Published in final edited form as:

J Adolesc Health. 2015 November ; 57(5): 468–474. doi:10.1016/j.jadohealth.2015.07.011.

Psychologists and the transition from pediatrics to adult healthcare

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Abstract

Purpose—Guidelines for optimal transition call for multidisciplinary teams, including psychologists, to address youth and young adults' multifactorial needs. This study aimed to characterize psychologists' roles in and barriers to involvement in transition from pediatric to adult healthcare.

Methods—Psychologists were invited via professional listservs to complete an online survey about practice settings, roles in transition programming, barriers to involvement, and funding sources. Participants also responded to open-ended questions about their experiences in transition programs.

Results—One hundred participants responded to the survey. Involvement in transition was reported at multiple levels from individual patient care to institutional transition programming, and 65% reported more than one level of involvement. Direct clinical care (88%), transition-related research (50%) and/or leadership (44%) involvement were reported, with 59% reporting more than one role. Respondents often described advocating for their involvement on transition teams.

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No conflicts of interests are reported.

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Various sources of funding were reported, yet 23% reported no funding for their work. Barriers to work in transition were common and included healthcare systems issues such as poor coordination among providers or lack of a clear transition plan within the clinic/institution.

Conclusions—Psychologists assume numerous roles in the transition of adolescents from pediatric to adult healthcare. With training in healthcare transition-related issues, psychologists are ideally positioned to partner with other health professionals to develop and implement transition programs in multi-disciplinary settings, provided healthcare system barriers can be overcome.

Keywords

Transition; Pediatric; Patient Care; Adolescent; Barriers; Behavioral Medicine; Psychology

Introduction

The process of transitioning from pediatric to adult healthcare has garnered increasing attention as a result of the growing number of children with chronic conditions who now exceed previous shortened life expectancy estimates. Given recommendations that transition processes should be purposeful and planned [1], the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians [2] issued a joint clinical report summarizing expert and consensus opinions about transition including an algorithm and steps that are critical to transition success: creating a clear timeline for transition with discussions beginning in early adolescence, discussing the medical home transition policy, initiating the transition plan developed, reviewing/updating the transition plan as needed, and implementing an adult care model. The development and implementation of transition plans are essential to continuity of care, particularly because adolescents and young adults are extremely vulnerable during this time and declines in health outcomes are extremely common [3]. Ideal models of transition support include a multidisciplinary team comprised of pediatric and adult physicians and nurses, psychologists, and other essential team members such as educators and dietitians [4], occurring in the context of healthcare systems that support and promote transition [5].

Pediatric oncology provides one model for the integration of psychologists into multidisciplinary pediatric medical teams. However, even in this subspecialty where pediatric psychologists have made remarkable contributions in a variety of areas (e.g., managing procedural pain, nausea and other symptoms, understanding and reducing neuropsychological effects), their focus in the area of transition has traditionally been the transition to palliative care and bereavement, with less focus on the transition from pediatric to adult medical care [6]. Indeed, across many medical and psychiatric conditions affecting youth, very little is known about the roles that psychologists play in the transition process as most of the extant literature has focused on describing models and strategies of care [3,7], creating standardized measures of transition [8,9], and assessing patient readiness to transition within specific diseases [4,10,11].

Psychologists have expertise in developmental and behavioral issues highly relevant to transition of care, such as adherence and health behavior change, patient-provider communication, patient self-advocacy skills, and developmental considerations relevant to

the adolescent and young adult period [12]. In fact, psychologists conduct much research, clinical, and policy work related to transition readiness and transition programs across a number of health and mental health conditions [13–21]. Despite these qualifications, to our knowledge, there are no studies documenting or describing the roles that psychologists have in the planning and implementation of transition models.

Therefore, the purpose of this study was to characterize psychologists' various roles and types of involvement in transition care, including roles and responsibilities in transition care, levels of involvement from individual care to high-level transition programming, collaboration with other disciplines on transition teams, the health and mental health populations with the greatest involvement of psychologists in transition, and barriers to involvement in transition efforts.

