Potential Resources for Families with Children with Behavior Support Needs Prepared by the Human Services Research Institute For the Florida Quality Improvement Council

Introduction

To identify resources for families with children with dual diagnoses/behavioral challenges, HSRI contacted several national experts in the field of behavior support and asked for their recommendations on a range of resources that these families could use to meet the needs of their family members. Each respondent is identified with their specific suggestions. Some of these resources will require paying for subscriptions and individual courses. Other resources, such as the College of Direct Support would require a state contract to make the courses available. Other resources, like the Vanderbilt toolkit and the work of David Pitonyak can be accessed for free.

Jeff Cross, CEO, Benchmark Human Services (provider of mobile crisis services in Georgia and Indiana)

Vanderbilt Health Center for Adults with IDD: http://vkc.mc.vanderbilt.edu/etoolkit/mental-and-behavioral-health/ -- useful checklists and other resources

Florida Positive Behavioral Interventions & Support Project (PBIS) designed for public schools and led by the Florida DOE and University of S. Florida, but could provide training resources to families: http://flpbis.cbcs.usf.edu/about/mission.html

David Rotholz, Ph.D., Clinical Professor of Pediatrics, University Specialty Clinics, University of South Carolina (one of the authors of *Positive Behavior Supports* published by the American Association on Intellectual and Developmental Disabilities)

I think the Home and Community Positive Behavior Supports Network (CPBS) website may be the best resource. The link below is probably the most relevant to your request, but the entire site is likely to be a good resource. This is a pretty new effort and growing. https://hcpbs.wordpress.com/practical-resources-tools/resources-support-planning/

The site lists resources related to planning and implementing positive behavior support interventions. It includes manuals, workbooks, case examples and stories, planning tools and templates, and other practical materials. In addition, there are 2-3-page articles that have been adapted by HCPBS specifically for caregivers and support staff.

David Pitonyak, Consultant and Founder of *Imagine: Finding New Stories for People Who Experience Disabilities*

David describes his work as follows:

The largest part of my work involves meeting individuals who are said to exhibit "difficult behaviors." Most of these individuals exhibit difficult behaviors because they are misunderstood and/or because they are living lives that don't make sense. Often, they are lonely, or powerless, or without joy. Often, they are devalued by

others, or they lack the kinds of educational experiences that most of us take for granted. Too often their troubling behaviors are the result of an illness, or even a delayed response to traumatic events.

I have done some work for *Open Future Learning* and *Conversations That Matter*, and they have created a series of presentations about behavior supports. Both work on a subscription basis, but they may have abbreviated packages that could work for as resources for families. There are links to both services on my web site (www.dimagine.com - Online Videos). Let me know if you want any additional information. David has also done a series of videos which are longer and available through YouTube. You can check out the links on my web site as well. They really focus on the importance of relationships, so I am not sure they will work.

Joan Beasley, Ph. D -- Author and Co-Founder of the START program and the Director of the National Center for START Services at the University of New Hampshire's Institute on Disability UCED.

The Center is a national learning and teaching center for the development of the START model dedicated to evidence-based development and implementation of effective services and supports to individuals with developmental/intellectual disabilities and behavioral health care needs and their families.

Joan and her colleagues facilitate learning communities that use Zoom conferencing software to deliver a six-month course with recorded trainings and learning sessions, and as part of the Professional Learning Community (PLC). Participants receive coaching to develop local trainings in study pairs. We find cross systems learners are best. So, our communities are made up of family members, teachers, mental health, IDD and other stakeholders who all learn together to develop a local learning community. This creates important dialogue between families and others.

The communities have access to the courses offered in the PLC but also national trainings and other optional course information. We design courses to meet local needs. All trainings are updated every two years. We want to train local people including families to be trainers and we can provide materials, and guidance once PLC is complete as part of the START network.

