Parent and Family Involvement Annotated Bibliography

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What is Parent and Family Involvement in Transition Planning?

No Child Left Behind (2011) defined parental involvement as "the participation of parents in regular, two-way, and meaningful communication involving student academic learning and other school activities" (107th Congress, 2002, section 9101, paragraph 32). The term "parent" refers to "a natural, adoptive, or foster parent of a child, a guardian, or an individual acting in the place of a natural or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare" (Individuals with Disability Education Act [IDEA], 2004; Sec. 602). For secondary transition, Kohler and Field (2003) defined family participation as practices that "focus on a wide array of roles through which families might be involved in planning and delivering individual and community-level transition education and services, such as assessment, decision making, policy development, and as trainers" (p. 178).

Why is Parent and Family Involvement in Transition Planning Important?

Parents can provide a foundation for the IEP team, keeping them grounded and focused on their child's individual strengths, needs, and preferences. Parents know their child's postsecondary and career ambitions and possible support needs, and can identify particular friends, family members, or community members who can provide additional support. It is recommended that educators create a reliable alliance with parents empowering them to emerge as partners and work together to promote successful student outcomes. While, parents and families can provide valuable information for developing and implementing educational programs due to their unique insights on living day to day with a student with a disability (Turnbull & Turnbull, 1997; Kochhar-Bryant, Shaw, & Izzo, 2007; Wandry & Pleet, 2009), little experimental research exists documenting effective interventions for increasing parent and family involvement in the secondary transition process.

References

Fourqurean, J. M., Meisgeier, C., Swank, P. R., & Williams, R. E. (1991). Correlates of postsecondary employment outcomes for young adults with learning disabilities. *Journal of Learning Disabilities, 24*, 400-405.

Kochhar-Bryant, C. A., Shaw, S., & Izzo, M. (2007). *What every teacher should know about transition and IDEA 2004.* Boston, MA: Pearson Education Inc.

Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundation for the future. *The Journal of Special Education, 37,* 174-183.

Kraemer, B. R., McIntyre, L. L., & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation, 41*, 250-262.

Reiter, S., & Palnizky, A. (1996). Transition from school to work of students with developmental disabilities and mental retardation: An Israeli perspective. *International Journal of Rehabilitation research, 19*, 27-38.

Turnbull, A. P., & Turnbull, H. R. (1997). *Families, professionals, and exceptionalities a special partnership.* Upper Sadler River, NJ: Prentice-Hall Inc.

Wandry, D. L., & Pleet, A. M. (Eds.). (2009). *Engaging and empowering families in secondary transition: A practitioner's guide*. Virginia: Council for Exceptional Children.

What Does the Literature Say About Parent and Family Involvement in Transition Planning?

The purpose of this annotated bibliography is to provide educators with sources that define parent and family involvement and offer suggestions for how to involve families in the transition planning process. Based on the categorical nature of the literature identified, the following information is organized by the following categories: parents of students with autism, emotional/ behavior disabilities, learning disabilities, intellectual disabilities, and culturally diverse families.

Across Disabilities

Hirano, K. A., & Rowe, D. A. (2015). A Theoretical model for parent involvement in secondary special education. *Journal of Disability Policy Studies*. Advance Online Publication: doi: 10.1177/1044207315583901 [Policy]

- Proposed a conceptual model of parent involvement that: (a) integrated transition and traditional academic-focused models of parent involvement, (b) incorporated predictors of post-school success, and (c) accounted for the continued role parents play in the lives of their adult children
- Described previous models of parent involvement in education in general and in special education

- Expanded definitions and dimensions of parent involvement in secondary transition
- Discussed expanded roles of parents in secondary transition
- Offered implications for practice

Autism

Field, S., & Hoffman, A. (1999) The importance of family involvement for promoting self-determination in adolescents with autism and other developmental disabilities. *Focus on Autism and Other Developmental Disabilities, 14,* 36-41. [Descriptive]

- Described the role of parents in supporting in the development of self-determination by their sons or daughters
- Provided descriptions of parent-child interactions that promote self-determination
- Provided sample activities to promote family involvement in self-determination

Emotional and Behavioral Disorders

Frith, G. H., & Armstrong, S. (1984) Career preparation for behavior disordered adolescents: Involving the family. *Family Relations, 33,* 143-147. [Descriptive]

- Described advantages and disadvantages for involving family members in the career preparation process for students with behavior disorders
- Discussed the role of families in the career preparation process for students with behavior disorders
- Offered strategies for encouraging parent participation, opportunities for families to offer direct assistance, and strategies for training family members to facilitate vocational independence

Jivanjee, P., Kruzich, J. M., & Gordon, L. J. (2008). The age of uncertainty: Parent perspectives on the transitions of young people with mental health difficulties to adulthood. *Journal of Child and Family Studies, 18*, 435-446. [Qualitative]

- Conducted focus groups with transition age youth who had utilized mental health services and parallel focus groups for their family members
- Family members were mostly female (95%) and European American (85%) while youth were most commonly diagnosed with depression, attention-deficit disorder, and post-traumatic stress disorder
- Questions for parents focused on a) the meaning of integration into the community for their children; b) their hopes, goals, and dreams for their children, and c) advice to others in similar situations
- Discussed family members' goals for their children, frustrations accessing appropriate services, and strategies for providing support their children needed
- Provided recommendations for service providers.

