Welcome to the Pennsylvania Dual Diagnosis Direct Support Curriculum training on Communicating with the Primary Care Physician (PCP) and other Medical Specialists.
The Commonwealth of Pennsylvania’s Office of Mental Health and Substance Abuse Services (OMHSAS) and the Office of Developmental Programs (ODP) have undertaken a joint initiative to address the needs of people who have an intellectual disability as well as mental health challenges. People who have both of these challenges are commonly referred to as those who have Dual Diagnosis. For the purpose of this training, Dual Diagnosis is not referring to co-occurring mental health challenges and substance abuse or dependence, although people can have substance abuse or dependence issues as well as a Dual Diagnosis of an intellectual disability and mental health challenges. The curriculum was designed for Direct Supporters, Supports Coordinators and others who work in either the intellectual disability field or the mental health field.

The ultimate goal of this training curriculum is to provide information that can aid in the understanding of the struggles and the triumphs of those you support or will support. This curriculum was designed to demonstrate the complexity of Dual Diagnosis and the factors that need to be considered to best support those with whom you come into
contact. The Pennsylvania Dual Diagnosis Direct Support Curriculum was also designed to demonstrate that all people in this world, regardless of their challenges, are much more alike than they are different.
• The information presented to you today is to increase your awareness. It is not intended to replace medical advice.

• If you believe you or someone you support have these conditions or concerns, please seek the advice of a physician.
By the end of this presentation you will:

• Learn the role caregivers/supporters play before, during and after medical appointments
• Learn pertinent information to report to physicians and other medical specialists
• Learn the importance of documentation and the team process

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• Learn the role caregivers or supporters play before, during and after medical appointments
• Learn pertinent information to report to physicians and other medical specialists
• Learn the importance of documentation and the team process
• Communication with the healthcare professional on behalf of an individual with a dual diagnosis is important in assisting the physician to make the correct diagnosis and order the proper medications and/or treatments. Caregivers are often aware of valuable information about the individual’s health, likes/dislikes, wants/needs and behaviors, and are usually the first to be aware of any physical or behavioral changes in the individual. Information and concerns regarding the individual are communicated verbally and through documentation in their notes to other caregivers and healthcare providers.

• Effective communication between caregivers, supervisors, and healthcare providers is vital. Providing a general picture of the individual and reporting any changes observed can mean the difference between life and death in some instances. When an individual has an appointment to see a physician, it is important
that caregivers not only effectively report the necessary information to the physician, but also document the outcome of the appointment to ensure that all of the doctor’s orders are followed.
Preparation means more than just the actual appointment itself; it means preparing before the physician’s appointment, during the appointment, and even after the appointment is over.

Staff changes can greatly affect the preparation for appointments with the primary care physician. For example, if someone calls out sick, they may not be prepared or have knowledge of what is expected with the appointment, or they may not even know what kind of appointment it is. That can make us look foolish and make the doctor feel like they are wasting their time.

Payment and insurance issues can present challenges and create problems and also waste valuable appointment time. Many times, people may not have first-hand knowledge of insurance, and perhaps it is the role of someone else at the agency who did not properly inform them.

Take a moment to think about these questions:
- What are some barriers that you have encountered? How were they resolved? What preventions have you or your agency put in place?
• It is important to plan ahead in order to help everyone have a more positive experience. We all have stories to share about negative times or moments in which things were not thought out ahead of time. In order to have positive interactions all around, we need to try and ensure that peoples’ time is not being wasted – theirs and ours.

• For the person scheduling the appointment, it is important to keep the following in mind.: What is the best time for the appointment? Does the person have a communication device or use a wheelchair or walker? Does the person become anxious in a noisy or crowded environment? Will the person have more than one person accompanying them? Will the person be pre-sedated? A well prepared office visit has the most chance of success.

Please keep in mind-
• Pre-sedation of certain individuals may be needed to help manage anxiety prior to appointments. This can affect different people in various ways, and may not have the desired effect of calming a person. Sometimes it can even make things worse and can be unpredictable. We must also allow adequate time for the meds to take effect, and that is difficult if the appointment is early in the morning.
• Having the first appointment can be desirable in some cases but in other cases, it can be problematic: some individuals may not be able to get ready in time, or staffing is not adequate to manage all of the peoples’ needs who are getting up and preparing for other
appointments. We need to think ahead to what will work best for some of the people we support – morning, afternoon or other time of day.

- There are times when the allotted amount of time is simply not enough time to cover everything. We can certainly be proactive and call ahead to the provider and request more than a typical “block of time”. We may be granted this extra time if we explain how we would need this time. Time management is important in the planning and organizing while preparing for a visit to a medical specialist.

