Social Support and Stress Reduction for Caregivers of Young Adults With IDD
Study Protocol

NCT Number: NCT05938998
Unique Protocol Id: STUDY00149679
Version date: 6/21/2023
Principal Investigator: Amy Bodde

University of Kansas Medical Center
RESEARCH PROTOCOL INVOLVING HUMAN SUBJECTS

Version date: 6/21/2023
Principal Investigator: Amy Bodde
Study Title: Social Support and Stress Reduction for Caregivers of Young Adults with IDD
Co- Investigator(s): Bethany Forseth, Lauren Ptomey

I. Purpose, Background and Rationale

1. Aim and Hypotheses

Being a caregiver to an individual with intellectual and developmental disabilities (IDD) can be stressful and may result in adverse health effects for the caregiver. Additionally, caregivers of individuals with IDD must navigate new support systems when the young adult with IDD reaches a transitional age and loses school-based supports. In conjunction with the *Chef BoyID* study (IRB # 148424), we propose a 12-week study which will consist of 12 group-based sessions offered to the caregivers of transitional age individuals with IDD, some of whom may be enrolled in the *Chef BoyID* study. These sessions will cover 1 hour of social support and resource provision, and 1 hour of stress reduction through yoga to help with the transition.

1. Evaluate factors impacting the feasibility of recruitment, retention, assessment, and satisfaction of a caregiver intervention providing social support and stress reduction.
2. Measure changes in psychosocial health (i.e., stress, social support, family empowerment), physiologic stress (salivary cortisol) and lifestyle health behaviors (i.e., physical activity, sleep) of caregivers participating in the intervention.
3. Assess impact of caregiver participation in the intervention on health behaviors of the young adult with IDD (i.e., physical activity, diet, sleep).
    a. Hypothesis 1: Young adults in Chef BoyID who have a caregiver partake in the intervention will have improved Chef BoyID outcomes compared to young adults in Chef BoyID who do not have a caregiver participating in the intervention.
    b. Hypothesis 2: Reduction in stress of caregivers improves caregiver health behaviors & dependent health behaviors.

A. Background and Significance

Family caregivers of youth with IDD are susceptible to poor health outcomes which may be due to the burdens and stressors of caregiving (Magaña et al., 2015; Magaña & Smith, 2008; Miodrag & Hodapp, 2010). Parenting children with IDD is a rewarding but challenging responsibility that continues throughout the lifespan (Grein & Glidden, 2015; Hastings & Taunt, 2002). The perpetual stressors of caring for a child with IDD include dealing with challenging behaviors (Drew et al., 2022; Lowe et al., 2007), financial strains (Genereaux et al., 2015; Parish et al., 2008), frequent advocacy for a child’s needs (Krueger et al., 2019), sleep loss (Marquis et al., 2019) and their child’s unique physical and psychosocial development. These responsibilities take a physical and emotional toll on parent caregivers (Gallagher et al., 2008; Singer, 2006).

Though caregivers of individuals with IDD will experience several complex transitions that may increase their caregiving strains, (Raina et al., 2004; Wang, 2012) the period of late adolescence and young adulthood (i.e. 18-21 years) is especially challenging (Dyke et al., 2013). Young adults with IDD and their caregivers prepare to lose school-based supports at age 21 and must consider and facilitate job opportunities and make decisions about living situations (McKenzie et al., 2017). Both formal and informal support needs are high during this transition; both of which and are associated with increased caregiver stress (Marquis et al., 2019). Parents of adolescents with IDD also report the adolescent years are a time of considerable stress (Young et al., 2018) in which they neglect their own health behaviors as they prioritize the needs of their children (Magaña et al., 2015; Magaña & Smith, 2008). These stressors may manifest as poor mental and physical health. For example, a systematic review by Scherer et al., found that parent caregivers of those with IDD are twice as likely to experience anxiety and four times as likely to have moderate depression compared to parents of children without IDD (Scherer et al., 2019). Limited data suggests that the prevalence of obesity and other chronic conditions, e.g., diabetes, hypertension, heart disease etc. are also higher in family caregivers of children with disabilities compared with family caregivers for children without disabilities (Bodde et al., 2022; Gallagher & Hannigan, 2015; Lee et al., 2017). Previous research implementing yoga or mind-body interventions have documented reductions in psychologic and physiologic stress and reductions in stress symptoms(Chong et al., 2011; Park et al., 2021; Pascoe et al., 2017). Because the physical and mental health of caregivers is associated with the health and wellbeing of their child with a disability (Murphy et al., 2007), it is important to assess interventions aimed at reducing stress and providing support for parents during these transition years.