Intellectual Disabilities

Ankeny, E. M., Wilkins, J., & Spain, J. (2009). Mothers' experiences of transition planning for their children with disabilities. *Teaching Exceptional Children*, 41, 28-36. [Descriptive]

- Described three themes that emerged from interviews with four mothers of children with disabilities
    - Goals and barriers to independence in adulthood
    - Transition as an ongoing process
    - Importance of communication and support from teachers
- Provided suggestions to case managers and teachers for:
    - Adolescent development and family stress (i.e., involve parents in the transition planning process, use a phased approach to adult service delivery, take a leadership role in interagency collaboration efforts, provide ongoing communication and collaboration with families)
    - Team collaboration and roles of families (i.e., recognize and include all parent and family structures, include family resources and community members in planning, respect family's goal for child)
    - Employment for transitioning youth (i.e., explain career options, inform parents about roles of adult service providers, consider quality of life issues)
    - Postschool roles of families (i.e., encourage parents to join advocacy groups, contact community resources on behalf of parents, provide information to parents on how to access a variety of adult services)
- Provided a brief list of transition related online resources for youth, families, and professionals

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. American Journal on Mental Retardation, 106, 173-188.

- Proposed a conceptual model for examining the transition to adulthood in young adults with an intellectual disability
- Discussed how individual factors, involvement/detachment, and environment and culture influenced transition success and family well-being

Blacher, J., Kraemer, B.R., & Howell, E.J. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities*, 4(1), 3-16. [Correlational]

- Conducted a survey to assess differences in expectations of parents with youth with autism, Down's syndrome, cerebral palsy (CP), and an undifferentiated learning disability (LD)
- Results indicated differences in expectations for post-school employment and community living among parents of youth with differing disabilities (e.g., parents of youth with CP were less likely to expect post-school employment; parents of

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youth with Down's syndrome were more likely to be optimistic about future employment and community living)
- Provided implications for practice

Brotherson, M. J., Turnbull, A. P., Bronicki, G. J., Houghton. J., Roeder-Gordon, C., Summers, J. A., & Turnbull, H. R. (1988). Transition into adulthood: Parental planning for sons and daughters with disabilities. *Education and Training in Mental Retardation, 23.* **165-174. [Descriptive]**

- Conducted a survey to examine future planning for families of young adults with disabilities
- Participants included parents of youth with an intellectual disability and physical disabilities
- Results indicated parents greatest concerns were (a) residential, vocational, and socialization needs, (b) positive relationship between planning and family functioning, and (c) positive relationship between using social relationships in planning and family functioning
- Authors provide implications for practice

Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation, 40,* **425-435. [Qualatative]**

- Examined how differences in attitudes, goals, and strategies each stakeholder brings to the transition team for students with severe cognitive disabilities affects the quality of the transition process
- Described student perspectives, parent perspectives, and professional perspectives of the transition process identifying different themes for each stakeholder
  - o Student themes: aspirations for the future and pursuit of independence
  - o Parent themes: views of children, promise for the future, and perspectives on transition
  - o Professional themes: perspectives on young adults or parents, viable options, and coping strategies
- Discussed how students in this study were products of transition planning rather than participants in the process
- Recommended parents and students be active partners with professionals to avoid professional only planning

Dixon, R.M., & Reddacliff, C.A. (2001). Family contribution to the vocational lives of vocationally competent young adults with intellectual disabilities. *International Journal of Disability, Development, and Education, 48*, **193-206. [Qualatative]**

- Described how families in Australia contributed to a student with mild intellectual disabilities efforts to maintain competitive employment

- Discussed characteristics that led to more successful employment outcomes (i.e., moral support, practical assistance, role models of appropriate work ethic, protection from difficulties and exploitation, and family cohesion
- Suggested implications for parents and vocational education practitioners

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *Journal of the Association for Persons with Severe Handicaps, 13*, 177-187. **[Qualitative]**

- Conducted interviews to determine parent perspectives of the events and relationships surrounding the transition process for young adults with severe disabilities
- Results indicated families tended to perceive three types of transition (i.e., bureaucratic, family life, adult status)
- Authors provided suggestions for improving parent/professional collaboration during transition

Gallivan-Fenlon, A. (1994). Their senior year: Family and service provider perspectives on the transition from school to adult life for young adults with disabilities. *Journal of the Association for Persons with Severe Handicaps, 19,* 11-23.

- Analyzed family and service provider perspectives on the transition from school to adult life for students with moderate mental retardation focusing on (a) student aspirations in the process of transitioning from school to adulthood, (b) student and other relevant participant perceptions of the transition process, (c) student and other relevant participant understanding of work, community living, and collaboration among families and service providers during the transition process, and (d) initial post-school outcomes
- Identified three broad categories consisting of seven major themes
  - Differing expectations and aspirations for young adult life
    - Young adults aspired to be in community employment and live lives of typical young adults
    - Adult providers, school personnel, and families held more restrictive expectations
  - Differing views of participation in transition related activities
    - Lack of family participation
    - Lack of knowledge and collaboration among transition teams
    - And delayed transition planning
  - Initial transition outcomes
    - Sitting home, either receiving no services or waiting for an employment opportunity to arise or be developed by an adult agency

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- Supported employment, sheltered workshops, or day treatment center

Hanley-Maxwell, C. Whitney-Thomas, J., & Pogoloff, S. (1995). The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. *Journal of the Association for Persons with Severe Handicaps, 20,* **3-15. [Qualitative]**

- Provided findings from in-depth interviews with parents of students with cognitive disabilities that (a) defined the meaning of students' transition from school to adult life for parents of children with cognitive disabilities and (b) identified needs of these parents during the transition period from school to adult life
- Found that parents, when asked to define transition, include topics such as school to work, residential and social issues, safety, happiness, reliable transportation, and filling free time with constructive activities
- Found parents needed the structure and support of the school system to continue through adulthood and feared waiting lists for residential and employment services and a lack of social networks

