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| **Review of Literature on Health Care Transition for Individuals with IDD** | | | | | |
| **Study** | **Sample/Setting** | **Research Design** | **Methods** | **Purpose** | **Significant/Major Findings** |
| Berg, L. A., Jirikowic, T., Haerling, K., & MacDonald, G. (2017). Navigating the Hidden Curriculum of Higher Education for Postsecondary Students With Intellectual Disabilities. The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 71(3), 7103100020p1–7103100020p9. https://doi.org/10.5014/ajot.2017.024703 | Case study examined experiences of students with IDD attending a PSE program and stakeholder perspective—  Thirty-two participants were interviewed (10 students with IDD, 5 parents or guardians,  4 college administrators, 8 college instructors, 4 occupational therapists, and a transition specialist). | After institutional review board approval, a single, bounded  exploratory instrumental case study (Yin, 2014) of the  Triumph program was conducted. This case study provided  an in-depth examination of the Triumph program  and the issues related to young adult PSE students with  IDD. A bounded system has clearly defined boundaries that  specifically limit study participants, context, and time  frame (Yin, 2014). Selection of the Triumph program  permitted access to key informants, documents, class observations,  and relevant participants. Multiple data points  permitted a significant understanding of the case and  served as a form of triangulation. | Data collection methods included a demographic survey,  one-on-one semi structured interviews, the Vineland  Adaptive Behavior Scales, Second Edition (VABS–II; Sparrow,  Cicchetti, & Balla, 2005), document reviews, and class observations.  Interviews were analyzed using conventional content (descriptive and in vivo coding) The semi structured interviews were the primary data source to obtain individual perspectives  (Creswell, 2013) and included open-ended questions to understand the experiences and perspectives of students  with IDD attending PSE and other stakeholders  involved with the students, supports for navigating the  PSE setting, and supports or accommodations to participate  in PSE activities. | To analyze the experiences of students with intellectual and developmental disabilities navigating the hidden curriculum—including meeting prerequisites for PSE and employment,  using support systems and community transportation and carrying out adulthood expectations. | Key theme: Navigating the hidden curriculum  Subthemes:   1. Adult-based system navigation, 2. Persisting challenges with adaptive behaviors 3. Disability awareness and disclosure   Contributing Factors:  Limited awareness of disability and supports and services needed for a successful PSE outcome.  Findings:  Occupational therapists have the skills to support  students with IDD in skill acquisition to successfully transition to and navigate PSE and the hidden curriculum. |
| Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family Quality of Life During the Transition to Adulthood for Individuals With Intellectual Disability and/or Autism Spectrum Disorders. American journal on intellectual and developmental disabilities, 120(5), 395–411. https://doi.org/10.1352/1944-7558-120.5.395 | Researchers examined the FQOL ratings of 425 parents with a child between 13–21 years of age with intellectual disability or autism to understand  FQOL and the factors that may shape it | Researchers computed Pearson correlation coefficients  to examine bivariate associations between  all predictor and outcome variables and used multiple regression to identify  which child- and family-level factors independently  predicted parents’ overall FQOL ratings.  Beta weights (standardized  multiple regression coefficients) and semi partial  (i.e., part) correlations were examined to determine the relative value of each predictor variable. The unique  predictive value for a given variable is the  percentage of variance in the FQOL outcome  variable accounted for by that predictor variable  over and above the variance explained by the  remaining predictors in the regression model.  For all correlation and regression analyses  coded variables were used. | Participants  Participants were 425 parents or primary caregivers of transition-age youth and young adults with developmental disabilities. To be included in the study, parents must have lived in Tennessee and had primary custodial care of a child with an intellectual disability or autism between the ages  of 13–21. Participants ranged in age from 31 to 72 years.  Recruitment  Researchers partnered with an array  of disability- and family-focused organizations and networks across Tennessee, extended invitations through these groups to parents meeting the inclusion criteria, and then distributed measures to  families who responded. | To explore the family quality of life (FQOL) among families  with transition-age youth and young adults as little is known/disclosed. | Parents of transition-age youth and young adults with disabilities were generally  satisfied with their family quality of life as  measured by the FQOL measure. Researchers were  somewhat surprised by this relatively high level  of satisfaction given prevailing descriptions of the  transition years as a time of stress and uncertainty. However, this finding is  consistent with research involving families of  younger children with disabilities.  (Kim & Turnbull, 2004)  Overall satisfaction with FQOL was somewhat high, with some variability across domains. Higher FQOL ratings were predicted by lower frequency of challenging behaviors, lower support needs, and higher strength of parental religious faith. |
| Allen, K. D., Vatland, C., Bowen, S. L., & Burke, R. V. (2015). An evaluation of parent-produced video self-modeling to improve independence in an adolescent with intellectual developmental disorder and an autism spectrum disorder: a controlled case study. Behavior modification, 39(4), 542–556. https://doi.org/10.1177/0145445515583247 | 17-year-old Caucasian female diagnosed with  ASD and IDD and 46-year-old stay-at-home mother. The parent  had 1 year of college with a general education focus and no specialized training  in video production. Participation in study was voluntary, and written consent was  obtained from the participant’s parent. The study was approved by the Institutional Review Board at the University of Nebraska Medical Center. | Controlled Case Study with concurrent multiple baselines.  **Analogue:**  The parent created a simulated store in her basement with a toy cash register, shelves, and common items the participant might purchase at a quick shop, a counter for simulating the process of paying for one’s  purchases, and a simulated fast-food counter with menu. The parent played  the role of the clerk in each routine. This format provided more opportunities for repeated observations of performance by the observers without disrupting activities in the community setting.  **Generalized Setting:**  Direct observations were also conducted in the natural  environment in settings where the targeted skills were to be used. Preferred community locations included a local Walmart and a Dollar Tree store and a nearby Dairy Queen and McDonald’s restaurant.  **Independent Variable—Video Production:** The parent used a mobile app called “Video Tote” for recording the video on an iPad 2 tablet device. The parent was not  provided with access to the task analysis performed by the investigators (used to  develop data coding forms) and the parent was not provided with specific feedback on the quality of the video production. | Direct observations of performance in each routine were conducted twice a week in analogue situations. During the routine, the parent participated as the store clerk, cashier, or restaurant worker taking orders, while observers recorded data.  