B. Rationale

Interventions focusing on providing resources, social support and mind body activities may help to reduce caregiver stress and improve their health behaviors (e.g., sleep and activity), and collectively, this may also result in improvements in the health behaviors of their young adult with IDD, some of whom may be participating in a concurrent physical activity and cooking skills intervention (see Dr. Lauren Ptomey's study: *The promotion of healthy lifestyles for young adults with intellectual disabilities, referred to as "Chef BoyID", IRB #148424).*

II. Research Plan and Design

A. Study Objectives

The purpose of this study is to examine the feasibility and initial efficacy of a social support, resources, and stress reduction intervention for the promotion of healthy lifestyle behaviors and the reduction of caregiver stress and strain.

B. Study Type and Design

This is a single arm longitudinal trial. We will recruit up to 40 caregivers of young adults with IDD. Some caregivers will be recruited as their young adult is participating in the Chef BoyID intervention, and some will be recruited for a cohort at Down Syndrome Innovations, unrelated to Chef BoyID participation. This is a 12-week social support, resources, and stress reduction intervention delivered in person to a group of caregivers of young adults with IDD of transitioning age at the Center for Children's Healthy Lifestyles and Nutrition, Down Innovations orat the University of Kansas Energy Balance Laboratory location. Participants will be asked to attend one 2 hour group session each week. All sessions will have a 1-hour discussion on resources and social support and 1-hour of yoga. All yoga sessions will be taught by 200 RYT certified instructors. Outcome assessments will be collected at baseline and after the 12-week intervention.

C. Subject Criteria

Inclusion: 1) caregiver of a young adult with IDD 2) self-reported ability to participate in a yoga class with no contraindications to participation. *Exclusion*: 1) Actively participating in another health lifestyles interventional research study.

D. Specific methods and techniques used throughout the study

1. Intervention:

   a. *In person, small group instruction:* Participants will attend weekly two-hour small group instruction sessions at the Center for Children's Healthy Lifestyles and Nutrition, Down Syndrome Innovations, or the University of Kansas Energy Balance Laboratory location. All sessions will have a 1-hour discussion on resources and social support and 1-hour of yoga.

      i. Discussion on resources and social support (1 hour): This session will consist of a brief presentation of resources to aid in the transition process for the young adult with IDD. In the first session, caregivers will be asked to provide topics of specific interest and sessions will be customized to their expressed needs. Examples of topics covered include: transportation, employment options, group home options, navigating

Medicaid waiver, respite care options, health, etc. Time will be provided for caregivers to connect with each other, ask questions, and share their own resources and experiences. A discussion guide will be provided for each week.

ii. Yoga class (1 hour): Each yoga class will be taught by a certified yoga instructor (Dr. Bethany Forseth or Ms. Jessie Danon). The session will include breathing / warm up (~5minutes), asanas/poses (~45min) and savasana/meditation (~10min).

2.Schedule of Evaluations

Assessment	Screening Visit: (Day-30 to Day -1)	Baseline: KUMC Visit 1 (Day -14 to Day -1)	KUMC Visit 2 (Week 12-Week 14)	Weekly	Monthly
Informed Consent Form	X				
Demographics	X				
Enrollment		X			
Anthropometrics		X	X		
Session Attendance				X	
Physical Activity – Accelerometer		X	X		
Caregiver strain		X	X		
Perceived Stress Scale		X	X		
Physiologic Stress (Cortisol)		X	X		
Social support		X	X		
Family Empowerment		X	X		
Sleep		X	X		
Satisfaction (semi-structured interview)			X		
Adverse Events		X	X	X	X

3. Description of Evaluations

A. **Caregiver demographics:** contact information, age, gender, relationship to person with IDD, income, education level, number of children, employment status, race, ethnicity (Hispanic/not Hispanic)

B. **Anthropometrics:** Participants will be weighed in shorts and a t-shirt between 7 and 10 AM, in duplicate, on a calibrated scale (Model #PS6600, Belfour, Saukville, WI) to the nearest 0.1 kg. Standing height will be measured in duplicate with a portable stadiometer (Model #IP0955, Invicta Plastics Limited, Leicester, UK).