Henninger, N.A. & Taylor, J.L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities, 52***(2), 98-111. [Correlational]**

- Conducted a survey with parents of youth with intellectual disabilities to examine differences in parent definitions of post-school success
- Results indicated parents valued a range of occupational outcomes based on their student's interests, preferences, and needs and did not necessarily align with traditional definitions of competitive employment
- Reported parent definitions of positive outcomes included skills required for functioning, relationship with peers, independence in daily living
- Results indicated goals of parents of youth with intellectual disabilities changed over time with less emphasis on things such as postsecondary education and occupation as students graduated from high school
- Provided implications for practice

Heslop, P., & Abbott, D. (2007) Schools out: Pathways for young people with intellectual   disabilities from out-of-area residential schools or colleges. *Journal of Intellectual   Disability Research, 51,* **489-496. [Qualitative]**

- Described what parents from five areas of the United Kingdom thought contributed to a satisfactory transition from school to adult life
- Described four components of good transition planning
  - Being well-connected with other parents and key professionals
  - Being proactive
  - The provision of information

o   Good forward planning with enough time to prepare

Hetherington, S.A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experience of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities, 25*(3), 163-172. **[Qualitative]**

- Conducted focus groups with youth with cognitive and physical disabilities and their parents to gain understanding of the experiences of youth with disabilities and their parents in the transition planning process and to determine to what degree youth and their parents perceptions match best practice and mandates
- Results indicated that although being engaged and involved in planning was important to students, most students were not involved in transition planning
- Results indicated parents felt schools failed to engage them in the transition planning process

Irvin, L. K., Thorin, E., & Singer, G. H. S. (1993). Family-related roles and considerations: Transition to adulthood by youth with developmental disabilities. *Journal of   Vocational Rehabilitation, 3,* 2, 38-46. **[Descriptive]**

- Described the role of family in transition using a theoretical foundation to facilitate a better understanding of transition for young adults and their families
- Described the impact of transition and the adult service system on families
- Discussed family concerns and stress that accompany the transition process

Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Person with Severe Disabilities, 29,* 53-57. **[Descriptive]**

- Provided an overview of person-centered planning (PCP) and family centered planning (FCP)
- Suggested a new approach that combines PCP and FCP called person-family interdependent planning
- Described five premises that support the person-family interdependent approach to planning
    - The transition of a young adult with a severe intellectual disability influences and is influenced by the family
    - Young adults with severe intellectual disabilities and their families have choices concerning their lives
    - No person is fully competent in all life's decisions and domains
    - Plans for the future should consider the need of young adults with severe intellectual disabilities and their families

- Comprehensive policies and programs providing social, emotional, and financial supports for young adults with severe disabilities and their families should be implemented

Kraemer, B.R. & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation*, **39(6), 423-435. [Descriptive]**

- Conducted a survey to examine the extent to which transition programming is occurring for youth intellectual disabilities
- Results indicated over 1/3 of parents surveyed did not know whether their child had a transition planning
- Results indicated parents were pessimistic views of post-school outcomes for their youth

Kraemer, B.R. & Blacher, J. (2008). Transition for Hispanic and Anglo young adults with severe intellectual disability: Parent perspectives over time. *Journal on Developmental Disabilities, 14*(1), 59-72. **[Descriptive]**

- Conducted survey to examine parent aspirations and expectations for post-school outcomes for youth with a significant intellectual disability and to determine if parent involvement differs by cultural group (i.e., Hispanic vs anglo)
- Results indicated minimal difference between parent groups regarding post-school employment goals; however, views of independent living differed (e.g., Hispanic families did not view moving out of the family home as a viable post-school goal)
- Results also indicated differences between parent groups on involvement in planning (i.e., Hispanic families reported less involvement); although Hispanic families reported the need for more information related to transition planning and reported more anxiety compared to Anglo parents

Lehman, J.P. (1998). Mothers' roles: A comparison between mothers of adolescents with severe disabilities and mothers of vocational students. *Career Development and Transition for Exceptional Individuals, 21*(2), 129-143. **[Qualitative]**

- Conducted interviews with mothers of youth with severe disabilities and youth without disabilities enrolled in vocational programs to explore differences in perceptions of preparing for the transition from school to post-school
- Results indicated differences in perceptions of mothers regarding the transition process (e.g., mothers of vocational students offered minimal support, whereas, mothers of youth with severe disabilities felt overwhelmed with the amount of work they perform)
- Both sets of mothers reported a desire to be involved but shared school environment influenced level of involvement

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- Illustrated differences in parents tasks of mothers with severe disabilities and those without

Martinez, D.C, Conroy, J.W., & Cerreto, M.C. (2012). Parent involvement in the transition process of children with intellectual disabilities: The influence of inclusion on parents' desires and expectations for postsecondary education. *Journal of Policy and Practice in Intellectual Disabilites*, *4*, 279-288.

