

The IDD Toolkit – Available Online for Health Care Providers and Caregivers

www.IDDtoolkit.org

The online IDD Toolkit (www.IDDtoolkit.org) offers a wealth of information for primary care providers who are treating adults with intellectual and developmental disabilities (I/DD). The website is easy to navigate and contains information that will also be very useful for families and other caregivers.

The IDD Toolkit was explained in detail at The Arc of New Jersey's 28th Annual Conference on Medical Care, by the morning Keynote Speaker, Janet Shouse, Program Coordinator for the IDD Toolkit, which was developed by the Vanderbilt Kennedy Center in Nashville, TN. The website's information is an adaptation for U.S. use of a Canadian book, "Tools for the Primary Care of People with Developmental Disabilities," (2011) which is based on consensus guidelines and has been peer-reviewed.

It is highly recommended that you visit the website to see for yourself how helpful it will be. The following is a brief summary of a few of the highlights available on the IDD Toolkit website.

The website includes **comprehensive Health Watch Tables** for persons with autism, Down syndrome, Fetal Alcohol Syndrome Disorder (FASD), Fragile X syndrome, Prader-Willi syndrome, Williams syndrome and 22q11.2 deletion syndrome. Although the [IDDtoolkit.org](http://www.IDDtoolkit.org) website states that the focus is on health care for adults with intellectual and developmental disabilities (I/DD), it should be noted that some of the valuable health watch information pertains to children also. For example, in the **Health Watch Table for individuals with Down syndrome**, *the IDD Toolkit provides "Considerations" and "Recommendations" for children and adults*, for these health systems:

1. Head, eyes, ears, nose and throat
2. Dental
3. Cardiovascular
4. Sleep
5. Respiratory
6. Gastrointestinal
7. Genitourinary
8. Sexual function
9. Musculoskeletal
10. Neurological
11. Dermatological
12. Behavioral/mental health
13. Endocrine and
14. Hematological

As a further illustration, the IDD Toolkit offers the following guidance for the Down Syndrome Health Watch, under the "**Cardiovascular**" heading:

- **“Children:** 30% - 60% have congenital heart defects. Recommendation for Newborns: Obtain an echocardiogram and refer to a cardiologist, even in the absence of physical findings.” Three additional cardiovascular recommendations are listed for children and adolescents with Down syndrome.
- **“Adults:** 50% have cardiovascular concerns, commonly acquired mitral valve prolapse (MVP) and valvular regurgitation.” Four cardiovascular recommendations are listed for adults with Down syndrome.

www.IDDtoolkit.org also has a comprehensive section on **Behavioral and Mental Health Issues** for adults with I/DD, which will be of great value to primary care physicians and to caregivers:

- Initial Management of Behavioral Crises in Primary Care
- Risk Assessment Tool for Adults with I/DD in Behavioral Crisis
- Behavioral Problems and Emotional Concerns – *Provider Checklist*
- Behavioral Problems and Emotional Concerns – *Caregiver Checklist*
- Psychiatric Symptoms and Behaviors Checklist
- ABC (Antecedent-Behavior-Consequence) Chart
- Crisis Prevention and Management Planning
- Crisis Prevention and Management Form
- Psychotropic Medication Issues
- Psychotropic Medication Checklist

It is also noteworthy that the IDD Toolkit website offers free online training for health care professionals (with free CME credit available upon completion) and also for individuals with I/DD, their families, and other caregivers.

The IDD Toolkit website was created by the Vanderbilt Kennedy Center in Nashville, TN, with credit given to the Developmental Disabilities Primary Care Initiative, Surrey Place Centre, Toronto, Canada, for developing the tools, except for the Autism table. The tools were adapted for use in the United States by the Developmental Disabilities Health Care E-Toolkit Project, which included as partners the Tennessee Department of Intellectual and Developmental Disabilities and the University of Tennessee Boling Center for Developmental Disabilities. The project was funded by a grant from the Special Hope Foundation of Palo Alto, CA.

In conclusion, www.IDDToolkit.org is an outstanding, free resource that should be widely utilized by primary care providers, families, and other caregivers who are seeking comprehensive, easy-to-access information on physical and behavioral health care for individuals with I/DD. The Arc of New Jersey extends our deep appreciation to Janet Shouse, the Program Coordinator of the IDD Toolkit, and to the others who participated in its development.