |
| Eye Doctor | yes | Kennett Square Eye Care | 610-444-5522 | 216 S Mill Rd Ste 112, Kennett Square, PA 19348 | http://www.kennettsquareeyecare.com/ |
| Eye Doctor | yes | Chester County Eye Care Associates | 610-696-1230 | 455 W Woodview Rd #25, West Grove, PA 19390 | https://www.chestercountyeyecare.com/?utm_source=GMB-WG&utm_medium=organic |
| Eye Doctor | yes | Miller Eye Care | 610-869-4200 | 57 Jenners Vlg Cr, West Grove, PA 19390 | http://www.millereyecareonline.com/ |
| Eye Doctor | yes | MyEyeDr. - Oxford | 610-932-9356 | 49 S 2nd St, Oxford, PA 19363 | https://locations.myeedr.com/pa/oxford/49-south-2nd-street?utm_source=google&utm_medium=organic |
| Adult Daycare | yes | Active Day of Kennett Square | 610-388-1166 | 500 Old Forge Ln, Kennett Square, PA 19348 | https://www.activead.com/locations/states/pa/ |
| Adult Daycare | yes | Kennett Area YMCA | 610-444-9622 | 101 Race St, Kennett Square, PA 19348 | https://ymcabgw.org/locations/kennett-branch |
| Adult Daycare | no | Jennersville YMCA | 610-869-9622 | 880 W Baltimore Pike, West Grove, PA 19390 | https://ymcabgw.org/locations/jennersville-branch |
| Dentist | no | P. Randall Eckman, DDS | 610-388-0223 | 966 E Baltimore Pike, Kennett Square, PA 19348 | http://eckmandds.com/ |
| Dentist | no | Kennett Center for Advanced Dentistry | 610-444-6311 | 208 N Union St, Kennett Square, PA 19348 | https://www.kennettcenter.com/ |
| Dentist | yes | Leardi Family Dentistry | 610-571-2520 | 600 Unionville Rd, Kennett Square, PA 19348 | https://www.leardidental.com/?utm_source=GMB&utm_medium=organic&utm_campaign=DevOptimization&utm_content=Website |
| Dentist | yes | Albert J Schmitt DMD | 610-444-6300 | 413 McFarlan Rd, Kennett Square, PA 19348 | http://www.doctorschmitt.com/ |
| Dentist | yes | Jay W. Dorgan DDS | 610-925-3222 | 127 W Street Rd #301, Kennett Square, PA 19348 | http://www.drdorgan.com/ |
| Dentist | yes | C Christian Franck Family Dental | 610-444-3212 | 721 E Baltimore Pike # 301, Kennett Square, PA 19348 | http://www.frankdental.com/ |
| Dentist | yes | Dental Health Associates | 610-444-0750 | 687 Unionville Rd, Kennett Square, PA 19348 | https://dentalhealthcareassociates.com/ |
| Dentist | no | Adey Family Dentistry | 610-444-2928 | 120 Lafayette St, Kennett Square, PA 19348 | https://www.adeyfamilydentistry.com/ |
| Dentist | yes | Kennett Dental | 610-444-4033 | 402 McFarlan Rd #303, Kennett Square, PA 19348 | |
| Dentist | ? | Avondale Family & Cosmetic Dentistry | 610-268-8300 | 8830 Gap Newport Pike, Avondale, PA 19311 | https://avondalefamilyandcosmetdentistry.com/ |
| Orthodontist | no | Gnealey Orthodontics | 484-346-0000 | 400 Old Forge Ln #606, Kennett Square, PA 19348 | https://gncvortho.com/ |
| Orthodontist | yes | The Orthodontic Group of Chester County | 484-218-0088 | 208 N Union St, Kennett Square, PA 19348 | https://www.chestercountyorthodontics.com/locations/kennett-square/ |
| Orthodontist | ? | Tamburino Family Orthodontics of Kennett Square | 484-730-1921 | 688 Unionville Rd #10L, Kennett Square, PA 19348 | https://www.tortho.com/ |
| Orthodontist | ? | Carl Orthodontics | 610-444-2343 | 201 Marshall St, Kennett Square, PA 19348 | http://carlorthodontics.com/ |
| Orthodontist | ? | Hendrix Orthodontics | 610-869-5850 | 695 W Baltimore Pike, West Grove, PA 19390 | https://leishhendrix.com/location/jennersville-orthodontics/ |
| Orthodontist | yes | McCormick Orthodontics | 888-333-3757 | 900 W Baltimore Pike #201, West Grove, PA 19390 | https://mccormickorthodontics.com/ |
| Attorney | yes | Randy Hope Steen, Esq | (215) 570-0047 | 600 Eagleview Blvd, Exton, PA 19341 | https://www.rsteenlaw.com/ |
| Attorney | yes | Stephan D. Potts, Esq | 610-254-0114 | 138 West Gay St, West Chester, PA 19380 | https://therpottsdnotts.com/attorney/stephen-d-potts/ |

Appendix U

Survey Questions for Adult Primary Care Clinician, Other Healthcare Clinicians and Hairstylist

The survey questions that will be used to screen are question #1 and #3c.