- Some of the people may need more support at the physician’s appointment and may require a second person to be present to provide additional support. This allows someone to be available to talk with the doctor and another person to provide direct support if needed to the patient.

- It is also important to plan ahead and figure out alternate routes to or from the appointment: many times there are regular routes that become blocked or there is construction, or detours. It is common when supporting those with mobility issues to have last minute things that happen to cause delays, so we should also try to leave earlier than usual. Simply planning ahead on gasoline and being sure the tank is full can relieve a good deal of stress too.
• You need to know the person you support. Know the information that you will be providing and be able to share and educate the team members regarding the information received during the visit.

• Your role is one of a health advocate – a person who assists another to navigate the health care system to address health care needs. This means:
  
  • Sharing information and documentation with the physician
  • Ensuring that the person has the communication devices to assist with their communication with the physician.
  • Directing the conversation toward the person if the physician is directing conversation towards the direct supporters. By doing this we can model inclusion and advocacy for the person.

• It is important to know the purpose of the visit. Is the objective to get an annual vaccination shot, or to complete an annual physical or check up? Would it be a good time to have other injections done, or have the current medications reviewed? Sometimes using the appointment for more than one purpose is good providing there is enough time carved out.

• The more organized and confident you are, the more relaxed you will be. The more relaxed you are, the better you will be able to support the person during the appointment.
• One thing to consider is to expect that the physician will not know anything about the person. Because of this, you will need to supply all the information.

• First, it is important to provide daily and on-going documentation of an individual’s level of activity, including appetite, bowel and bladder habits, usual behaviors and sleep patterns. If applicable, any seizure activity should be tracked and the chart or records shared. This information communicates to other providers and caregivers what an individual’s normal daily habits may be.

• Documentation is an important resource for other caregivers who may be new or working alone when there is a question concerning an individual. Documentation of what an individual’s daily habits and behaviors are can allow others to be more aware of any changes the individual may be experiencing. It is important to note any change in an individual’s routine or behavior and to communicate these changes to all staff, supervisors, as well as healthcare professionals, by writing this in an individual’s daily file, logs or chart.

• Forms should be reviewed for any changes. Discuss habits and patterns such as eating, activities, or any significant symptoms or conditions with those who need to know. Organization is key. Find out if there were any recent emergency room or urgent incidents lately. For example, an individual you support has a bad fall. Were there any test results as an outcome – x-rays, CAT scan, MRI, etc... This is especially important if you’re getting a physician involved for a second opinion.

• Before a medical appointment, speak to the individual being supported about any concerns or questions he or she may have for the doctor. Confer with other staff members regarding concerns or questions anyone else may have. Read the notes documented in the chart, and gather facts that are of concern for this appointment. It is also a good idea to write down all of the information you plan to take to the appointment.
• Please be sure to review the handouts included with this presentation. On this slide, I will be referring to the Medical Visit Check List, Family Health History Form, and the Medication Listing Log.

• Most agencies have their own medical appointment summary forms that are to be taken with an individual on every medical and/or psychiatric appointment. This form includes: an individual’s personal information, allergies, and current medications as well as the reason for the appointment. There will be an area on the form for the physician to share information. In order to prevent medication errors, it is recommended that a copy of the current Medication Administration Record be shared with the physician. It is critical that there is enhanced team communication and all must be alert for any change when a new medication is ordered.

• The person’s insurance information should always be taken to any medical appointment.

• It is important to share all history including family health history, medical health history and psycho and/or social history. You should also take a list of all the medications the person is currently taking along with a list of past medications that were prescribed. A Medication Listing Log may be helpful to the physician in determining what medications have been effective and/or ineffective in the past.

• When an individual is visiting a physician for the first time, the information may need to be more comprehensive than it would be for follow-up appointments. There should be a brief description on why the individual is being seen, as well as a description of the individual’s current signs and symptoms. This should also include the length of the most recent illness, and the treatment already given and its effectiveness. If the person is being evaluated by a specialist, the reason for the referral from the primary care physician must be communicated.
• On this slide, I will be referring to the following handouts: Bowel Movement Record, menstrual chart, peri-menopausal symptom chart, seizure chart, annual seizure summary, and health appointment log.

• It is also important to take all assessments, any charts, graphs, and other documentation which was gathered by the team to the medical appointment; also, it is helpful to make a list of all questions that the person or any team members may have for the physician.

• Healthcare providers who are specialists need and rely on certain information. They need to know the reason for the referral and any tests or lab work that might be of assistance in evaluating the individual. An example may be if someone is being evaluated by a neurologist, a copy of the seizure record should then be included along with any recent blood work or results of an electroencephalogram (EEG).