Method

Procedure

The current study was approved by the governing institutional review board (IRB) at the institution hosting the survey; IRB approval was also obtained from each of the authors' institutions, when required. In order to capture a broad cross-section of psychologists involved in transition care, a brief description of the study and an invitation to participate were distributed via listservs whose membership included primarily US-based adult or child psychologists who were most likely to be involved in transition-related work. This included select divisions of the American Psychological Association (Society of Pediatric Psychology, Health Psychology, and Association of Psychologists in Academic Health Centers) and the Society of Behavioral Medicine. All psychology professionals, including masters- and doctoral-level trainees, were eligible for participation. Interested participants were invited to click a link within the email, which provided a brief description of the study and requested their voluntary participation. As this was online work, completion of the survey was considered implied consent. Those who were willing to participate were directed to a brief online anonymous survey hosted via a secure, web-based application designed to support data capture for research studies (Research Electronic Data Capture; REDCap, <http://project-redcap.org/>) [22]. Two self-report screening questions, which confirmed the respondent's identity as psychologist or psychology trainee and their involvement in transition work, were used to determine eligibility. No compensation was provided.

Measures

An 18-item survey assessing psychologists' involvement in transition care was developed for this study by the study investigators, all of whom have a background in transition research and/or clinical care (See Supplementary Material for a copy of the full survey). Survey questions were guided by the existing transition literature and authors' expertise and focused on characterizing the participants' involvement in transition care, including: practice settings (e.g., children's hospital), roles and responsibilities in transition care (e.g., clinical, research, leadership), involvement of other medical disciplines in transition (e.g., physicians), patient populations worked with (e.g., ages, medical and/or psychiatric conditions), and barriers to their involvement in transition efforts). Additionally, participants

were asked to rate their institutional culture with regard to transition using a 1 (not a focus, no investment) to 100 (full investment) scale. Sociodemographic information was also collected. Participants reporting direct involvement in transition programs in clinical, research, and/or leadership roles were invited to complete the full survey. Those not reporting current involvement completed an abbreviated version of the survey, which assessed barriers experienced to participation in transition efforts and demographic information.

Data Analytic Plan

Descriptive statistics were used to characterize the study sample and survey responses. When appropriate, data were analyzed separately for participants actively involved in transition work compared to those not involved. The criterion level of significance was set to $p < .05$. Free-text responses provided by participants were extracted and coded using conventional thematic content analyses [23]. Two of the study authors independently reviewed, analyzed, and coded all responses to identify key themes and create labels that reflected the thematic content. Any coding discrepancies were discussed and a final code was agreed upon by both coders and the full study team.

Results

Sample Characteristics

One hundred five surveys were initiated. *Five were excluded (1 ineligible, 4 incomplete data), resulting in a sample of 100. Seventy-seven* were directly involved in tasks related to transition and completed the full survey. Those not directly involved in transition work completed the abbreviated survey ($N = 23$). Sample characteristics are reported in Table 1. There were no significant demographic differences between groups.

Patient Populations

Over two-thirds (68%) of participants reported working with more than one single condition population in relation to transition issues ($M=4.2$ populations, $SD=4.0$; See Table 2). Two-thirds of respondents reported working with patients with medical diagnoses, most commonly patients with diabetes, cancer, cystic fibrosis, chronic pain, and sickle cell disease. Although involvement with patients with psychiatric diagnoses was less frequently reported, the most common psychiatric diagnoses included anxiety and depressive disorders, disruptive behavior and conduct disorders, trauma- and stressor-related disorders, and autism spectrum/developmental disabilities.

Psychologists' Transition Activities

Roles and Responsibilities—Participants reported clinical, research, and/or leadership roles in transition programs (59.2% had more than one role) across multiple levels from individual contact with patients and families to institutional programming (64.9% had more than one level of involvement) (Table 3). Clinical care comprised the largest portion of participants' roles in transition work, mostly taking place as a part of multidisciplinary medical clinics (67.5%) and as an adjunct to medical care (39.0%). Participants reported

various funding sources for their transition work, most frequently billing for clinical services (50.7%), and 42.9% of participants reported more than one source of funding.

Collaboration with Other Individuals—Almost all (92.2%) of respondents reported being directly involved in transition teams, along with other team members including physicians (85.7%), physician’s assistants and nurse practitioners (52.0%), nurses and nurse educators (61.0%), social workers (67.5%), medical clinic staff (15.6%), dietitians and nutritionists (31.2%), child life (20.8%), pastoral care (5.2%), and others (e.g., respiratory therapists, educators/teachers; 16.9%). Over one-half (53.3%) of respondents indicated that patients and parents are members of their transition teams. These teams were most often led by physicians (39.7%) or psychologists (27.4%).