Target responses were initially identified by participant and  parent (e.g., crossing the street independently), but participants  prioritized (a) requesting help from a quick shop employee, (b) checking out from a store, and (c) ordering food at a fast-food restaurant (more commonly encountered routines). Task analyses were conducted by investigators to identify the critical steps in each task and target responses were defined.  Measurement involved written event recording by observers  for each task routine.  During all events, the parent was asked to allow the participant time to respond before verbally prompting completion of the step if necessary. Observers  recorded whether each step was performed and if there was any verbal or physical prompting by the parent. The primary dependent measure was percentage of steps completed without prompting in each routine.  Treatment: The Video Model Rating Scale (VMRS) was used to rate six aspects of production  quality on a 3-point scale (0, 1, or 2) that included the clarity with which the observer could see critical steps in the routine, the length  of the video, and the presence of distractions. The parent was asked to complete a nine-item, modified treatment evaluation form.  Once stability was observed in one routine, the parent was provided with the Video Tote Mobile app, was prompted to watch the tutorial, and then create a video in which the participant would  show the proper way to perform that routine. The parent and participant then rehearsed and filmed a video of the first routine followed by the second and third until stable baseline  performance was observed. | To evaluate an intervention  to improve independence in an adolescent diagnosed with Intellectual  Developmental Disorder (IDD) and Autism Spectrum Disorder (ASD). | The adolescent showed marked, immediate,  and sustained improvements in performing each routine following the production and implementation of the VSM. Performance was found to  generalize to the natural community setting. Results suggest that parents can  use available technology to promote community independence for transition  age individuals. The primary outcome measure was percentage of steps in a task performed without prompting. The results of this investigation suggest that a parent can, with minimal training,  effectively use available tablet-based technology to record and implement  VSM to enhance independence in the community for an individual with ASD and intellectual disabilities. |
| Pennington, R. C., Bross, L. A., Mazzotti, V. L., Spooner, F., & Harris, R. (2021). A Review of Developing Communication Skills for Students with Intellectual and Developmental Disabilities on College Campuses. Behavior modification, 45(2), 272–296. https://doi.org/10.1177/0145445520976650 | The participants across the eight studies included 13 males and 14 females between the ages of 18 to 28 years. 70% (19) had ASD and 30% (8) had an ID. 7% of participants (2) were reported to have ASD and ID. Of the participants reported to have an ID, three had a mild ID, four had a moderate ID, and for two participants, the level of ID was not reported. 48% (13) of participants were enrolled in a traditional degree seeking program at a university or community college. 41% (11) of participants were in postsecondary programs for individuals with disabilities,  and 11% (3) of participants were enrolled in a high school transition program housed on a college campus. | Systematic literature review of single case studies to identify evidence-based practices for teaching communication skills to individuals with ASD and ID. | **Inclusion Criteria** To be included in the review, studies met the following criteria: (a) published  in a peer-reviewed journal or as a dissertation in English between January of  2000 and May of 2020; (b) used a group or single-case experimental design; (c) included at least one participant with an intellectual or developmental disability,  including ASD; (d) evaluated an intervention to increase communication  skills among individuals with IDD; and (e) was conducted on a college  campus (community and 4-year with participants enrolled in any type of postsecondary  educational program including Transition and Postsecondary  Programs for Students with Intellectual Disability (TPSID), degree seeking programs, and secondary transition programs housed on college campuses.  **Literature Search Procedure**: Databases included APA PsycINFO (EBSCO),  CINAHL (EBSCO), ERIC (EBSCO), Educational Administration Abstracts  (EBSCO), Education Research Complete (EBSCO), Web of Science  (Clarivate), and PubMed. The initial electronic search generated 387 articles for review.  Research team members reviewed titles, abstracts and conducted an ancestral search of reference lists and identified eight articles for inclusion in the  review.  **Coding Procedures and Interrater Reliability**  For each study, researchers coded numerous participant variables including (a) gender, (b) age, (c) disability category, (d) response topography  taught, (e) type of post-secondary program enrollment, and (f) communicative  partner. Researchers also coded whether the intervention produced (a) improved performance over baseline conditions, (b) maintenance of target skills, (c) generalized responding, and (d) socially validity for each participant. Data was also extracted on study variables including: (a) setting, (b) instructional arrangement (i.e., one-to-one, group), (c) change agent,  (d) intervention components, (e) research design, (f) communication skills  taught, (g) independent variable reliability, and (h) dependent variable reliability. Researchers also coded studies for methodological rigor and quality using a checklist developed by the National Technical Assistance Center on Transition (NTACT). | Many individuals with intellectual and  developmental disabilities (IDD), including autism spectrum disorder  (ASD), often have difficulty acquiring critical communication skills and developing and maintaining relationships. The purpose of this study was to review and evaluate the current literature on teaching communication skills to students with IDD  on college campuses and to provide guidance on the application of communication supports for college-based support personnel. | All participants in the  reviews had functional vocal repertoire, and none were reported to use augmentative and alternative communication (AAC)  systems. The review yielded little information  on guidance pertaining to providing communication supports, including AAC, to students with the most complex communication  needs. Specifically, these students may graduate from high school with communication skills insufficient for navigating complex postsecondary  environments and are at an increased risk for isolation and exploitation.  The lack of literature and guidance highlights the need for increased research attention to the application of interventions for teaching  full range of communication skills to these learners.  Even though researchers in the included studies targeted a small set of communication  skills, throughout their process they did teach skills that are critical for success in the college environment. These included skills related to starting, maintaining, and  ending conversations, overt skills such as asking  questions, elaboration, emotional sharing, and subtle conversation skills  such as talking about a conversational partner’s interest, reducing awkward  pauses, and eye contact). Investigators also commonly used modeling, role play, and feedback during instruction which provided opportunities for students to observe correct performance  through video models or video feedback. |