- Conducted a survey to examine parents' of youth with an intellectual disability (ID) means of accessing information regarding secondary transition
- Results indicated varied levels of parent involvement in transition planning
- Reported parents preferred direct, face-to-face, structured, formalized communication
- Provided recommendations for parents of youth with ID in the transition planning process

McNair, J., & Rusch, F. R. (1991). Parent involvement in transition programs. *Mental Retardation, 29*, 93-101. [Descriptive]

- Conducted a survey of parents to examine current parent involvement in the transition process, the kinds of involvement they desire, and what responsibilities they would be willing to assume in order to be involved
- Described three roles parents can assume in the transition process: facilitator, nonparticipant, or difficult parent
- Identified discrepancies between parents' expectations versus desires for post-school outcomes
- Identified actual versus desired transition program involvement
- Comparisons among parents according to their level of involvement were also explored relative to expected school outcomes and activities they would be willing to participate in to be involved

Neece, C.L., Kraemer, B.R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities, 47*(1), 31-43. [Descriptive]

- Examined parent satisfaction with the transition from high school of their young adult with severe intellectual disability
- Examined the relation between parents' level of satisfaction with their young adult's transition and the level of the family's wellbeing
- Exploration of how traditional indicators of post-school success may not apply to students with severe disabilities
- Results indicated that level of satisfaction with transition is related to young adult, family, and environmental characteristics, with environmental characteristics being the strongest predictor of transition satisfaction

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Rowe, D. A., & Test, D. W. (2010). The effects of computer-based instruction on the transition planning process knowledge of parents of students with disabilities. *Research and Practice for Persons with Severe Disabilities, 35,* 102-115. **[Experimental]**

- Examined the effects of a computer-based instructional program on acquisition of parents' knowledge of the transition planning process in three domains: a) post-secondary goals; b) transition services; and c) post-secondary transition service providers
- Participants in this single-subject study were four Caucasian parents of two males and one female with mild- to moderate intellectual disabilities
- Results indicated a functional relation between computer-based instruction and increased knowledge in all three domains of transition planning
- Provided suggestions for future research and implications for practice

Stineman, R. M., Morningstar, M. E., & Bishop, B. (1993). Role of families in transition planning for young adults with disabilities: Toward a method of person-centered planning. *Journal of Vocational Rehabilitation, 3,* 2, 52-61. **[Descriptive]**

- Described families' roles in the transition process for young adults with severe disabilities
- Identified barriers to family involvement
  - Professional perceptions about family involvement
  - Past negative experience
  - Limited and conflicting expectations
  - Lack of opportunity to participate actively in the planning process
- Discussed strategies to increase successful collaboration in particular person-centered planning which is comprised of the following steps
  - Profile positives
  - Complete relationship diagram
  - Envision the future
  - Setting a goal
  - Brainstorm obstacles
  - Brainstorm resources
  - Prioritize options and resources
  - Develop an action plan

Thorin, E. J., & Irvin, L. K. (1992). Family stress associated with transition to adulthood of young people with severe disabilities. *Journal of the Association for Persons With Severe Handicaps, 17*, 31–39. **[Descriptive]**

- Conducted a survey to examine family members' transition-related concerns for their young adults with severe developmental disabilities
- Identified family members who shared concerns and measured the related levels of stressfulness and frequency of occurrence of the concern

- Family stress associated with seven domains:
  - school
  - work life
  - residential services
  - professionals and agencies: SSI, advocacy, respite, case management
  - young adult daily life
  - family life
  - future
- Identified domains that were most frequently mentioned, concerns rated most stressful, and concerns reported to occur most frequently
- Discussed results in terms of Lazarus and Folkman's (1984) stress and coping theory
- Highlighted the impact on responses of the way questions are framed as part of the implications for future research

Thorin, E., Yovanoff, P., & Irvin, L. (1996). Dilemmas faced by families during their young adults' transitions to adulthood: A brief report. *Mental Retardation*, *34*(2), 117-120.

- Conducted a survey to examine potential dilemmas for families of young adults with disabilities during the transition to adulthood
- The survey contained 14 dilemmas and families were asked to indicate a) the frequency with which each of the dilemmas occurred; b) the importance of each of 23 aspects of the dilemmas; and c) the relative importance of paired aspects of dilemmas
- The six most prominent dilemmas are discussed with implications for practice

Learning Disabilities

Haring, K. A., Lovett, D. L., & Saren, D. (1991). Parent perceptions of their adult offspring with disabilities. *Teaching Exceptional Children, 23,* 6-10. [Qualitative]

- Described parent perceptions related to:
  - School program. 23% of parents perceived that they had no involvement in their child's education; 43% felt they were somewhat involved; 34% felt their input had a definite impact on their child's program
  - Involvement in child's present life. 7% of parents reported being not involved; 35% reported being somewhat involved; 58% reported being actively involved
  - Independence. 60% wanted their children to be as independent as possible; 18% reported their child would always require some degree of supervision; 22% reported their children should never live or work independently

- o Transportation. 20% reported child could never be independently mobile; 22% reported their child could travel with some supervision; 59% indicated their child should and could access public transportation
  - o Employment. 21% reported not wanting their child to work but rather stay at home; 19% felt their child would always need to work in a sheltered workshop; 60% encouraged their child to be as independent as possible
  - o SSI benefits. 70% did not perceive the loss of SSI as a problem; 30% feared the loss of benefits;
  - o Residence. 50% wished the child would live in the family home; 30% desired independent residential situation; 17% expressed a desire for youth to live in a group home or other supported living arrangement
- Offered strategies for including parents in educational and transition related decision making including but not limited to:
  - o School program: Teachers should encourage parents to visit the program for observation, and volunteer time. Also keep open lines of communication with parents practicing listening skills.
  - o Involvement in child's present life: Adult service providers could foster parent involvement and learn about the family dynamics
  - o Independence: Schools can alleviate parental concerns by encouraging better communication between professionals and parents and explanation of procedures
  - o Transportation: Teachers can explain to parents that with systematic instruction, fading supervision, most young adults can access public transportation independently relieving the burden from the family
  - o Employment: Teachers can educate parents about the advantages of community-based instruction and community-based vocational training
  - o SSI benefits: Teachers can identify individuals who can assist with SSI benefits
  - o Residence: Teachers can help parents identify agencies that can assist them with acquiring services and supports