Initial Involvement in Transition Services—Fifty-seven of the 77 respondents to the full survey (74%) responded to an open-ended question about how they became involved in transition efforts at their institution. The majority of participants described how they first became involved through clinical efforts (70%), with a smaller percentage first becoming involved through research (19%), pre-doctoral or post-doctoral training (9%), or concurrent clinical and research work (2%). Responses from participants who first contributed to transition services through research or training were straightforward, with respondents indicating that they received a grant to evaluate an aspect of transition or worked directly under a supervisor already involved in transition efforts.

Inroads to clinical transition activities varied, and four key themes emerged. Many participants reported participating in transition efforts as part of an established multidisciplinary care team, noting the natural contribution of psychology skills to transition goals. For example, one participant noted, “I’m well integrated with the medical team and have been for many years. Given the psychosocial issues involved in transition, I think everyone on the team always assumed I’d be involved.” Participants also noted that providing transition-related service was a routine part of clinical care when working with adolescent and young adult patients, with one participant indicating, “Patient care leads me there.” Some participants reported being invited to participate in transition efforts by a physician, hospital administrator, or treatment team, particularly when transition was perceived to affect behavioral goals such as adherence or when expertise in assessing transition readiness was needed. Respondents noted being recruited most often by physicians to join transition efforts. Of note, a number of participants reported initiating transition services themselves based on interest or identified need. One participant stated, “I saw the need for the development of a transition program and advocated for this within our clinic setting.” Another pushed for inclusion in the creation of a transition program, indicating, “I let it be known that...I wanted to be involved from the ground up.” Thus, content analysis suggests that psychologists actively participate in numerous transition-related efforts and, when not otherwise available, are leading efforts to improve services for adolescents and young adults. **Barriers to Involvement in Transition Services**

All survey respondents, including both abbreviated and full survey completers, reported on their perceptions of their institution’s culture in relation to transition and on specific barriers they had encountered in their involvement in transition work. The average perceived

institutional culture ranking as rated by participants was 57.7 (SD=20.4) out of 100 (full investment). Participants who were not involved in transition programming, and thus completed the abbreviated portion of the survey, reported lower ratings of culture regarding transition programming (M=47.8, SD=23.5) than participants who were actively involved in transition work (M=59.7, SD=18.9; $t=-2.03$, $p=.05$).

Overall, 98.9% of participants responded with “Agree” or “Strongly Agree” to experiencing at least one barrier on a list of 10 possible barriers to their involvement in transition efforts (M = 4.3 barriers, SD = 1.6). Table 4 presents the percentage of respondents endorsing each barrier. Participants who completed the abbreviated survey did not differ from those who completed the full survey with two exceptions. First, 14.5% of full survey respondents endorsed a lack of training or experience in transition issues, in contrast to 45.0% of abbreviated survey respondents ($\chi^2(1)=32.7$, $p<0.0001$). Second, 6.7% of full survey respondents endorsed a lack of interest in transition, in contrast to 14.3% of abbreviated survey respondents ($\chi^2(1)=65.7$, $p<0.0001$).

Among full survey completers, the number of barriers endorsed differed significantly across different work settings ($\chi^2(8)=2,10$, $p<0.05$): the fewest barriers were endorsed by respondents working in “other” settings such as high schools or residential programs (M=3.0, SD=1.9) and freestanding children’s hospitals with formal care relationships with adult hospitals (M=3.4, SD=1.7). In contrast, the greatest barriers were endorsed by respondents working in freestanding children’s hospitals with informal (M=4.9, SD=1.4) or without any relationships with adult hospitals (M=5.0, SD=1.4) or in private/public hospitals that are not specifically pediatric (M=5.5, SD=2.1). Number of barriers endorsed did not differ by career stage or by type of population (i.e., medical, psychiatric, no diagnosis) with which the respondents worked.