C. **Session Attendance:** The session leaders will record attendance at weekly sessions. The participants will only be considered present if they complete the entire 2-hour session. The outcome variable will be the number of sessions attended (count) and percentage of attendance out of the total 12 scheduled sessions.

D. **Physical activity (accelerometers):** Physical activity will be assessed by accelerometer at baseline and 12 weeks. Participants will be asked to wear the accelerometer for 7 days and then return in a pre-paid envelope.

E. **Cortisol:** Physiologic stress will be collected and analyzed through salivary cortisol. Caregivers will be provided Salimetrics® collection tubes while at their baseline visit and at the final intervention week. They will be asked to collect a sample of their saliva within 30 minutes of waking up, around the same time at all time points, and prior to consumption of food or beverages; they will log the exact time of their sample and place this in the freezer until their next visit (first day of intervention or post-intervention testing) when researchers will collect the sample. Once collected by researchers, samples will be frozen until analysis. The cortisol will be analyzed using an ELISA-based immunoassay analysis by the Disease Model and Assessment Core (DMAC) at the University of Kansas Medical Center. The ELISA kit agreed upon with the DMAC has a sensitivity of 0.111ng/mL and an assay range between 0.2-10 mg/mL for saliva, and has a reliable intra- and inter-assay precision (0.41, 0.58, respectively).

F. **Caregiver strain:** Caregiver Strain will be assessed using the Modified Caregiver Strain Index, with minor modifications in wording to reflect care of someone with IDD. The Modified Caregiver Strain Index is a 13-question tool that measures strain related to care provision.
G. **Social Support:** Social support will be assessed with the Multidimensional Scale of Perceived Social Support, which is a 12-item measure of perceived social support from family, friends, and significant others.
H. **Family Empowerment**: Family Empowerment will be assessed using the Family Empowerment Scale, subscales 1 and 2, which assess satisfaction with caregiving and service supports for families.
I. Stress: will be assessed using the Perceived Stress Scale (10 questions).
J. **Sleep:** will be assessed using the Pittsburgh Sleep Quality Index. This is a 10-question index to evaluate overall sleep quality.
K. **Satisfaction / semi-structured interviews:** Semi-structured interviews will be conducted with each caregiver within 2 weeks after the intervention to assess satisfaction with the intervention components and to gather suggestions for future iterations. Interviews will be recorded and transcribed for analysis with Dedoose software Version 9.0.17, (Los Angeles, CA: SocioCultural Research Consultants, LLC, 2021, www.dedoose.com)

F. Risk/Benefit Assessment

Risks to the caregivers are minimal and may include general muscle soreness or strains from participating in yoga, no more than would be expected from participating in exercise in the community. These risks are minimized as the yoga program will gradually progress over the 12-week intervention, will include warm up and cooldown poses/periods, and will be taught be a certified yoga instructor. Other risks may include discomfort in participating in a support group or discussing needs with other caregivers. However, to minimize these risks, participants will be assured that there is no obligation to share personal information with the support group.

The benefits of participating in a social support, resources, and stress reduction intervention are that participants may learn of new resources in the community to assist their transition-age child; they may gain social support by interacting with other caregivers and sharing resources; and they may see reductions in stress, improvements in physical activity, and improvements in sleep from participating in the yoga portion of the intervention. The risks are minimal and the benefits to caregivers are potentially large.

G. Location Where Study Will Be Performed

Research activities will take place at the joint KUMC/CMH funded Center for Children’s Healthy Lifestyles and Nutrition,at the University of Kansas Energy Balance Laboratory location or at Down Syndrome Innovations. All data will be saved on a KUMC Redcap database, and all study related documents will be saved on a KUMC P-Drive.

H. Assessment of Subject Safety and Development of a Data and Safety Monitoring Plan

The intervention and measurement protocols proposed for this feasibility study pose minimal risk to participants. Because of this low-risk status, the data safety monitoring plan (DSMP) for this trial focuses on close monitoring by the principal investigator (PI) along with prompt reporting of excessive or serious adverse events to the Human Subjects Committee (HSC) at The University of Kansas Medical Center. Safety reports will be sent by the yoga instructors to the PI. The PI will be responsible for assembling the data and producing these reports. The frequency of data review for this study differs according to the type of data, the availability of data collected, and the perceived level of risk.