Lindstrom, L., Doren, B., Metheny, J., Johnson, P., & Zane, C. (2007). Transition to employment: Role of the family in career development. *Exceptional Children, 73,* **348-366. [Descriptive]**

- Provided a brief description of the role of the family in career development and post-school outcomes of young adults with learning disabilities
- Described the role of the family in shaping career development and post-school outcomes by identifying how family structure variables (e.g., SES, education, and parental occupation) and process variables (e.g., advocacy, support, and career expectations) relate to career development and post-school outcomes for young adults with learning disabilities

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Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career Development and long-term employment outcomes for young adults with disabilities. *Exceptional Children, 77*, 423-434. [Qualitative]

- Described themes that emerged from focus groups about family support and expectations related to career development (e.g., women played more active roles in planning for the future than men)
- Discussed other issues related to career development of young adults with disabilities (e.g., work experiences during high school and transition services and supports)

Morningstar, M. E., Turnbull, A. P., & Turnbull, H. R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life. *Exceptional Children, 62,* 249-260. [Qualitative]

- Described themes that emerged from focus groups (i.e., creation of a vision for the future, family and student involvement in the transition planning process, and family involvement in facilitating self-determination)
- Discussed issues surrounding student views of family involvement (i.e., family role in creating a future vision, family involvement in the planning process, and family involvement in facilitating self-determination)

Salembier, G., & Furney, K. S. (1997). Facilitating participation: Parents' perceptions of their involvement in the IEP/transition planning process. *Career Development for Exceptional Individuals, 20*, 29–42. [Descriptive]

- Conducted a survey to examine (a) parent perceptions of their participation in the last transition planning meeting, (b) the degree to which parents were satisfied with their participation in the meeting, (c) the degree to which parents believed plan was based on students interests, strengths, and needs, and (d) characteristics of the meeting that promoted or inhibited parent participation
- Results suggested a variety of means of parent participation in transition meetings (e.g., answering questions, talking about child's strengths)
- Results indicated the majority of parents surveyed felt their child's strengths and needs were incorporated into the transition plan
- Described factors that contributed to both positive parent/professional relationships (e.g., open communication with school) and negative parent/professional relationships (e.g., lack of teacher attendance at meeting, professionals not prepared to answer questions)

Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities, 18*, 228-237. [Descriptive]

- Conducted a survey to examine families involvement in and perceptions of

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students special education services

- Participants were parents of youth ages 4-18 with autism or other developmental delays.
- Results indicated that the majority of parents felt they were knowledgeable about the IEP process but felt schools were not doing enough to address their students needs

Tarleton, B., & Ward, L. (2005). Changes and choices: Finding out what information young people with learning disabilities, their parents and supporters need at transition. *British Journal of Learning Disabilities, 33,* **70-76. [Qualatative]**

- Described the information needs of students with learning disabilities, their parents, and supporters at the time of transition
- Identified questions about the transition process identified by all stakeholders
- Described methods to present information to students, parents, and stakeholders

Wehmeyer, M. L. (2014). Self-determination: A family affair. *Family Relations Interdisciplinary Journal of Applied Family Studies, 63***, 178-184. Doi: 10.1111/fare.12052 [Professional Opinion]**

- Discussed the importance the role families play in the development of self-determination of youth with disabilities
- Provided recommendations for supporting families to promote self-determination

Whitney-Thomas, J., & Hanley-Maxwell, C. (1996). Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children, 63***, 75–87. [Correlational]**

- Conducted a survey to examine experiences of transition for both parents of youth with and without disabilities
- Results of factor analysis indicated three major components of parental transition experiences (i.e., parents comfort with the process, vision for child's future, and response to school services
- Results indicated parents of youth with disability show great discomfort with the transition from school to adulthood and have less optimistic visions about their students future
- Authors provide recommendations for future research and implications for practice

Young, J., Morgan, R. L., Callow-Heusser, C. A., & Lindstrom, L. (2014). The effects of parent training on knowledge of transition services for students with disabilities. *Career Development and Transition for Exceptional Individuals***, Advanced Online Publication. Doi: 10.1177/2165143414549207 [Experimental]**

- Examined effects of two parent training approaches in secondary transition on

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knowledge of transition services and contact with community service providers.

- Participants were primarily (72%) parents of youth with high incidence disabilities (e.g., learning disabilities, mild intellectual disability, high functioning autism) and were primarily white females.
- Results indicated that the group who received a brochure plus training had higher levels of knowledge at posttest and were more likely to contact community service providers
- Provided suggestions for future research and implications for practice

Culturally Diverse Families

Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2000). Group action planning as a support strategy for Hispanic families: Parent and professional perspectives. *Mental   Retardation, 387*, 262-275. **[Qualitative]**

- Examined the effectiveness of action planning, a person-centered planning approach, with Hispanic parents of youth/young adults with a variation of disability classifications such as autism, mental retardation, and cerebral palsy
- Described perceived advantages and disadvantages of group action planning by participants

Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research & Practice for Persons with Severe Disabilities, 27*, 204-219. **[Qualitative]**