Thirty of the 77 respondents to the full survey (39%) responded to an open-ended prompt to describe their experiences as part of a transition planning team. While individual experiences varied widely, four common themes emerged (Table 5). The first three themes represented barriers encountered as part of the treatment team, including lack of consensus in the field or within an institution about best practices in transition, lack of leadership for transition efforts, and low priority within the clinical team. In comparison, a number of participants also noted that their transition efforts were in the early stages of development and that they were actively working to create resources and programs, again highlighting the leadership role of psychologists in advancing transition efforts. A fifth category of responses simply described the respondent’s role within a treatment team; the responses were largely positive but did identify areas for increased engagement. For example, one noted, “I have had some excellent experiences with the teams I consult with on transition issues. However, I have also seen that mental health is not always at the table even though they have been asked to participate.”

Discussion

The current study characterizes the state of psychologists’ involvement in transition to adult care services for youth with chronic health and mental health conditions. Several

conclusions can be drawn from this study. First, psychologists are involved in transition efforts across a number of chronic condition populations and often adopt multiple roles (e.g., clinician, researcher, program leader) with regard to transition. Despite this, psychologists frequently experience a number of barriers related to becoming involved in, and maintaining, their current work in transition services.

Although most survey respondents reported clinical involvement in transition to adult care, more than 59% reported serving in more than one role. Psychologists also tend to work across multiple populations. Thus, in order to be an active contributor to transition services, psychologists are often required to possess many skills including that of a clinician, researcher, and program leader, all the while maintaining an adequate level of disease-specific knowledge across more than one chronic illness/psychiatric population.

In order to allocate time to serve these multiple roles in transition, psychologists must be resourceful in funding their work. Indeed, survey participants reported accessing multiple sources: most participants were able to obtain funding through clinical billing (50.7%) or research (32.5%) and less than one-quarter of participants reported that their work was unfunded. The success of psychologists in obtaining clinical reimbursement or research funds to support their work in transition speaks to the viability of psychology services within a multidisciplinary team and the increasing recognition of the value psychological and behavioral expertise adds to this area. Psychologists can contribute to the financial solvency of transition programs; in the U.S., the services provided are often reimbursable through Health and Behavior Codes or traditional CPT codes [24]. However, there is likely room for improvement in the reimbursement rate for these services, as nearly half of the sample also report billing concerns as a barrier to involvement in transition services. Reimbursements may vary widely by institution or state [24]. Recognition of psychologists' contributions to transition care teams can support advocacy efforts at institutional, state, and national levels to improve reimbursement rates for such efforts.

Although 77% of survey respondents reported current involvement in transition efforts, almost all individuals reported barriers limiting their involvement or current work in transition. These barriers do not appear to be related to perceptions that psychologists' expertise is not valued by patients/families or the medical team, but rather indicate that larger issues at the healthcare systems level can impede psychologists' work. These larger systems issues (e.g., lack of a clear transition plan within one's practice setting and poor coordination of care among providers) may make it difficult for psychologists to establish a clear role as part of the transition team or effectively provide the best possible care for patients and their families. Of note, psychologists are not the only ones impacted by these two health systems issues. Such barriers are a recurring theme in the broader research literature and are often reported by patients, parents, and providers from a variety of subspecialties [25–27]. Although a variety of medical associations have issued policy and position statements to improve transition services and outcomes, our findings suggest that, at least with regard to psychologists' involvement in transition care, larger, healthcare systems-level barriers remain. Such barriers may be difficult for psychologists to overcome if they are not in leadership positions that enable them to address large scale barriers or if the

contributions of psychologists are not explicitly addressed in published best practices for transition care.

Approximately half of our sample reported being actively involved in the development of transition programs within a subspecialty and one-quarter reported being involved in transition on a larger, institutional level. Such roles represent promising steps psychologists are taking to address institutional and healthcare systems barriers related to their involvement in care. Evidence-based transition frameworks such as the Six Core Elements of Health Care Transition include attention to readiness for transition and development and refinement of tailored, collaborative transition plans [28]. Many aspects of psychologists' training – including a strong background in developmental and socioecological influences on children's health and illness, behavioral approaches to health promotion, research methodology, program design and evaluation, and evidence-based practice – are well aligned with these core elements and support psychology contributions to the design and implementation of effective transition to adult care programs. Indeed, understanding the transition from pediatric to adult healthcare has recently been added as a cross-cutting knowledge competency area in the training of pediatric psychologists [29], preparing a new generations of psychologists to be well-versed in transition issues. No single profession alone can make the many changes needed to address transition. Ultimately, a collaborative effort by multidisciplinary teams of providers, along with broader healthcare system changes, are needed to make important contributions to future transition care and research [5, 30].