| De Portes, V. (2020). Intellectual Disability . Handbook of Clinical Neurology. Neurocognitive Development: Disorders and Disabilities 174(3), 113-126. https://doi.org/10.1016/B978-0-444-64148-9.00009-0 | A regular multidimensional evaluation of  cognitive, educational, socioemotional, and adaptive skills throughout life provides a better understanding of how individuals with ID function and will contribute toward the planning of more appropriate strategies for learning, care, and support, leading to a better quality of life and participation in society. | Qualitative Descriptive Design | Intellectual handicap or mental handicap results from an interaction between the individual  vulnerability of a person with ID and their ecosystem (family, cultural, and institutional environment) which can be a barrier or a facilitator. Identifying a child with developmental  delays requires professionals to have a good understanding of psychomotor development. ID  may be isolated but is often aligned with other neurodevelopmental disorders, including autism, motor or sensory difficulties (hearing, vision), serious sleep and eating disorders, and medical conditions such  as epilepsy, as well as a wide variety of psychopathologic problems, including anxiety, depression, and emotional regulation disorders. | Intellectual disability (ID) or intellectual developmental disability (IDD) is one of the most common neurodevelopmental  disabilities worldwide.  There are many causes of ID. More than half of all cases are genetic in origin. There is also an underdiagnosis of medical problems in those with ID including prevalence, etiology, pathophysiology, molecular and cellular neurobiological  dysfunction, identification, and screening. | Findings: The regular evaluation of  cognitive, educational, socioemotional, and adaptive skills throughout life provides a better understanding of  how individuals with ID function and will contribute toward the planning of more appropriate strategies for  learning, care, and support, leading to a better quality of life and participation in society.  The transition to adulthood needs to be planned, with  specific support to identify the wishes of the adolescent  to prolong education and facilitate the transition toward employment or a non-salaried activity (such as a day center) in cases where the individual’s situation does not permit them to work. It should also include support for families, who are facing their own transition, on how they see their child, as well as support for training institutes and companies. |
| Lee, C. E., Day, T. L., Carter, E. W., & Taylor, J. L. (2021). Examining Growth Among College Students With Intellectual and Developmental Disability: A Longitudinal Study. Behavior modification, 45(2), 324–348. https://doi.org/10.1177/0145445520982968 | This study included 30 college students enrolled in Next Steps at Vanderbilt, an inclusive postsecondary education (IPSE) program in a southeastern state. | Longitudinal Study Design | Participants:  To participate in Next Steps at Vanderbilt, students had to (a) be 18–26 years old; (b) have an intellectual or developmental disability; (c) have completed high school and received a standard or alternate diploma (i.e., occupational or special education); (d) not meet eligibility requirements for admission into a standard college program; and (e) exhibit sufficient communicative and functional skills as determined by program staff through a day-long observation and by contacting references (communicate reliably with others, exhibit socially responsible behavior on campus). The mean age of students was 20.45 years. Most were male and more than one third were racial/ethnic minorities. The most reported disabilities included intellectual disability, autism spectrum disorder, and unspecified developmental disability. Nearly all students lived at home with their parents as Next Steps at Vanderbilt did not offer on-campus residential opportunities.  Recruitment: First year students; person-centered planning meetings; data was collected form 4 cohorts | There has been limited research on the growth that college students with IDD may experience during their time on campus. | Researchers addressed gaps in research by using a longitudinal design to examine the adaptive behavior, self-determination, executive functioning, and social skills of college students with IDD across three points in time-upon initial entry into the program, at the end of their first year, and at the end of their second year. Analyses suggested significant improvements in adaptive behavior and self-determination across the first year of the program. We offer recommendations for research and practice aimed at documenting and promoting growth for students with IDD throughout their collegiate experience. |
| Gilson, C. B., Gushanas, C. M., Li, Y. F., & Foster, K. (2020). Defining Inclusion: Faculty and Student Attitudes Regarding Postsecondary Education for Students With Intellectual and Developmental Disabilities. Intellectual and developmental disabilities, 58(1), 65–81. https://doi.org/10.1352/1934-9556-58.1.65 | Researchers conducted a campus-wide survey at a large public university to evaluate the perspectives of 1,867 faculty and students regarding their views of inclusion in student life and their attitudes toward prospective students with IDD. | Qualitative Design | Researchers incorporated a mixed methods approach to summarize these views by using correlations, linear regression, and qualitative analysis of open-ended responses. | To highlight Inclusion across education contexts for students with I/DD. | Researchers offered recommendations for research and practice aimed at increasing inclusive opportunities for students with IDD and their peers on college campuses. |
| Oakes, L. R., Milroy, J. J., & Hickerson, B. D. (2020). Health disparities and health promotion needs of college students with intellectual and/or developmental disabilities: A systematic literature review. Journal of American college health : J of ACH, 68(7), 742–753. https://doi.org/10.1080/07448481.2019.1615495 | 24 articles were selected for final review, 45.83% were completed within the United States.  The largest sample size of an individual article that utilized primary data analysis was 667 undergraduate students. The largest sample size of an individual article was 10,782 women between the ages of 15 and 44 years, which utilized secondary data analysis. | Systematic Literature Review | Inclusion criteria for full-text review included (1) college students with disabilities and/or adolescents or adults with disabilities, (2) health or wellness related topic that is common to the college environment and/or overall college experience (physical fitness, physical activity, or exercise; food choices or nutrition; drugs or alcohol; sex, dating, or relationships; mental health; and socialization, leisure, or recreation), and (3) article must have downloading capabilities. | To explore whether the health and wellness needs of individuals with IDD are being identified and met as this new population of students with IDD are emerging on college campuses and the health education and related support college students with IDD have access to and receive for health issues is relatively unknown.  Researchers also noted that the development of health/mental health services for individuals with IDD is limited due to a lack of recognition at the primary care level and insufficient numbers of trained professionals with specialized services. | Continued research is needed as specific health and wellness topics were highlighted: transition experiences and worries; college experiences, coping strategies, and support needs; sexuality, dating, and romantic relationships; mental health; and drugs and alcohol.  Recommendations for student concerns include:  The use of a developmental approach to support transitioning young people well before they reach the later stages of their transition; the development of interventions that focus on coping strategies to compensate for or bypass skill deficits, as well as access to coaches in the areas of education, student life, and daily living; and customized programs to promote social communication competence, standardized testing, self-efficacy questions, observation in natural environment, and full inclusion programing on college campuses. |