- Described visions of Hispanic parents about their children with disabilities which focused on acceptance, future living, employment, and free time options
  - o Lack of acceptance from family, friends, and others is a source of distress in the immediate family structure
  - o Parents' vision on future living varied. Some feared what would become of their child's life when they were no longer able to take care of them, expressing a desire to find a future caretaker that would be comparable to what they could provide. Others envisioned their children living independently with concerns of safety
  - o Parents stressed the importance of employment being consistent with child's preferences and a desire that their children have a meaningful job
  - o Parents valued leisure activities for their children, envisioning their son or daughter participating in community activities typically enjoyed by their same age nondisabled peers

Boone, R. S. (1992). Involving culturally diverse parents in transition planning. *Career Development for Exceptional Individuals, 15*, 205-221. **[Experimental]**

- Examined the effect of a parent training program on culturally diverse parent's knowledge about school to community transition and participation in the transition planning meeting in Hawaii

- Found that parents who received training scored significantly higher on a transition awareness training instrument developed by the researcher than those who had no training but no significant differences in parental contributions to the Transition planning meeting

Canha, L., Owens, L. A., Simoes, C., Gaspar de Matos, M. (2013). American and Portuguese parent perspectives on transition. *Journal of Voational Rehabilitation*, *38*, 195-205. [Qualitative]

- Conducted focus groups of parents of youth with disabilities in the U.S. in Portugal. Guiding questions for the groups centered around five areas: a) opportunities for employments post-secondary education, and independent living; b) school-based transition supports; c) service supports; d) family resources to support transition, and e) areas of improvement for transition planning
- Compares and contrasts legislative impact on transition services for youth with disabilities in the U.S. and Portugal

deFur, S.H., Todd-Allen, M., & Getzel, E.E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Individuals, 24*(1), 19-36. [Qualitative]

- Conducted four focus groups of Virginian parents of adolescents with disabilities to gain a deeper understanding of a) Virginian families; experiences in transition planning; b) family relationships with school professionals in the transition planning process; c) implications for policy and practice
- Families consistently identified the quality of relationships with service providers as a key factor affecting their involvement in transition planning
- Authors propose a Cycle of Family Empowerment Model to illustrate the potential effect of family-provider interactions on the transition planning process and serve as a guide for effective family involvement practices

Gallegos, A. Y., & Medina, C. (1995). Twenty-one ways to involve families: A practical approach. *Rural Special Education Quarterly, 14,* 3-6. [Descriptive]

- Discussed involving the entire family, factors influencing involvement, and factors affecting rural communities
- Provided strategies that have been used and found to be effective by special education teachers working in rural districts of southern New Mexico

Geenen, S., Powers, L.E., & Lopez-Vasquez, A. (2001). Multicultural aspects of parent involvement in transition planning. *Exceptional Children, 67,* 265-282. [Qualitative]

- Conducted a survey to examine the extent and type of parental involvement in transition and to identify differences in parent and professional perceptions
- Described the role of the parent in the transition process

- Identified activities parents are currently involved in during their child's transition planning and how the activities varied by cultural group
- Identified what types of participation are most important to parents from various cultural backgrounds
- Described the differences in perceptions of professionals and parents as relates to level of involvement and importance

Grady, M., & Bost, L. W. (Eds.). (2014). Decreasing dropout rates for minority male youth with disabilities from culturally and ethnically diverse backgrounds. Clemson, SC: National Dropout Prevention Center for Students with Disabilities.

This report lists specific strategies to decrease drop-out rates of African-American and Latino males with disabilities. These strategies include:

- Schools should work in partnership with parents of African American males. They should employ strategies that foster, expand, and encourage parental engagement and that value the critical role parents can play in their child's educational experience
- Parents and family members must be involved in the school life of their children. Families play an especially vital role in the lives of Latino males. Family members must know about the educational options open to their children, the implications of staying in school, and the promise of their options when they do
- Conduct home visits to develop relationships with family members
- Provide transportation or arrange car-pooling to school events and offer to meet parents in locations that are convenient for them
- Provide assistance for parents in reinforcing classroom instruction and providing behavioral support for their children at home
- Contact parents with positive information about their children and thank them for their support

Greene, G. (1996). Empowering culturally and linguistically diverse families in the transition planning process. *The Journal for Vocational Special Needs Education, 19,* 26-30. [Descriptive]

- Discussed effects of low socioeconomic status, medical model of disabilities, and other factors that prevent participation in transition planning meetings for culturally diverse parents of students with disabilities
- Offered strategies and suggestions to IEP team members to empower culturally diverse families to be better advocates during the transition planning process

Howland, A., Anderson, J.A., Smiley, A. D., & Abbot, D. J. (2006) School liaisons: Bridging the gap between home and school. *The School Community Journal, 16,* 2, 47-68. [Descriptive]

- Described a school liaison program funded by the Indianapolis Public Schools Office of Special Education and student services, designed to serve families from African American or Hispanic backgrounds, specifically those families with students identified as having a disability or those at-risk for such identification
- Described the three psychological constructs that this model incorporates, parents' motivational beliefs, parents' perceptions of invitations for involvement, and parents' perceived life context

Kim, K., & Morningstar, M. E. (2005). Transition planning involving culturally and linguistically diverse families. *Career Development for Exceptional Individuals, 28,* 92-103. [Literature Review]

- Reviewed the results from five articles regarding parent involvement in transition for families from culturally and linguistically diverse backgrounds
- Described barriers to family involvement (i.e., professional attitudes, diversity concerns, contextual barriers, and bureaucratic barriers)
- Provided culturally responsive strategies to enhance parent professional partnerships