Survey Questions for Adult Providers about their Willingness to Accept Young Adults With and Without Chronic Illnesses¹

Below are suggested questions and example answer choices that can be used to learn about adult providers' willingness to accept young adult patients with and without chronic illnesses.

1. Will you accept new young adult patients ages 18-25?
 - a. Yes, all
 - b. Yes, but only those without chronic illness
 - c. Yes, only those with chronic illness
 - d. No, none

2. If you prefer **NOT** to accept ANY new young adult patients, what are the important reasons for this decision?
 - a. Full practice
 - b. Lack of time in appointment
 - c. Payment for RVUs for time needed to care for YA
 - d. Problem with adherence to care of YA
 - e. High no show rate for appointments by YA
 - f. Training and/or experience gaps
 - g. Specialty referral difficulties
 - h. Lack of pediatric consultation support
 - i. Lack of care coordination
 - j. Other (please specify) _____

3. Will you accept new young adult patients with the following specific conditions? (Possible answers for each below: Yes; Yes, but only oversee their primary care needs; Yes, but with pediatric provider consultation support; No)
 - a. Asthma
 - b. ADHD/ADD
 - c. Autism Spectrum Disorder
 - d. Congenital Anomalies
 - e. Congenital Heart Disease
 - f. Cystic Fibrosis
 - g. Depression/behavioral health problem
 - h. Genetic disorders (Down Syndrome, Rett Syndrome, CHARGE Association)
 - i. Juvenile arthritis
 - j. Obesity
 - k. Type 1 Diabetes

¹Data taken from poster presented at the 2016 Health Care Transition Research Consortium in Houston, Texas from Got Transition, Cleveland Clinic, Henry Ford Health System and University of Rochester

Barbers and hairstylist were asked “Will you take young adults with ASD and accommodate them?”

Appendix V

Questions for Local Mom's Group

What information or resources helped you the most when transitioning your students with ASD as a young adult?

- Is there any information you wished you had?

- What advice would you give to parents/guardians or students who are about to transition from school to young adulthood who have ASD?

- Do you have any other thoughts or information you would like to share with me that might help these students?

Appendix W

IRB Approval



[Redacted], Prof. [Redacted]

To: [Redacted]

Cc: [Redacted]



Mon 12/5/2022 12:50 PM

Dear Applicant,
Thank you for your submission to the IRB requesting exempt review. Based on the application submitted, the IRB is pleased to approve your submission and we wish you great success in your research.

Sincerely,
[Redacted]
Chair, IRB



Director, Exercise and Sport Science M.S. Program
Associate Professor
College of Health Professions



To learn more about the M.S. in Exercise and Sport Science program, click [here](#).

To see where our M.S. alumni are working, click [here](#).

Appendix X

Setting's IRB Determination Review



Date: September 12, 2023

To: [REDACTED]
CC: Dawn Boal
From: The Committees for the Protection of Human Subjects (IRB)

Re: [IRB 23-021121](#), **Protocol Title:** Toolkit for Transitioning Young Adults with Autism Spectrum Disorder (YA-ASD) to Primary Care and Personal Care Service Providers
Sponsor or Funder: null

IRB SUBMISSION: DETERMINATION OF NOT HUMAN SUBJECTS RESEARCH

Dear [REDACTED]

The IRB acknowledges receipt of the above-referenced proposal. This proposal was reviewed on 9/11/2023. It has been determined that the proposal does not meet the criteria for human subjects research (see below) and, therefore, ongoing IRB oversight is not required.

PLEASE NOTE: A determination of not human subjects research by the IRB does not necessarily constitute authorization to initiate the project. The Investigator is responsible for satisfying any additional institutional requirements that may apply (e.g. execution of the appropriate agreement with the Office of Collaborative and Corporate Research Contracts for sending or receiving data or samples, execution of an [internal Data Use Agreement](#) for sharing or receiving a limited data set, etc.).