| Rachel Tokarski, Jeryl Benson, Ashlyn Geubtner; A Qualitative Study of the Transition From an Educational Setting to Adulthood for Youth With Intellectual and Developmental Disabilities (IDD). Am J Occup Ther August 2020, Vol. 74(4\_Supplement\_1), 7411515376p1. doi: https://doi.org/10.5014/ajot.2020.74S1-PO3203 | Inclusion criteria were adolescents aged 16-21 with IDD experiencing the transition process or the parent of such an individual. There were 13 total participants: 2 adolescents and 11 parents. Researchers utilized snowball sampling to gather participants. | Qualitative Study | Semi-structured interviews were conducted. An interview guide was utilized to provide structure to each interview and each interview was recorded and transcribed. | Adolescents with disabilities experience unique challenges during the transitional phase and institutional/personal barriers can lead to educational, vocational, interpersonal, and medical challenges. | Findings indicate that parents identify client-centered planning, staff guidance, resource sharing, and communication as the desired practices during transition.  Important themes identified:  1. Finding the right fit: Match between client & context 2. “Walking the path alone”: Understanding parent & student perspectives 3. Going above & beyond: Relationship between family & the professionals 4. “A different world”: Building a bridge between family & community 5. “Pathway of the transition process”: Exploration to implementation 6. Creating a supportive environment through open communication 7. Falling short: Parents’ desire for more 8. No progress without parents: Parents as the (sometimes reluctant) driving force. |
| Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. Journal of applied research in intellectual disabilities : JARID, 32(5), 1116–1128. https://doi.org/10.1111/jar.12601 | Adults with IDD and their families were selected for the study if they reported navigating the transition to adulthood; ages ranged from 18 to 30 years. | Qualitative Case Study | Qualitative case studies were conducted with two Canadian families who participated in semi‐structured interviews every quarter for one year. Analyses were informed by family systems theory and self‐determination theory. | To explore the way families support self‐determination in young adults with intellectual and developmental disabilities (IDD) during life transitions. | Families considered the needs and preferences of the young adults with IDD, suggesting individualized approaches for balancing independence and protection. Families set short‐term and long‐term goals for increased independence, scaffolded the learning of new skills and collaborated on important choices. Collaboration occurred to the extent that all family members perceived agency in planning and implementing transitions.  Families supported the young adults with IDD in their needs for competence, social connection, and autonomy, which allowed them to experience self‐determination. Findings have implications for supporting self‐determination and transition planning in the family system. |
| Heron, L. M., Agarwal, R., Greenup, J., Maddux, M., Attong, N., & Burke, S. L. (2020). Disparities in healthcare transition support received by adolescents with special healthcare needs. Journal of applied research in intellectual disabilities : JARID, 33(2), 180–192. https://doi.org/10.1111/jar.12658 | Data from the 2016 National Survey of Children's Health (NSCH) was used to examine the transition to adult healthcare systems. For this study the sample was constrained to include only adolescents with special healthcare needs aged from 12–17. The average age was 14 and the racial backgrounds represented were: 57.6% White, 19.1% Hispanic, 15.8% Black, 1.6% Asian and 5.9% multiracial/other. | Cross sectional design | Researchers utilized the 2016 National Survey for Children's Health; several analyses were conducted to examine doctor–patient interactions and discussions about transitioning to adult health care. Researchers accounted for demographic and diagnostic indicators which allowed for the assessment of disparities. | The purpose of the study was to investigate whether individuals between the ages of 12 and 17 are receiving the support needed to transition into adult health care.  Transitioning to adult healthcare systems can be challenging for individuals with IDD and research on healthcare‐specific transition planning is lacking. | Researchers identified significant disparities between age, disability, and race relative to various healthcare transition support services.  Further research in needed to enhance the development of training programs for healthcare providers, influence policy, modify procedures and interventions, and to highlight the need for increased advocacy. |
| Benson, J. D., Tokarski, R., Blaskowitz, M. G., & Geubtner, A. (2021). Phenomenological Study of the Transition Process for Adolescents With Intellectual and Developmental Disabilities. The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 75(3), 7503180040. https://doi.org/10.5014/ajot.2021.044289 | Community-based setting with interviews conducted face-to-face in the participants’ residence or via telephone. Eleven parents of adolescents and young adults (ages 16–22 years) with IDD were included. | Phenomenological design | Semi-structured interviews in person or via phone focusing on parent and family experiences with the transition process. | To explore the lived experience of parents of adolescents with IDD participating in the transition process as some practices have not changed in many years. | Themes: Several themes emerged from the findings representing parent perceptions related to the use or lack of person-centered practices, needing more communication from the team, frustration with being the driving force of progress, feelings of defeat, gaps between programming options, positive team collaboration, and planning for the future.  Parents also identified person-centered planning, guidance from school staff, and resource sharing as desired practices in the transition planning process.  Occupational therapy practitioners are encouraged to assert their role in the transition planning process to increase self-determination and quality of life. |
| Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., Trachtenberg, S., Coccia, A., Devaney, M., & Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. Journal of applied research in intellectual disabilities : JARID, 32(5), 1103–1115. https://doi.org/10.1111/jar.12600 | Eligible participants were parents and siblings of adults with IDD who were 18 years or older and still living in family homes; 15 parents and 10 siblings were included in the study. The mean age of parents in our sample was 59.9 (43–70), and of siblings was 29.0 (18–44). Both parents (67%) and siblings (100%) were predominantly White. Additionally, 60% of parents and 40% of siblings had a yearly household income of over $75,000. Parents and siblings both reported overall poor health. | Qualitative Design | Researchers conducted interviews with parents and siblings of adults with IDD and performed qualitative coding using a modified grounded theory to explore domains of future planning and identify barriers and facilitators. | Research shows that adults with intellectual and developmental disabilities (IDD) increasingly outlive caregivers, who often struggle to plan for the future and have little support and knowledge surrounding long‐term care planning. | Themes from the interviews revealed seven major domains of future planning that should be considered by caregivers of adults with IDD. These domains are housing, legal planning, identification of primary caregiver(s), financial planning, day‐ to‐day care, medical management, and transportation. Approaches to planning within each domain varied greatly. |