Website: https://iod.unh.edu/projects/center-start-services

Susan O'Nell, Director of Quality Assurance & Enhancement DirectCourse RTC-CL Curriculum - Institute on Community Integration, University of Minnesota

The College of Direct Support is an online training resource with multiple modules on a range of issues affecting people with intellectual and developmental disabilities. The CDS content remains primarily focused on direct support professionals or supervisor roles at this point. However, in roughly the order of priority, the functional assessment course, the positive behavior course, and our soon to be released depression course all have child focused (as well as adult focused) content and could be very useful to parents trying to sort this

out. Other courses such as: Communication, Mental health or Autism may be helpful as well since much of this stems from processing differences and communication barriers.

Not sure how parents get the "access" to the modules/lessons as most content is purchased through large contracts. Some states like MN make this available to families but not all do.

Website: http://directcourseonline.com/direct-support/

Robert Fletcher, Ph D., President Emeritus, NADD, An Association for Individual with Developmental and Mental Health Needs.

Dr. Fletcher thinks the following NADD resources could be helpful to families with children with dual diagnoses/behavior issues:

- Comprehensive Competence-Based Parenting Assessment:
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=parenting+assessment&prd_key=4adb296a-1985-4fc6-9771-68e662c1a4ac
- Mental Health and Wellness Supports for Youth with IDD:
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=wellness&prd_key=9728775d-59cd-4d23-a505-f04736a92e46

He also suggests the following links to resources from the NADD Store, which are related to families and children and that are available on compact discs:

- Overcoming the Trials and Tribulations of Life's Transitions; a Perspective from Families
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=
 - shopping&shopsearch=1257&prd_key=2773514f-8b75-410b-b6e0-f03a130c6fdf
- Transition: Real Life Challenge and Real Life Success
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1295&prd_key=6642e1cc-bf09-455a-9155-e55e4a75f953
- Partnering with Families to Achieve Competitive Employment for Individuals with Significant Disabilities
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1291&prd_key=27377298-03d1-43a1-be91-b317c6da6b62
- The Coordinated Children's Services Initative: A Family-Centered Approach
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1096&prd_key=0eb43fd3-3316-4019-84f9-4e0b973a1f93
- The Application of Family Systems Theory to Therapy with People with ID/DD
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1206&prd_key=421b144d-ca72-4525-aa18-67a39f123494
- Finally... A Plan That Works...At ½ the Price!
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1061&prd_key=a547419e-7e0b-45fa-b75f-f43c1f03ebcd
- Best Practices in Dual Diagnosis: An Overview of Issues in Children, Adolescents and Family
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=930c&prd key=8abb04df-eea0-49fd-92e8-e0d558e1df37

- Community Support Planning
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=946c&prd_key=e3efd210-b3d9-4b96-934d-76c0f14b7a4e
- Family-Professional Collaboration in the Care of Individuals with Developmental
 Disabilities
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=791c&prd_key=f56bf672-93eb-4197-96ee-4aef7b467c74
- Therapeutic Alliances: What Helps and What Hinders From a Consumer and Family
 Perspective
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=713c&prd key=6b950748-d186-47da-bd30-7c07da41c976
- Successful Intervention Strategies with Dually Diagnosed Adolescents
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1296&prd_key=7142ebea-3946-48cb-b9e2-14e0c3523352
- Adapted CBT Group Therapy for Youth Who Have a Dual Diagnosis
 https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1281&prd_key=7608d7e1-d1e3-4282-8ab7-e0883263db8f
- The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&shopsearch=1253&prd key=2df09660-4836-4cd5-b9a5-d25b311ecc1d

Dr. Fletcher suggests that you also look at the rest of the NADD store and search for the topics that are of interest to you. If I can be of further assistance, please do not hesitate to contact me.

Ruth Luckasson, Chair, Department of Special Education, University of New Mexico

https://www.amazon.com/product-reviews/B003OSVHCK/ref=acr dpx hist 5?ie=UTF8&filterByStar=five star&showViewpoints =0 - Book called the Kazdin Method for Parenting a Defiant Child - lots of great reviews and comes with a CD