Documents Reviewed:

- Toolkit Flyer (attached 9/6/2023)
- REDCap Welcome Page (attached 9/6/2023)
- REDCap Participation Agreement (attached 9/6/2023)
- Automated Link to Toolkit (attached 9/6/2023)
- REDCap Caregiver Feedback Survey (attached 9/6/2023)
- Letter of Support (dated 6/1/2023)
- Toolkit for Caregivers (attached 9/6/2023)
- Education Video (attached 9/6/2023)
- Staff Attestation (attached 9/6/2023)

To: NS

CC: DB

From: The Committees for the Protection of Human Subjects (IRB)

Re: [IRB 23-021121](#), **Protocol Title:** Toolkit for Transitioning Young Adults with Autism Spectrum Disorder (YA-ASD) to Primary Care and Personal Care Service Providers

Sponsor or Funder: null

IRB SUBMISSION: DETERMINATION OF NOT HUMAN SUBJECTS RESEARCH

Dear Dr.

The IRB acknowledges receipt of the above-referenced proposal. This proposal was reviewed on 9/11/2023. It has been determined that the proposal does not meet the criteria for human subjects research (see below) and, therefore, ongoing IRB oversight is not required.

PLEASE NOTE: A determination of non-human subjects research by the IRB does not necessarily constitute authorization to initiate the project. The Investigator is responsible for satisfying any additional institutional requirements that may apply (e.g. execution of the appropriate agreement with the Office of Collaborative and Corporate Research Contracts for sending or receiving data or samples, execution of an [internal Data Use Agreement](#) for sharing or receiving a limited data set, etc.).

Documents Reviewed:

- Toolkit Flyer (attached 9/6/2023)
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- REDCap Participation Agreement (attached 9/6/2023)
- Automated Link to Toolkit (attached 9/6/2023)
- REDCap Caregiver Feedback Survey (attached 9/6/2023)
- Letter of Support (dated 6/1/2023)
- Toolkit for Caregivers (attached 9/6/2023)
- Education Video (attached 9/6/2023)
- Staff Attestation (attached 9/6/2023)

This proposal does not meet the following regulatory definitions of human subjects research:

Does not meet the definition of "research": According to 45 CFR 46.102(l), "Research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."

Please note: It is the responsibility of the Principal Investigator to communicate any changes in the proposal to the IRB, including the use or incorporation of other data sets which may not be de-identified or publicly available. If you wish to change any aspect of this study, a new proposal will need to be submitted for review. New procedures cannot be initiated until IRB review and approval has taken place.

If you have any questions, please click on the IRB# (above) and contact the IRB analyst listed in the study workspace.

DHHS Federal Wide Assurance Identifier: FWA00000459

Appendix Y

Executive Summary

It is estimated that 1 in 44 children in the United States is diagnosed with autism spectrum disorder (ASD). Young adults (YA) with autism spectrum disorder (ASD) transitioning from pediatric to adult care may have more difficulty finding a primary care clinician trained to address their unique medical and mental health needs. Transition resources need to be developed to help these patients and their caregivers while they are patients under their pediatrician.

The purpose of this evidence-based quality improvement project was to develop a toolkit with resources designed to help YA-ASD ages 15-21 years and their caregivers with the transition from pediatric care to adult primary care services. The Model for Improvement guided this project. The setting was a single pediatric primary care office within a large pediatric health system. The ASD resource toolkit encapsulates the range of support and resources available for individuals with ASD and their caregivers in Pennsylvania, covering various aspects such as healthcare, education, employment, legal considerations, and community support. Access to the ASD resource toolkit was offered by nurses and clinicians to potentially eligible caregivers of YA-ASD during well-child visits.

During the 18-week project, only three caregivers met the project's criteria for inclusion. Only one caregiver started the initial participant survey but did not complete the form to express their interest in project participation. No toolkits were distributed to caregivers during the project's implementation. The next steps must focus on finding the caregivers of YA-ASD transitioning to adult primary care and effective strategies for getting the toolkit to caregivers of YA-ASD.

Appendix Z

Poster



An Evidence Based Project : Improving the Transition of Young Adults with Autism Spectrum Disorder (ASD) to Primary Care

DNP Student, Project Lead, Faculty Advisor, Project Site Clinical Mentor

Background

The lack of a coordinated transition plan may lead to adolescents/young adults (YA) with ASD continuing to receive extended care from their pediatric providers or having adult primary care providers who lack the training to address their health care needs. Efforts are necessary to ensure that the health care transition is seamless, high quality, and tailored to the individual needs of adolescent/young adult with ASD and their parent/guardian.