| Kipping, Kayla & Phillips, B. & Whicker, John & Landon, Trenton & McKnight, Michelle. (2021). Exploring the Knowledge, Perceptions and Practice Patterns of School Counselors Regarding Vocational Rehabilitation for Transition Age Youth with Disabilities. Journal of Rehabilitation. 87. 38-47. | Participants in this study included 178 secondary school counselors from across the United States. The participants included 158 women and 20 men, ranging in age from 23 to 64 years. 154 participants (86.5%) indicated White, 9 (5.1%) indicated Black and another nine indicated Hispanic/Latino, 2 (1.1%) indicated Asian and another two indicated Native Hawaiian or Other Pacific Islander, and 2 (1.1%) indicated a primary race/ethnicity of “other”. A master’s degree was the highest level of education for 156 (87.6%) of participants, with 17 (9.6%) others having a degree or certification beyond the master’s degree, and 4 (2.2.%) had a bachelor’s degree with some graduate level training. | Cross Sectional Design | A questionnaire was developed, with 12 demographic components including age, gender, race, level of education, years of practice, familiarity of VR services, and the state or territory of the counselor. | Students exiting the special education system experience significant barriers as they transition from the secondary education system to adult life- low graduation rates, poor employment rates, and are more likely to be living in poverty than their peers without disabilities. Without the proper supports in play the transition process can be very challenging.  School counselors have access to all students prior to their transitioning from high school, therefore it is critical that the counselors providing transition services to students with disabilities are aware of VR services, make appropriate referrals, and engage in collaboration with VR. | Significant findings: School counselors and rehabilitation counselors are mandated to assist students with disabilities in their postsecondary college and career planning however further research examining their professional collaboration in the transition process is needed.  Barriers such as poor employer networks, dysfunctional community transition teams, and lack of administrative support may prevent collaboration efforts between VR and school districts.  Recommendations for future practice include: (a) VR counselor-initiated collaboration and information dissemination process, (b) professional accountability and (c) interdisciplinary counseling training programs. |
| Ipsen, C., Kurth, N., McCormick, S., Hall, J., & Chambless, C. (2019). Exploring the PROMISE of transition services for youth with disabilities receiving SSI. Journal of Vocational Rehabilitation, 50(1), 95–108. https://doi.org/10.3233/JVR-180991 | Between August 2014 and April 2016, ASPIRE staff recruited adolescents aged 14 to 16 who were receiving SSI benefits and their families (2,051). | Case Control Design | Youth receiving SSI aged 14–16 were randomly assigned to a control or intervention condition. Intervention activities included ongoing case management and training opportunities in self-determination, financial literacy, transition planning, and benefits counseling. Data collection included a survey about factors associated with post-high school education, employment, and independent living outcomes (current living arrangements, disability status, SSI status, and behaviors related to self-determination and expectations). | Transition-aged youth with disabilities fall behind same-aged peers without disabilities in education and employment, contributing to economic disparities across the lifespan. To address these disparities, federal partners jointly funded the PROMISE Initiative, which includes six demonstration research projects targeting youth with disabilities receiving Supplemental Security Income (SSI). | Participant data from enrollment, 12-months, and 24-months post-enrollment showed significantly better outcomes for intervention youth compared to control youth in terms of parent encouragement about having a job, youth expectations of working, and participation in employment activities. These factors are associated with improved long-term economic outcomes.  Findings indicate that providing case management and self-determination services to youth on SSI might result in improved long-term outcomes. |
| Razon, A. N., Greenberg, A., Trachtenberg, S., Stollon, N., Wu, K., Ford, L., El-Hage, L., Quinn, S., & Szalda, D. (2019). A Multidisciplinary Transition Consult Service: Patient Referral Characteristics. Journal of pediatric nursing, 47, 136–141. https://doi.org/10.1016/j.pedn.2019.04.021 | The Adult Consult Team received 197 referrals from July 2017 to June 2018. Patients had at least two specialists (73%), IDD (71%), technology dependence (e.g., gastrostomy tube, 37%) and Medicaid insurance (57%). The team assisted patients seen in its outpatient clinic with navigating mental health services (39%), insurance issues (13%), IDD services (15%), and the guardianship process (37%) and creating comprehensive care plans. | Systematic Review | The Adult Consult Team's tiered population framework stratifies patients by medical complexity. The team coordinates HCT services for patients with the highest complexity. Patients at least 18 years old are eligible if they have at least two specialists or an intellectual or developmental disability (IDD). Through a comprehensive medical and psychosocial assessment, the team prepares patients/families for adult-oriented healthcare. | Children's hospitals must provide developmentally appropriate care to increasing numbers of young adults with complex healthcare needs as they transition to adult-oriented care. This article describes the patients, service, and short-term outcomes of an interprofessional healthcare transition (HCT) consult team comprised of nurses, social workers, a community health worker, and physicians. | The Adult Consult Team transferred 30 patients with medical complexity to adult primary and specialty care, significantly improving pediatric inpatient and outpatient capacity for pediatric-aged patients. A broad range of young adult medical, psychosocial, legal, educational, and vocational needs were addressed.  An interprofessional team approach can help large pediatric healthcare systems address the multi-faceted needs of patients who are medically and psychosocially complex as they enter adulthood.  An interprofessional team approach can help large pediatric healthcare systems address the multi-faceted needs of patients who are medically and psychosocially complex as they enter adulthood. |
| Blaskowitz, M. G., Hernandez, B., & Scott, P. W. (2019). Predictors of Emergency Room and Hospital Utilization Among Adults With Intellectual and Developmental Disabilities (IDD). Intellectual and Developmental Disabilities, 57(2), 127–145. https://doi.org/10.1352/1934-9556-57.2.127 | Researchers identified predictors of utilization among 597 adults with IDD. | Retrospective | Using a retrospective survey of medical charts, descriptive statistics and logistic regressions were conducted. Individual-level risk factors for ER utilization included age, number of chronic health conditions, a diagnosis of cerebral palsy or neurological disorder, mental illness, and polypharmacy.  Environmental predictors included community-based supported living. Hospitalization predictors included age and number of chronic illnesses. | Emergency room (ER) and hospital utilization among people with intellectual and developmental disabilities (IDD) are significant contributors to rising healthcare costs. | Individuals living in group homes were less likely to be admitted to the ER. Researchers found risk factors unique to individuals with IDD that should be addressed with specific interventions as states transition to Medicaid managed care. |