Data type	Frequency of review
Subject accrual (adherence to protocol regarding demographics, inclusion/exclusion)	Monthly

Adverse event rates (injuries/illness)	Monthly
Compliance to treatment	Monthly
Stopping rules	Semi-annually

Measurement and Reporting of Subject Accrual, Adherence to Inclusion/Exclusion Criteria
Review of the rate of subject accrual and adherence to inclusion/exclusion criteria will occur monthly to assure that participants meet eligibility criteria outlined in IRB proposal.

Measurement and Reporting of Adverse Events
Data on adverse events will be reported monthly to the PI throughout this trial. We anticipate that most adverse events will be mild in nature and will allow a complete return to the same activities after a short period of time; that is, later that day or a day or two later.

Measurement and Reporting of Participant Compliance to the Treatment Protocol
Compliance to the program will be monitored by attendance to the group sessions. Compliance to the intervention protocol will be reviewed monthly by the PI.

Stopping Rules
We believe this trial conveys minimal risk. Indeed, increases in physical activity and stress management resources are desirable and may convey health benefits. The most likely scenario indicating the need to stop the investigation would be a failure to recruit or deliver the intervention as planned. Another issue relating to stopping rules for this trial would be new information. It is unlikely that any new information will become available during this trial that would necessitate stopping the trial.

III. Subject Participation

A. Recruitment

Caregivers of young adults with IDD in the ChefBoyID study will be recruited and informed about the caregiver portion of the study when their young adult is recruited/consented to participate to the ChefBoyID study. Caregivers may also be recruited through informational flyers distributed through Down Syndrome Innovations' email list and quarterly promotion materials. Flyers and emails will be modified to reflect the addition of the caregiver portion of the intervention.

Interested caregivers will be asked to contact the study coordinator via email, our website or a dedicated study phone number that will be included in all recruitment materials. The study coordinator will contact the interested individuals by phone to answer questions and conduct an initial eligibility screening. Zoom meetings will be scheduled with those who remain interested and potentially eligible to complete the exercise screening session and to obtain informed consent.

B. Screening Interview/Questionnaire:

Caregivers with a young adult with IDD who are interested in participating in the social support, resource, and stress reduction intervention will be contacted to by the research team. Researchers will go over the eligibility criteria, and if eligible, review the study and the informed consent.

C. Informed Consent Process And Timing Of Obtaining Of Consent

Remote video chat sessions (Zoom) will be scheduled with participants who are deemed to be initially eligible to participate. This video chat session will provide an opportunity to describe the project in detail, answer questions, verify eligibility, and to obtain consent immediately following the consent/assent of the participant with IDD (For the ChefBoyID study, if applicable). Prior to the consenting session, the participant will be sent the consent form and cover letter through The University of Kansas Medical Center's (KUMC) secure email system. The study team will use the "share screen" option on Zoom to walk through each section of the consent document while noting questions that arise and answering these questions fully. Participants who are willing to participate in the study will sign and date the consent and/or assent forms electronically via REDCap. The study team member who conducted the consent meeting will also sign and date after reviewing the signed consent forms and verifying completeness. Study staff will provide the participant with a fully signed consent form for their records.

D. Alternatives to Participation

Participants may join other health or resource programs/lectures or exercise classes.

E. Costs to Subjects

There will be no costs to the participant or their family for this study.

F. How New Information Will Be Conveyed To The Study Subject And How It Will Be Documented

New information will be told to the participants before, during, or after their participation in the study by email that will be sent to all participants.

G. Payment, Including a Prorated Plan for Payment

There will be no participant compensation. Travel costs will not be directly reimbursed.

H. Payment for a Research-Related Injury

There will not be any payment for a research-related injury.

IV. Data Collection and Protection

A. Data Management and Security: Data base creation and management will be performed by experienced research staff. Research staff that enters data will be supervised and will be blinded to condition. The PI and study coordinator will have access to study data. We have extensive experience in data entry, data checking, and quality control from previous and current projects. The primary database will be maintained through KUMC's Redcap. Additional data (semi-structured interview recordings via Zoom) will be maintained a KUMC P-Drive. Prior to transfer of data files to non-study personnel (i.e., for statistical analysis), the files will be de-identified. Data will be categorized and entered into separate tables within a database, all linked by participant number. All key personnel have current Human Subjects/HIPPA certificates. Physical files will be stored in a locked filed cabinet, in a locked office, in our space in the KUMC endowment building suite 100.