Evidence

- Internal Data**
- Local practice expressed the need to improve the transition of adolescent /YA-ASD to adult primary care
 - The current process for transition is done individually
 - There is no resource list of adult primary care providers that will accept YA-ASD to give caregivers
 - Providers want to be able to direct patients to available adult primary care providers who are willing to take YA-ASD and want to be able to communicate the available services.
- External Data**
- Young adults with ASD, despite a higher usage of health care services, have poorer health outcomes than the general population.
 - Once the obstacles are identified, implementations can be made for YA-ASD to improve their access to healthcare providers trained to work with ASD patients.
 - YA-ASD and their caregiver's main concern is integrating different health services and family support.
 - There is a need for increased training for adult primary care providers in caring for YA-ASD.

PICO Question

In the primary care setting (P) does a transitional resource toolkit (I) compared to usual care (C) affect YA-ASD transition to adult primary care (O)?

Project Goals

- To develop a universal precautions transition resource toolkit for English speaking caregivers of adolescents/YA-ASD ages 15-21 and to distribute during well visits in a pediatric primary care office.
- To train clinicians and registered nurses (RNs) on the toolkit and process for caregivers of adolescents/YA-ASD to access the toolkit.
- To obtain feedback on the toolkit from caregivers of adolescents/YA-ASD.

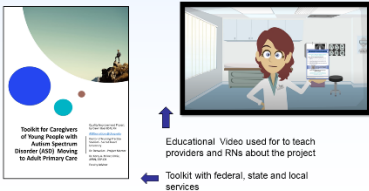
Methods / Implementation Plan

Setting/Population: Children's Hospital of Philadelphia Primary Care Office Kennett Square, PA
Participants: 1 LPNs, 13 RNs, 6 Providers (2 APRNs, 4 Physicians) & Caregivers
Design: The Model for Improvement will guide this evidence-based quality improvement (EBQI) project
PLAN: Gather resources for YA-ASD transitions and create a toolkit
DO: Educate the staff (e.g., nurses and providers) via video through REDCap
STUDY: Staff Implementation YA-ASD QI project from October 11, 2023, to February 8, 2024
ACT: Revise process implementation based upon what was observed in the PDSA cycle

Toolkit Creation

Information Sources
 CINAH, MEDLINE, Nursing & Allied Health Premium, TRIP, Provider's of Kennett Square project setting, project setting's online resources, AHRQ – Health literacy guide, U.S. General Services Administration- Accessibility for Teams: Visual design: Typography, Venngage.com. Accessible Color Palette Generator: WCAG compliant, Readable.com.
Key Words
 ASD or autism, autism spectrum disorder, transition* resource*, primary care or primary health care, "adolescent / young adult" or emerging adult, health care or healthcare transition resource, transition resources, primary care transition. Limits for all searches were English language, adolescents (age 13-18), adults (age 18 and over), and published between 2012-2022.

Model and Evaluation
 Rapid critical appraisal (RCA) using Melyk & Fineout-Overholt's (2019) tool..
 Level of evidence appraisal
Article/Study Selection
 There were 52 articles collected and reviewed/skimmed for relevance to the project and level of evidence (LOE). Since the LOE was low due to YA-ASD transitioning to primary care being a new phenomenon, articles selected for critical appraisal had a primary focus on improvements for transitioning care from pediatric to adult primary care for YA-ASD. (n=7 articles).



Results

- Universal precautions toolkit created
- Using REDCap education video and an entry for attestation for all the staff. Over a 2-week period, all six (100%) of the clinicians participated, and 85% (n=11) RNs.
- Flyer developed using universal precautions with a QRcode to access REDCap
- REDCap survey tool using universal precautions developed to explain project to participant, distribute toolkit and survey evaluation.
- During the 18-week project, only three caregivers had YA-ASD transitioning. Only one initial survey was accessed but none were filled out. No toolkits were distributed.



Sustainability Plan

The staff at the project setting will be educated to distribute resource toolkit, continue with the implementation of the process improvement project and oversee REDCap. This will be overseen by the project site's clinical mentor

Lessons Learned

- REDCap survey is an effective way to account for attestation of the project
- Conducting a Project in Health System as a Non-employee required more time and approvals to start the project.
- Small Numbers of YA-ASD Prevented Assessment of Toolkit Impact
- project settings Approval and Protecting Patient and Staff Information
- Complex Toolkit Distribution
- Time it Takes to Create a Quality Toolkit
- Access to Data in Real-time
- Leadership Change Resulting in Project Change and Longer Timeline
- Time it Takes to Create a Quality Toolkit

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