Landmark, L. J., Zhang, D. D., & Montoya, L. (2007). Culturally diverse parents' experiences in their children's transition: Knowledge and involvement. *Career Development for Exceptional Individuals, 30,* 68-79. [Qualitative]

- Described the transition planning process experiences of 19 culturally diverse families
  - Knowledge of children's transition planning
  - Knowledge of legal requirements for transition
  - Involvement in the transition process
- Described parents' articulation of indicators of good participation in the transition process, their perceived barriers to involvement in the transition process, and supports needed to increase involvement in the transition process
- Discussed recurring themes and prominent differences among the different ethnic groups
  - Transition planning
  - IEP and transition meetings
  - Employment
  - Home support
  - Parent emotions

Navarrete, L. A., & White, W. J. (1994). School to community transition planning: Factors to consider when working with culturally diverse students and families

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in rural settings. *Rural Special Education Quarterly, 13,* 51-56. [Literature Review]

- Reviewed selected literature related to multicultural issues that have a direct impact on the transition planning process
- Described the variations of communication styles between cultural groups (e.g., nonverbal cues, eye gazing, turn-taking, and impersonal versus personal modes of communication)
- Provided recommendations for effective transition planning with diverse populations

Povenmire-Kirk, T., Lindstrom, L., & Bullis, M. (2010). School to adult life: Transition needs for latino youth with disabilities and their families. *Career Development for Exceptional Individuals, 33*(1), 41-51. [Qualitative]

- Conducted individual and focus group interviews with school and transition professionals, Latino youth, and their families to identify available transition services and barriers faced by this population
- Results were summarized into five major categories: a) language issues; b) concerns regarding documentation and citizenship; c) lack of culturally appropriate practices; d) barriers to family participation; and e) limited school and community resources
- Identified practice areas of critical need and suggestions for future research

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with disabilities. *Exceptional Children, 71,* 401-414. [Qualitative]

- Described a model of home-centered, sheltered adaptation by identifying five themes surrounding transition for Latino mothers of young adults with disabilities
    - basic life skills and social adaptation
    - independence and the role of the home
    - the mother's role and expertise in deciding transition issues
    - access to information
    - dangers of the outside world
- Provides evidence that there may be multiple perspectives on transition, some of which may conflict with the views of transition implied in various official policies and definitions
- Described a group of Latino mother's perspectives of transition services, their roles, their feelings about interagency collaboration, and the dangers of the outside world

Shapiro, J., Monzo, L., Rueda, R., Gomez, J., & Blacher, J. (2004). Alienated advocacy: The perspective of Latina mothers of young adults with developmental disabilities on service systems. *Mental Retardation, 42*(1), 37-54. [Qualitative]

- Conducted three focus groups with 16 low-income Latina mothers of young adults with developmental disabilities about their relationship with educational and service delivery systems.
- Five primary concerns were identified:
  - poor communication
  - low effort in providing services
  - negative attitudes of professionals toward the client-children
  - negative treatment of parents by professionals
  - the mother's role as central to the well-being of her child
- Authors found that although these mothers were compelled to become advocates for their children, it was not expressed by functioning as part of the team within the system but instead took the form of alienated, adversarial interactions to ensure their children were not neglected or ignored

Sheehey, P. H. (2006). Parent involvement in educational decision-making: A Hawaiian perspective. *Rural Special Education Quarterly, 24,* **3-15. [Case Study]**

- Provides three case analyses for children of Hawaiian descent living in rural Hawaii focused on the families' experience with educational decision-making
- Families faced obstacles with advocacy on behalf of themselves and their children
- Parents defined involvement in educational decision-making as a) talking with teachers; b) helping in the classroom; c) searching for information regarding special education
- Several discrepancies between home and school culture contributed to discomfort for parents including a) the context of the IEP meeting; b) the skills and behaviors targeted for instruction; and c) the lack of collaboration at IEP meetings
- Implications for practice provided

Sileo. T. W., & Sileo, A. P. (1996). Parent and professional partnerships in special education: Multicultural considerations. *Intervention in School and Clinic, 31,* **145-154. [Descriptive]**

- Highlighted the importance of parent-professional relationships to student's academic and social development and the impact of ethnic, linguistic, and cultural diversity on the establishment of partnerships
- Provided four general strategies for parent-professional interactions
  - Parent education programs that help parents with limited access to formal education settings to learn basic schools subjects and life skills
  - Parent education programs that are designed to increase parents' influence on their children's education

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- Awareness training programs that provide opportunities for role play and simulations to help increase parent's confidence levels when they are working with school personnel
- Bilingual and special education programs that address linguistic and cultural diversity

Taylor, J. L. (2009). The transition out of high school and into adulthood for individuals with autism and their families. *International Review of Research in Medicine and Mental Retardation, 38*, **1–32. [Literature Review]**

- Reviewed literature on transition to adulthood for adolescents and young adults with ASD.
- Explores how Erickson's psychosocial theory and Attachment theory can inform the study of the transition to adulthood for adolescents and young adults with ASD.
- Reviews research on how individuals with ASd and their families experience the transition to adulthood.
- Provides directions for future research grounded in theory and encourages a more systematic investigation of the transition time.

Timmons, J. C., Whitney-Thomas, J., McIntyre, J. P., Butterworth, J., & Allen, D. (2004). Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation, 70, 2,* **19-26. [Qualitative]**

- Described parents' perceptions of their child's transition planning and process and the challenges they have faced to trying to plan for their child's transition from school to adult life
- Described the role parents in the study played while planning for their child's transition from school to adult life; parents referring to themselves as linchpins
- Discussed resources and strategies for negotiating systems as well as resources and strategies parents lacked
- Included in the implications for practice suggestions were building informal supports, case management, person-directed resources, and building young adult self-determination

Other Relevant Sources

The following resources about family involvement in secondary transition were recommendations provided by the PACER parent training and information center and the Center for Parent Information and Resources (CIPR).