These findings should be considered within the context of study strengths and limitations, all of which have implications for future research. Strengths of the study include the participation of respondents from a variety of practice settings, clinical populations, and levels of training experience. This was made possible by our diverse recruitment strategy, which purposefully targeted those professional listservs most likely to have psychologists involved in transition work. The inclusive nature of our study, which solicited the perspectives of both those who were currently involved in transition services as well as those not involved, provided a more comprehensive view of current psychologist involvement in transition care as well as those factors that impede psychologists' abilities to contribute. Such findings can inform future efforts to increase psychologists' roles in transition care.

Regarding study limitations, the majority of psychologists and psychology trainees who responded to our survey were actively involved in transition efforts at their practice setting, suggesting possible selection bias (e.g., individuals who were not involved in transition may have self-selected out of participation). Additionally, most participants were involved in transition of youth with chronic medical conditions, and fewer worked with psychiatric conditions or in a primary adult care setting. Individuals working with patients with primarily psychiatric conditions or in adult care settings may not have been reached by our survey despite our diverse recruitment efforts. Alternatively, it is possible that psychology's current involvement in transitioning youth with psychiatric conditions is limited, and that the majority of transition efforts occur in a pediatric setting and have not yet been well-integrated into the adult health care system. The international implications of study findings

are also limited as the listservs used for recruitment are primarily comprised of psychologists in the United States. Research among international samples is needed to clarify the roles of psychologists in other settings. Finally, as with all unfunded survey-based research, low response rate may be a concern. As our survey was sent to listservs with an unknown number of subscribers, some of whom may not have met inclusion criteria or may have been members of more than one listserv, we do not know to what extent our results are representative of all psychologists working with transition-aged individuals.

While some psychologists appear to be heavily involved in transition, others continue to struggle to become involved. Examination of how psychologists in the former group have overcome barriers may help pave the way for additional psychologists to contribute to transition. National guidelines for transition care often reference developmental needs, psychosocial functioning, and family relationships, all of which psychologists are trained to assess, but often fail to specifically include psychologists as integral members of transition teams. Thus, advocacy work is needed to promote psychology's role in transition initiatives [31]. Documentation of the many ways psychologists support transition care can contribute to advocacy efforts to promote psychology inclusion at team, institution, and national levels. Studies examining the impact of psychologists' involvement in transition care will enhance our understanding of the unique role these professionals play in enhancing patient outcomes and furthering research in best practices in transition to adult care. As one respondent in this study noted, "It's a long and rewarding road and we are finally beginning to see some true results [after] long years of work."

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors appreciate support of the Adolescent/Young Adult and Adherence Special Interest Groups of the Society of Pediatric Psychology. MM is currently funded by NIH K23 DK099250. MEH is currently funded by NIH K12 KD097696.

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Implications and Contribution

Psychologists contribute to the process of transitioning adolescents with chronic health or mental health needs from pediatric to adult healthcare in numerous ways via clinical, research, and leadership roles. Findings highlight the diverse contributions, funding strategies, and barriers experienced by psychologists in supporting transition efforts.

Table 1

Sample characteristics.

Characteristic	% or Mean (SD)		
	Abbreviated Survey Participants (n=23)	Full Survey Participants (n=77)	Total Sample (n=100)
Gender, % female	82.6%	85.5%	84.6%
Race/Ethnicity			
White/Caucasian	86.4%	87.8%	87.5%
Black/African-American	0%	2.7%	2.08%
Hispanic/Latino	9.1%	4.1%	5.21%
Asian-American/Pacific Islander	4.6%	4.1%	4.17%
Age, years	40.23 (12.5)	40.0 (11.8)	40.0 (11.9)
Highest degree, % PhD or PsyD	91.3%	85.3%	86.7%
Career stage			
Graduate Student/Intern	8.7%	14.5%	13.3%
Postdoctoral Fellow	21.7%	5.3%	9.1%
Early Career (0–7 yrs)	26.1%	38.2%	35.4%
Mid-Career (8–15 yrs)	17.4%	18.4%	18.2%
Established (>15 yrs)	26.1%	23.7%	24.2%
Practice Settings ^a			
Children's hospital/department of Pediatrics	-	84.4%	-
Private/public hospital (general)	-	2.6%	-
College/university	-	16.9%	-
Private practice	-	7.8%	-
Other	-	11.7%	-