| Ally, S., Boyd, K., Abells, D., Amaria, K., Hamdani, Y., Loh, A., Niel, U., Sacks, S., Shea, S., Sullivan, W. F., & Hennen, B. (2018). Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective. Canadian family physician Medecin de famille canadien, 64(Suppl 2), S37–S43. | Case: An 18-year-old women with IDD is undergoing transition to adult healthcare. | Case/Literature Review | Researchers utilized interdisciplinary input and literature reviews to assess the case. | To demonstrate how family physicians can help in improving quality-of-life outcomes for people with intellectual and developmental disabilities (IDD) when they undergo the transition from adolescence to adulthood.  Researchers believe that family physicians can be more proactive in anticipating and supporting the transition of people with IDD from adolescence to adulthood. Family physicians also have a role in helping people with IDD and their families to navigate this new transition. | Community and team-based family physicians can increase/optimize the quality of life of people with IDD and their families by adopting a proactive developmental and systems approach to preparing youth with IDD for adulthood.  Interventions should be guided by a developmental perspective regarding the person with IDD and a life-cycle approach to supporting families.  Recommendations:   1. To participate in and promote early preparations for transitions using a person-centered, integrated model of care that includes the person with IDD, family, caregivers, and other members of the care team. 2. To proactively engage such supports to enhance resilience and coping skills. 3. To develop and regularly review and update a transition plan. |
| Wendy N Gray, PhD, Megan R Schaefer, MS, Alana Resmini-Rawlinson, PhD, Scott T Wagoner, MA, Barriers to Transition From Pediatric to Adult Care: A Systematic Review, Journal of Pediatric Psychology, Volume 43, Issue 5, June 2018, Pages 488–502, https://doi.org/10.1093/jpepsy/jsx142 | Fifty-seven articles were included. The most common barriers to transition fell within the “Relationships” domain (e.g., difficulties letting go of long-standing relationships with pediatric providers) followed by “Access/Insurance” (e.g., difficulty accessing/finding qualified practitioners, insurance issues), and “Beliefs/Expectations” (e.g., negative beliefs about adult care). Barriers related to “Knowledge” (e.g., limited patient/caregiver knowledge about medication/illness and the transition process) and “Skills/Efficacy” (e.g., lack of self-management skills) were also common. While relationship barriers were commonly reported by all, some barriers varied by transfer status (pre- vs. post transfer) | Systematic Review | Medline, CINAHL, Psych INFO, Social Services Abstracts, Web of Science, and the Cochrane library databases were searched. Peer-reviewed English articles presenting original data on barriers to transition to adult care, focused on a specific pediatric chronic illness population, and conducted in the United States were included. Study design, population, and barriers were extracted. Barriers were categorized according to the Socioecological Model of Adolescent/Young Adult Readiness to Transition. Articles were evaluated for study quality. | Transition research in each disease group is developing in its own “silo.” A comprehensive review of barriers to transition within and across chronic illness groups is needed to facilitate information sharing and larger-scale efforts to overcome barriers and improve patient care. This study systematically reviews and identifies the barriers to transition from pediatric to adult care across pediatric illness populations. | Each chronic illness group experiences illness-specific challenges but certain barriers transcend chronic illness populations. Suggestions to overcome these barriers are provided. |
| Campbell F, Biggs K, Aldiss SK, O'Neill PM, Clowes M, McDonagh J, While A, Gibson F. Transition of care for adolescents from pediatric services to adult health services. Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD009794. DOI: 10.1002/14651858.CD009794.pub2. Accessed 29 March 2023. | Researchers included four RCTs (N = 238 participants) that explored: a two‐day workshop‐based transition preparation training for adolescents with spina bifida; a nurse‐led, one‐on‐one, teaching session with the additional support of a ‘health passport’ for adolescents with heart disease; a web‐ and SMS‐based educational intervention for adolescents with a range of different conditions; and a structured comprehensive transition program with a transition coordinator for adolescents with type 1 diabetes. | Systematic Review | Researchers searched The Cochrane Central Register of Controlled Trials 2015, Issue 1, (including the Cochrane Effective Practice and Organization of Care Group Specialized Register), MEDLINE, EMBASE, PsycINFO, and Web of Knowledge to June 2015. Researchers also searched reference lists of included studies and relevant reviews and contacted experts and study authors for additional studies. | To evaluate the effectiveness of interventions designed to improve the transition of care for adolescents from pediatric to adult health services. | There was evidence of improvement in patients' knowledge of their condition in one study, and improvements in self‐efficacy and confidence in another, but since limited studies were eligible for this review, and the overall body of evidence is low, researchers did not draw any firm conclusions about the effectiveness of the evaluated interventions. Further research is needed on the intervention effect as there is a large scope for the evaluation of other models of transitional care, reporting on clinical outcomes with longer term follow‐up. |
| Lydie A. Lebrun-Harris, Margaret A. McManus, Samhita M. Ilango, Mallory Cyr, Sarah Beth McLellan, Marie Y. Mann, Patience H. White; Transition Planning Among US Youth With and Without Special Health Care Needs. Pediatrics October 2018; 142 (4): e20180194. 10.1542/peds.2018-0194 | The total NSCH sample was 50,212 children and youth, including 20,708 youth ages 12 through 17 years. The overall weighted response rate was 40.7%. The survey completion rate (proportion of households with children and youth who completed a detailed topical questionnaire) was 69.7%. | Cross-Sectional Design | The 2016 National Survey of Children’s Health is nationally representative and includes 20,708 youth (12–17 years old). Parents and/or caregivers were asked if transition planning occurred, based on the following elements: (1) doctor or other health care provider (HCP) discussed the eventual shift to an HCP who cares for adults, (2) an HCP actively worked with youth to gain self-care skills or understand changes in health care at age 18, and (3) youth had time alone with an HCP during the last preventive visit. Sociodemographic and health system characteristics were assessed for associations with transition planning. | Researchers identified that most youth with special health care needs (YSHCN) are not receiving guidance on planning for health care transition. This study examines current transition planning among US youth with and without special health care needs (SHCN). | The study revealed that very few youth with and without SHCN receive transition planning support. There is an increased need for HCPs to work with youth independently and in collaboration with parents and/or caregivers throughout adolescence to gain self-care skills and prepare for adult-focused care. |
| Schwartz, L.A., Tuchman, L.K., Hobbie, W.L. and Ginsberg, J.P. (2011), A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. Child: Care, Health and Development, 37: 883-895. https://doi.org/10.1111/j.1365-2214.2011.01282.x | Cancer survivorship clinic | Qualitative Design | SMART development was informed by related theories, literature, expert opinion and pilot data collection using a questionnaire developed to assess provider report of SMART components with 100 consecutive patients in a childhood cancer survivorship clinic. | Policy and research related to transition to adult care for adolescents and young adults (AYAs) has focused primarily on patient age, disease skills and knowledge.  In an effort to broaden conceptualization of transition and move beyond isolated patient variables, a new social-ecological model of AYA readiness for transition (SMART) was developed. | SMART consists of inter-related constructs of patients, parents and providers with emphasis on variables amenable to intervention. Results support SMART's broadened conceptualization of transition readiness and need for assessment of multiple stakeholders' perspectives of patient transition readiness. A companion measure of SMART, which will be able to be completed by patients, parents and providers, will be developed to target areas of intervention to facilitate optimal transition readiness. Similar research program to establish evidence-based transition measures and interventions are needed. |