B. Procedures to Protect Subject Confidentiality

Confidentiality for participants may be at risk during data collection, entry, and storage. However, we will use a secure, HIPAA compliant system (i.e., REDCap) to serve as the study database to store all the demographic information that may lead to subject identification. All paper records will be kept in a locked file cabinet and information will not be released without written permission of the participant, except as necessary for monitoring by the KUMC IRB.

C. Quality Assurance / Monitoring: At logical time points, the data will be checked for outliers and normalcy. Questionable data (e.g., >3 standard deviations from the mean) will be re-checked for accuracy and re-entered if necessary.

V. Data Analysis and Reporting

A. Statistical and Data Analysis

To determine the feasibility of social support, resource, and stress reduction sessions, we will calculate the mean number of sessions attended, and the percent of participants who attended ≥ 75% of the scheduled sessions. Chi-Square or t-tests will be used to compare baseline characteristics (age, sex, BMI, PA, income, other demographic characteristics) between participants who attended ≥ 75% vs. <75% of sessions. To assess changes in physical activity, social support, family empowerment, stress, caregiver strain, and sleep across the intervention, we will compare baseline and 12-week assessments using a t-test or non-parametric equivalent for paired samples, and we will determine effect size using Cohen's D. Per Aim 3, Hypothesis A of the caregiver intervention, we will compare outcomes of participants with IDD (cooking skills, fitness, weight, dietary intake, physical activity) between participants who had a caregiver participate and those who did not using independent samples t-tests. Per Aim 3, Hypothesis B, we will analyze correlations between change in caregiver stress (perceived stress scale; cortisol; caregiver strain) and caregiver health behaviors (physical activity, sleep) and dependent health behaviors (cooking skills, fitness, weight, dietary intake, physical activity). Finally, we will complete a qualitative analysis of the semi-structured interviews to gain insight on the acceptability and satisfaction with the program.

B. Outcome

We expect to know the feasibility and acceptability of the social support, resources, and stress reduction program for caregivers and determine if we should apply for external funding to complete and adequately powered trial.

C. Study results to participants

Study results will not be sent to the participants.

D. Publication Plan

The research results will be presented at a conference and published in a peer-reviewed journal upon completion of the pilot study.

VI. References

Bodde, A. E., Helsel, B. C., Hastert, M., Suire, K. B., Washburn, R. A., Donnelly, J. E., & Ptomey, L. T. (2022). The Prevalence of Obesity and Lifestyle Behaviors of Parents of Youth with Intellectual and Developmental Disabilities. *Disability and Health Journal*, 101430. https://doi.org/https://doi.org/10.1016/j.dhjo.2022.101430

Chong, C. S., Tsunaka, M., Tsang, H. W., Chan, E. P., & Cheung, W. M. (2011). Effects of yoga on stress management in healthy adults: A systematic review. *Altern Ther Health Med*, *17*(1), 32-38.

Drew, C. M., Machalicek, W., Crowe, B., Glugatch, L., Wei, Q., & Erturk, B. (2022). Parent-Implemented Behavior Interventions via Telehealth for Older Children and Adolescents. *J Behav Educ*, 1-20. https://doi.org/10.1007/s10864-021-09464-z

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *J Intellect Dev Disabil*, *38*(2), 149-162. https://doi.org/10.3109/13668250.2013.789099

Gallagher, S., & Hannigan, A. (2015). Child problem behaviours are associated with obesity in parents caring for children with developmental disabilities. *Res Dev Disabil*, *36c*, 358-365. https://doi.org/10.1016/j.ridd.2014.10.038

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *J Pediatr Psychol*, *33*(10), 1129-1136. https://doi.org/10.1093/jpepsy/jsn040

Genereaux, D., van Karnebeek, C. D., & Birch, P. H. (2015). Costs of caring for children with an intellectual developmental disorder. *Disabil Health J*, *8*(4), 646-651. https://doi.org/10.1016/j.dhjo.2015.03.011