^aNote: Percent totals >100% because 19.5% of respondents indicated working in more than 1 setting; Practice settings only collected for full survey respondents

Table 2**Patient Populations**

Age Groups	Percent
• Pediatric patients only	20.6%
• Pediatric and young adults	49.4%
• Young adults only	6.5%
• Young adults and adults	5.2%
• Adults only	1.3%
• All age groups	11.7%
Patient Diagnoses	
• Medical diagnoses only	66.2%
• Medical and psychiatric diagnoses	16.9%
• Psychiatric diagnoses only	9.1%
• Patients without diagnoses	1.3%
• All groups of patients	6.5%
Most common medical diagnoses	
• Diabetes	32.5%
• Cancer	31.2%
• Cystic fibrosis	26.0%
• Chronic pain	22.1%
• Sickle cell disease	20.8%
Most common psychiatric diagnoses	
• Anxiety disorders	27.3%
• Depressive disorders	27.3%
• Disruptive behavior/conduct disorders	26.0%
• Trauma-/stressor-related disorders	22.1%
• Autism spectrum/developmental disabilities	14.3%

Table 3

Participants' roles in transition work across programming levels and funding sources.

Roles^a	Percent
•Clinical only	35.5%
•Research only	5.3%
•Clinical and research	15.8%
•Clinical and leadership	14.5%
•Research and leadership	6.6%
•Clinical and research and leadership	21.1%
•Clinical and research and leadership and consulting	1.3%
Levels	
•Individual	81.8%
•Group	8.8%
•Subspecialty	55.8%
•Institutional	24.7%
Funding Sources	
•Billing for time using traditional psychotherapy codes (CPT)	36.4%
•Billing for time using health and behavior codes	29.9%
•Bundled services (single co-pay for clinic)	9.1%
•Sub-specialty pays for psychologist service	2.6%
•Hospital pays for psychologist service	11.7%
•Grant or foundation funds	32.5%
•Unfunded, not reimbursed	23.4%
•Other sources (self-pay, state/county funds)	6.5%

^aNote: Percent endorsing involvement across levels totals >100% due to respondents who participate in programming at multiple levels; funding sources total >100% due to 42.9% who endorsed multiple sources of funding.

Table 4

Barriers experienced in creating/maintaining a transition program

Barrier	% endorsed
Lack of clear transition plan within the clinic/institution	78.9%
Poor coordination of care among providers	74.7%
Lack of follow-through by referred patients	70.5%
Too busy with other clinical demands/Lack of time	68.4%
My work is not reimbursed	54.7%
Transition efforts are spearheaded/managed by other disciplines	52.6%
My own lack of training/expertise in transition issues	21.1%
Psychology's role in transition efforts not welcomed/valued by medical team	8.4%
Transition is outside of my area of interest	8.4%
Other	4.2%
Psychology's role in transition efforts not welcomed/valued by patients/families	1.1%

Table 5

Qualitative data on psychologists' experiences planning transition services

Key Themes for Experiences in Planning Transition Services- <i>"Please share any experiences you've had as part of a transition planning team"</i>	
<u>Psychologists encounter barriers to providing transition services</u> <ul style="list-style-type: none"> <u>Lack of consensus about best practices in transition</u> "We are unclear, as many are, about what a 'good transition' entails. What is the best age to transition?" "There is not a consensus among (and within) chronic illness clinics/providers about a transition timeline... so the hospital as a whole has disparate responses/reactions to AYA in terms of the messages being given about how transition occurs across the hospital." <u>Lack of leadership for transition efforts</u> "There seemed to be a diffusion of responsibility in that everyone on the team was willing and interested to help, but no one was willing or able to take on the lead role. As such, some formal efforts have fizzled." <u>Transition is a low priority within institution or clinical team</u> "The main issue is getting everyone, pediatric & adult staff, the young person and family on board, and on board over time... This suggests it is not seen as a priority." 	
<u>Psychologists are developing and working to create transition resources and programs</u> "We are developing resources for providers to share with patients. Many providers are enthusiastic but most struggle with taking the time to include more formal assessment of transition readiness and transition planning into an already busy clinic schedule." "Created transition materials, coordinate meetings among multidisciplinary team to discuss creation/implementation of transition program, discussing transition with patients & families."	