| Szalda, D., Steinway, C., Greenberg, A., Quinn, S., Stollon, N., Wu, K., Trachtenberg, S., & Jan, S. (2019). Developing a Hospital-Wide Transition Program for Young Adults With Medical Complexity. The Journal of adolescent health : official publication of the Society for Adolescent Medicine, 65(4), 476–482. https://doi.org/10.1016/j.jadohealth.2019.04.008 | Between July 2015 and March 2017, MINT identified 11 transition champions, increased the number of divisions with drafted transition policies from 0 to 7, increased utilization of electronic medical record-based transition support tools from 0 to 7 divisions, held seven psychoeducational events, and developed a clinical pathway. MINT has received more than 70 patient referrals. Of patients referred, median age is 21 years (range, 17–43); 70% (n = 42) have an intellectual disability. Referring pediatric providers (n = 25) reported that MINT helped identify adult providers and coordinate care with other Children's Hospital of Philadelphia specialists (78%); and that MINT saved greater than 2 hours of time (48%). | Retrospective | The Multidisciplinary Intervention Navigation Team (MINT) was developed to decrease variations in pediatric to adult medical transitions. System-level goals were to (1) increase provider and leadership engagement, (2) increase transition tools, (3) increase use of electronic medical record–based clinical decision supports, (4) improve transition practices through development of transition policies and clinical pathways; (5) increase transition education for patients and caregivers; (6) increase the adult provider referral network; and (7) implement an adult transition consult service for complex patients (MINT Consult). | Transitional age adults (18–24 years) are the fastest growing cohort of patients in children's hospitals across the nation. The purpose of the study was to standardize pediatric to adult healthcare transfers of complex adult patients through a tiered and multimodal population-based intervention. | MINT improved the availability, knowledge, and use of transition-related resources; saved significant time among care team members; and increased provider comfort around transition-related conversations.  A multidisciplinary transition program with the dual focus of building health system infrastructure and a direct patient consult service shows promise as a method for effectively transitioning young adults with medical complexity to adult care. Health systems should consider this approach as they embark on addressing the needs of this population. |
| Bourne, M. J., Smeltzer, S. C., & Kelly, M. M. (2021). Healthcare inequities among adults with developmental disability: An integrative review with implications for nursing education. Nurse education in practice, 57, 103225. https://doi.org/10.1016/j.nepr.2021.103225 | This integrative review synthesized research on the healthcare inequities experienced by adults with developmental disability in the United States and discussed implications for nursing education. | Systematic Review | Application of inclusion criteria to database and ancestry searches resulted in 26 articles that were assessed for quality and analyzed thematically. | Individuals with developmental disability are living longer with chronic comorbidities and experience healthcare inequities. | Three categories of inequity were identified: knowledge deficits, communication challenges and poor quality of care. Knowledge deficits and communication challenges can lead to frustration, errors, and unmet needs. Poor quality of care encompasses the decreased availability and access to services, limited health promotion participation and higher rates of hospitalizations and complications for adults with developmental disability.  Healthcare inequities may be reduced by targeting patient and provider knowledge. Inclusion of developmental disability content and clinical experiences in nursing education may improve care and reduce inequities for this underserved population. |
| Rodriguez, C.D., Cumming, T.M. & Strnadová, I. (2017). Current practices in schooling transitions of students with developmental disabilities. International Journal of Educational Research, 83(1), 1-19. Elsevier Ltd. https://www.learntechlib.org/p/203437/ | 167 teachers from three states (California, Texas and North Carolina) were surveyed about transition practices for students with developmental disabilities. The transitions from primary to middle school, middle to high school, and high school to post-school life, as well as home-school collaboration, were the focus. The teachers responded to demographic and open-ended survey questions. | Qualitative Design | Open ended online survey consisting of eight demographic items and seven open-ended questions. Three of the seven questions focused on determining teachers’ experiences with preparing their students for transitions from primary to middle school, from middle school to high school, and from high school to post-school life. Two of the questions surveyed what teachers believed needed to be done to improve transition processes in general. The last two questions surveyed teachers’ practices for home-school collaboration during transition planning. | Early school transitions strongly influence the outcomes of later schooling and transition to post-school settings.  There is limited literature on the best practices for school stage transition. | Findings indicated several areas of satisfaction as well as need, particularly for the transition from primary to middle/high school, including: district-level support people, self-determination instruction, more time allocated for teachers to plan, and better home-school communication and collaboration. |
| Havlicek, J., Bilaver, L., & Beldon, M. (2016). Barriers and facilitators of the transition to adulthood for foster youth with autism spectrum disorder: Perspectives of service providers in Illinois. Children and Youth Services Review, 60, 119–128. https://doi.org/10.1016/j.childyouth.2015.11.025 | The majority of participants in each focus group were female (n = 31; 76%), white (n = 36; 85%), and non-Hispanic (n = 38; 93%). About one-third were case managers (n = 15; 36%), followed by specialists (n = 9; 22%) and therapists (n = 6; 15%). Length of time in current position ranged from less than 6 months to 17 years, with a majority (n = 35; 85%) working in their position for at least one year. There were thirty-five service providers (85%) employed in a child-serving program and six service providers employed in an adult serving program (15%). | Qualitative Design | Five focus groups were conducted with 41 service providers to understand the adult transition of foster youth with ASD. Focus groups were conducted between May 1, 2014 and July 30, 2014 | The lack of established and well-evaluated models of coordination between child welfare agencies and other public institutions presents continual challenges to preparing foster youth to make the transition to adulthood. | Focus group results indicated the need for increased collaboration between child and adult service systems. Barriers included perceptions of two separate systems and abrupt transitions; a lack of training, identification, and tracking of autism; and confusion about services and funding. Facilitators included persistence and professional relationship building, and consistent communication and information sharing. |