Grein, K. A., & Glidden, L. M. (2015). Predicting well-being longitudinally for mothers rearing offspring with intellectual and developmental disabilities. *J Intellect Disabil Res*, *59*(7), 622-637. https://doi.org/10.1111/jir.12166

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *Am J Ment Retard*, *107*(2), 116-127. https://doi.org/10.1352/0895-8017(2002)107<0116:Ppifoc>2.0.Co;2

Krueger, K., Cless, J. D., Dyster, M., Reves, M., Steele, R., & Nelson Goff, B. S. (2019). Understanding the Systems, Contexts, Behaviors, and Strategies of Parents Advocating for Their Children With Down Syndrome. *Intellect Dev Disabil*, *57*(2), 146-157. https://doi.org/10.1352/1934-9556-57.2.146

Lee, M. H., Park, C., Matthews, A. K., & Hsieh, K. (2017). Differences in physical health, and health behaviors between family caregivers of children with and without disabilities. *Disabil Health J*, *10*(4), 565-570. https://doi.org/10.1016/j.dhjo.2017.03.007

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: prevalence and topographies. *J Intellect Disabil Res*, *51*(Pt 8), 625-636. https://doi.org/10.1111/j.1365-2788.2006.00948.x

Magaña, S., Li, H., Miranda, E., & Paradiso de Sayu, R. (2015). Improving health behaviours of Latina mothers of youths and adults with intellectual and developmental disabilities. *J Intellect Disabil Res*, *59*(5), 397-410. https://doi.org/10.1111/jir.12139

Magaña, S., & Smith, M. J. (2008). Health behaviors, service utilization, and access to care among older mothers of color who have children with developmental disabilities. *Intellect Dev Disabil*, *46*(4), 267-280. https://doi.org/10.1352/1934-9556(2008)46[267:Hbsuaa]2.0.Co;2

Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors Affecting the Health of Caregivers of Children Who Have an Intellectual/Developmental Disability. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(3), 201-216. https://doi.org/https://doi.org/10.1111/jppi.12283

McKenzie, K., Ouellette-Kuntz, H., Blinkhorn, A., & Démoré, A. (2017). Out of School and Into Distress: Families of Young Adults with Intellectual and Developmental Disabilities in Transition. *J Appl Res Intellect Disabil*, *30*(4), 774-781. https://doi.org/10.1111/jar.12264

Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Curr Opin Psychiatry*, *23*(5), 407-411. https://doi.org/10.1097/YCO.0b013e32833a8796

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev*, *33*(2), 180-187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L., & Andrews, M. E. (2008). Material hardship in US families raising children with disabilities. *Exceptional Children*, *75*(1), 71-92.

Park, C. L., Finkelstein-Fox, L., Sacco, S. J., Braun, T. D., & Lazar, S. (2021). How does yoga reduce stress? A clinical trial testing psychological mechanisms. *Stress Health*, *37*(1), 116-126. https://doi.org/10.1002/smi.2977

Pascoe, M. C., Thompson, D. R., & Ski, C. F. (2017). Yoga, mindfulness-based stress reduction and stress-related physiological measures: A meta-analysis. *Psychoneuroendocrinology*, *86*, 152-168. https://doi.org/10.1016/j.psyneuen.2017.08.008

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatr*, *4*, 1. https://doi.org/10.1186/1471-2431-4-1

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS One*, *14*(7), e0219888. https://doi.org/10.1371/journal.pone.0219888

Singer, G. H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *Am J Ment Retard*, *111*(3), 155-169. https://doi.org/10.1352/0895-8017(2006)111[155:Mocsod]2.0.Co;2

Wang, K. Y. (2012). The care burden of families with members having intellectual and developmental disorder: a review of the recent literature. *Curr Opin Psychiatry*, *25*(5), 348-352. https://doi.org/10.1097/YCO.0b013e3283564248

Young, R. A., Marshall, S. K., Stainton, T., Wall, J. M., Curle, D., Zhu, M., Munro, D., Murray, J., El Bouhali, A., Parada, F., & Zaidman-Zait, A. (2018). The transition to adulthood of young adults with IDD: Parents' joint projects. *J Appl Res Intellect Disabil*, *31 Suppl 2*, 224-233. https://doi.org/10.1111/jar.12395