Family as a Critical Partner in the Achievement of a Successful Employment Outcome, Twenty-Sixth Institute on Rehabilitation Issues 2000. **Retrieved May 19, 2008, from http://www.pacer.org/tatra/26IRIinside.pdf**

- Examined how a consumer's family can be a critical partner in the achievement of successful employment outcomes

- Provided training resources that can be used to help vocational rehabilitation counselors effectively engage families in the VR process.

Ferguson, C. (2005). *Reaching Out to Diverse Populations: What Can Schools Do to Foster Family-School Connections?* A Strategy Brief of the National Center for Family and Community Connections with Schools, September 2005. Retrieved May 19, 2008, from http://www.sedl.org/connections/resources/rb/rb5-diverse.pdf

- Described on teachers efforts to foster effective family and community involvement in student learning
- Provided recommendations for building effective programs

Ferguson, C., & Rodriguez, V. (2005). *Engaging families at the secondary level: What schools can do to support family involvement*. Retrieved May 19, 2008, from http://www.sedl.org/connections/resources/rb/rb3-Secondary.pdf

- Described considerations when engaging families at the secondary level
- Provided strategies to help school staff develop effective family and community connections with schools

***Helping Families Transition to the Future: Rehabilitation Service Administration Parent Information and Training Projects Outcome Data 2005-2006*. Retrieved May 19, 2008, from http://www.pacer.org/tatra/resources/RSA/RSA.pdf**

- Presented data on positive outcomes associated with transition-focused parent training activities of seven Parent Information and Training Programs funded by the U.S. Department of Education Rehabilitation Services Administration (RSA) over a 12-month period in 2005 and 2006

Henderson, A. T., Mapp, K. L. (2002). *A new wave of evidence: The impact of school, family, and community connections on student achievement*. The National Center for Family and Community Connections with Schools.

- Examined parent and community involvement and its role in impacting on student achievement

***ICI Impact newsletter, 19(2):* Feature Issue on Parenting Teens and Young Adults with Disabilities. Retrieved May 19, 2008, from http://ici.umn.edu/products/impact/192/default.html**

- Provided overviews of issues that arise when parenting teens and young adults with disabilities
- Suggested ways parents can become involved in the transition process
- Described Case Studies

The Iris Center (2015). Secondary Transition: Helping Students with Disabilities Plan for Post-High School Settings: Online Module. Retrieved from http://iris.peabody.vanderbilt.edu/module/tran/#content

- Module focuses on the transition process from high school to post-secondary settings. Among other topics, it discusses IEP planning, engaging students in the process so as to become better advocates for their own needs, and the importance of outside agencies such as vocational rehabilitation.

Kreider, H., Caspe, M., Kennedy, S., Weiss, H. (2007). *Family Involvement in Middle and High School Students' Education, 3,* Retrieved May 19, 2008, from http://www.hfrp.org/publications-resources/publications-series/family-involvement-makes-a-difference/family-involvement-in-middle-and-high-school-students-education

- Synthesized the latest research that demonstrates how family involvement contributes to adolescents' learning and development
- Summarized the latest evidence base on effective involvement—specifically, the research studies that link family involvement during the middle and high school years to outcomes and programs that have been evaluated to show what works

Leake, D. W., Black, R. S. (2005). Cultural and Linguistic Diversity: Implications for transition Personnel. *NCSET Essential tools*, Retrieved May 19, 2008, from http://www.ncset.org/publications/essentialtools/diversity/default.asp

- Summarized current research on transition issues and Culturally and Linguistically Diverse (CLD) youth with disabilities

- Offered information on how transition personnel can effectively support youth by building on their strengths and enhancing natural supports available within their families and communities

- Provided several practical tools, and information on further resources

Martin, S.S., & Baker, D.C. (2001). Families and children with severe disabilities: Daily lives, systems, and concerns. Paper presented at the 2001 meeting of the American Association of Behavioral and Social Sciences (AABSS). Las Vegas, Nevada.

- Described issues of family life, the systems that affect the families, and current and future concerns related to having a child with severe disabilities

Muller, E. (2004). Autism: Challenges related to secondary transition. Retrieved from: http://nasdse.org/DesktopModules/DNNspot-Store/ProductFiles/20_456673bb-7700-4e97-8ba4-2d59a20d21a1.pdf

- Describes efforts of several state education agencies (SEAs) to address the needs of transition-aged students with autism, describe the major barriers to providing effective secondary transition services to this population, and generate policy recommendations

National Dropout Prevention Center/Network Newsletter, 20 (2). Family/School Relationships: Relationships That Matter. Retrieved May 19, 2008, from

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http://www.dropoutprevention.org/downloads/docs/webcast/20090210/NDPN_News_FamilySchool.pdf

- Defined family engagement
- Described Home Visit Connection program in California

Peterson, K. (2004) Supporting Dynamic Development of Youth with Disabilities During Transition: A Guide for Families. *NCSET Information Brief*, 3(2), Retrieved May 19, 2008, from http://www.ncset.org/publications/viewdesc.asp?id=1432

- Offered concrete, useful information about adolescent development to guide families in supporting youth with disabilities
- Provided the compassionate perspective of a parent of a youth with a disability regarding the transition process
- Offered a list of further resources

IDEAs that Work
U.S. Office of Special Education Programs