| Fremion, Ellen and Cowley, Rachel and Staggers, Kristen A. and Berens, John and Kemere, K. Jordan and Kim, Judy and Acosta, Elisha and Peacock, Cynthia, Improved Health Care Transition for Young Adults with Developmental Disabilities Referred from Designated Transition Clinics. http://dx.doi.org/10.2139/ssrn.4002249 | Patients were included in study if they had a diagnosis ASD, cerebral palsy, Down syndrome, genetic syndromes, spina bifida, or other IDD-related diagnoses; were transferring from a pediatric clinic; and completed a Got Transition.org Sample Health Care Transition Feedback Survey 2.0 at their initial visit. | Qualitative Design | 408 young adults or their families were surveyed through the HCT Feedback Survey | Young adults with intellectual/developmental disabilities are a vulnerable population during HCT due to their complex care coordination and adaptive needs, however factors related to transition preparedness are not well defined. Researchers aimed to determine factors associated with health care transition (HCT) preparation satisfaction for young adults with IDD establishing care with an adult medical home. | Individuals who participated in a structured HCT program prior to transfer to adult care experienced higher transition preparation satisfaction. Compared to patients who were referred from the community, the odds of feeling very prepared versus somewhat or not prepared were 3.7 times higher (adj OR 3.73, 95% CI: 1.90, 7.32) among patients referred from a designated HCT program.  Health care transition (HCT) should maximize lifelong functioning by providing high quality healthcare that is uninterrupted, coordinated, and developmentally and psychosocially appropriate. |
| Hughes, M. M., Shaw, K. A., Patrick, M. E., DiRienzo, M., Bakian, A. V., Bilder, D. A., Durkin, M. S., Hudson, A., Spivey, M. H., DaWalt, L. S., Salinas, A., Schwenk, Y. D., Lopez, M., Baroud, T. M., & Maenner, M. J. (2023). Adolescents With Autism Spectrum Disorder: Diagnostic Patterns, Co-occurring Conditions, and Transition Planning. The Journal of Adolescent Health : Official Publication of the Society for Adolescent Medicine. https://doi.org/10.1016/j.jadohealth.2022.12.010 | Out of the 1,846 children as having ASD, 11.6% were first identified after 8 years old. Children who were more likely **to** have ASD identified at older ages were Hispanic; were born with low birth weight; were verbal; had high intelligence quotient or adaptive scores; or had certain co-occurring neuropsychological conditions by 8 years old. By age 16, neuropsychological conditions were common with more than half of the adolescents with ASD having a diagnosis of attention-deficit/hyperactivity disorder or anxiety. Intellectual **disability** (ID) status was unchanged for over 80% of children from ages 8-16 years. A **transition** plan was completed for over 94% of adolescents, but disparities were observed in planning by ID status. | Qualitative Design | Researchers utilized a longitudinal population-based surveillance cohort from the Autism **Developmental Disabilities** Monitoring Network during 2002-2018 in five catchment areas in the US. Participants included 3,148 children born in 2002 whose records were first reviewed for ASD surveillance in 2010. | The objectives of this study were **to** describe child characteristics associated with later autism spectrum disorder (ASD) identification and the health status and educational **transition** plans of adolescents with ASD. | A high percentage of adolescents with ASD have co-occurring neuropsychological conditions, notably higher than at age 8. Researchers identified that while most adolescents received **transition** planning, it occurred less often for those with ID. Ensuring access **to** services for all people with ASD during adolescence and **transition** **to** **adulthood** may help **to** promote overall health and quality of life. |
| Hothi, H., Bedard, C., Ceccacci, A., DiRezze, B., & Kwan, M. Y. W. (2022). Evaluated interventions addressing developmental transitions for youth with mental health disorders: a meta-analysis. Disability and Rehabilitation, 44(21), 6155–6165. https://doi.org/10.1080/09638288.2021.19604 | For neurodevelopmental studies (6), the effect size of interventions measuring social outcomes was 1.00 (95% CI: -0.01 **to** 2.00), parental stress levels was -0.10 (95% CI:-0.74 **to** 0.55), autism symptoms was -0.40 (95% CI: -1.58 **to** 0.78), and self-determination was 0.16 (95% CI:-0.38 **to** 0.70).  For mental illness studies (3), the effect size of interventions measuring adolescent depressive symptoms was 0.48 (95% CI: 0.01 **to** 0.96) and parental depressive symptoms was 1.09 (95% CI: 0.20 **to** 1.97). | Meta-Analysis | Studies, between January 1992 and March 2021, were included if they contained a sample population with a median age between 12 and 25 years and with a mental health disorder and described the results of health interventions addressing aspects of **developmental**  **transitions**. Independent reviewers screened study texts and assessed the risk of bias. | The objective of this analysis was **to** provide a quantitative synthesis of the effects of studies evaluating developmentally appropriate programs or interventions for **transition**-age youth with mental health disorders. | There was no effect of interventions except on parental depressive symptoms under mental illness studies. Additional research with comparable outcomes and assessments is needed.  Recommendations: Interventions for youth with mental health disorders should be developmentally appropriate and incorporate elements **to** assist youth in multiple aspects of their lives. Recommended approaches in interventions include skills training, prevocational/vocational guidance, a client-centered approach, and/or an ecological/experiential approach. Intervention researchers and practitioners should incorporate similar outcome assessment tools and measures in order **to** allow for valid comparisons between intervention effectiveness. |
| Reyes, C., Perzynski, A., Kralovic, S., Taylor, H. G., Wexberg, S., Zhu, S., Frazier, T. W., & Roizen, N. (2022). Factors Associated with Transition Planning in Autism and Other Developmental Disabilities. Journal of Developmental & Physical Disabilities, 34(1), 43–56. https://doi.org/10.1007/s10882-020-09785-3 | 167 parents of youth aged 10–22 years with autism spectrum disorder, ADHD and/or other developmental disabilities were surveyed. | Qualitative Design | This multi-site study consisted of 167 parents of youth aged 10–22 years with autism spectrum disorder, ADHD and/or other developmental disabilities who completed a questionnaire on transition to adulthood. Parent-rated child self-care status was measured using a six-item scale. Multivariable logistic regression models were used to assess results. | To determine whether functional self-care skills and presence of behavior problems in youth with developmental disabilities are associated with parents planning for the youth’s transition to adulthood. | A child’s increased need for assistance with self-care was associated with lower parental expectations that their children would live independently by age 22. The presence of behavioral problems (aggression, sexual behaviors and safety issues) was also associated with lower odds of parental expectations that their child would live independently in adulthood.  Despite parents’ awareness of the difficulties their children will encounter, limited youth independence with self-care skills was associated with lower odds of plans for transition to adulthood and expectations for independent living. Findings support the need for continued interventions targeted at improving daily living skills to achieve functional independence in adulthood, as well as interventions focused on aggression, safety and sexuality of the individuals. |