• Take a moment to think about what information should be shared with an individual’s gynecologist. Some answers could be results of the last mammogram, documentation from monthly self breast exams, date of last menses, menstrual chart, and bowel and bladder charts.
If this is a follow up appointment, the last appointment form from that particular physician should be reviewed. Many times blood work or tests have been recommended and ordered. The results of these tests should be included with information that is necessary for the physician to provide a comprehensive evaluation. Often results are sent to the physician and not to the agency. The office or the testing site can be called to have the results of the tests sent to your agency. It is important to remember that test results should always be reviewed by a physician and should never be held by an agency without being reviewed by a physician. Upon receipt of laboratory testing results, forward them to the physician. If there are any abnormal results, be sure to ask the physician about them.
• An important part of preparation is to review questions and concerns with the team. It is critical to discuss with all team members what other pertinent information needs to be shared with the physician at the appointment.

• If it is a follow up appointment, it should include information on how the person has been since the last evaluation. The physician may ask these types of questions: are there any changes? If yes, are the changes better or worse? If there has been treatment, has the treatment been effective or ineffective? They may also wonder: were all recommendations from last appointment followed? If not, why? There may also be a question about any results of tests and blood work which may be attached to the question or summary form.

• It is very important to take the time to prepare information that is pertinent to the issue being addressed at the appointment. For example, if someone is going to see a specialist for epilepsy, we know that they would be very interested in reviewing any seizure charts that staff has been tracking for that person. Certain questions have to be answered including the following:
  • What is the reason for the visit – what is the main problem for the individual being supported?
  • What do I (the individual) need to do?
  • Why is it important for me (the individual) to do this?
• Some people have a difficult time with doctor’s appointments. Unfamiliar people or places and being touched and examined by strangers can cause anxiety. Helping an individual to prepare for an appointment ahead of time can often make an examination go more smoothly for the individual, as well as for the examining healthcare professionals.

• It is important to involve the individual in the process as much as possible. This may include asking them what time of the day is best for their appointment. Finding out if they have a special activity planned that may interfere with the appointment and if the appointment may be moved to a better time. Using wall calendars or other appointment books can help keep the visit dates visible for individuals.

• When preparing an individual for a medical visit, it is important to educate them on several things: where they are going and why, and what they will encounter during the visit. Knowing in advance will help some people feel calmer, while others may prefer to wait until the morning of the visit to know about it. It is important that you allow the individual time to process the information you are sharing with them.

• An explanation about what may occur at the appointment can be done by using Social Stories. Social stories are short stories with pictures that can explain what might occur in various situations an individual may encounter. Social stories designed for medical appointments can explain
through words and pictures what might happen at a medical appointment. These stories can be helpful in making the individual feel more comfortable at the appointment. They can be developed by anyone and read to the individual a number of times before the appointment. They should include what the individual may expect – the exam itself, discussion with the physician, or equipment that will be used. Before the first visit, a phone call or form may be sent to the office to explain the needs of the individual and accommodations that may be necessary for a successful evaluation. Included is a Philadelphia Coordinated Health Care Active News issue entitled The Importance of an Annual Physical Examination.

• For some people it helps to visit the office prior to the first visit and meet staff, view equipment, etc.
• Discuss with the individual any concerns they may have. Sometimes sharing a positive experience you have had at a physicians office will help the person understand. Listen to their concerns. If necessary, get the other team members involved to assist in the education process.

• Encourage the individual to wear comfortable clothing that is loose and easy to remove and redress. Suggest the person take a quiet activity and explain that there may be a waiting time to be seen. Encourage the person to ask questions to the physician and to voice their concerns.
The individual may feel more at ease when accompanied by a supporter with whom they are most comfortable and who can reassure them throughout the examination. At the appointment, caregivers should introduce themselves and the individual to the staff and physician. They should be prepared to answer questions from the physician, especially if the individual is not able to communicate. The supporter should also be prepared to relay important information to the physician on behalf of the individual as needed.
• Be on time

• Know your person – if they have a difficult time waiting, make certain that information was shared before the appointment was scheduled

• It may seem like a simple thing, but things will go much better for everyone if the individual and supporter are on time for the appointment. Delays cause additional problems and frustration mounts since not all will be addressed adequately. Another reminder is to know the individual being supported. For example, if they have a difficult time waiting, make certain that information was shared with the medical office staff before the appointment was scheduled.
Many times the physician asks questions that the person is fully capable of answering, but directs them to the staff person or family member who is accompanying the person. Be respectful by encouraging the individual to answer questions independently. Offer additional information as needed once the individual is done speaking. As an advocate, encourage the individual to not only answer questions from the doctor, but to express concerns and ask questions about things they don’t understand.

During the appointment, it is important to share all verbal and written information. Be sure to ask questions when words are unfamiliar or the instructions are unclear. You should also ask about expected outcomes of treatment as well as the potential side effects or interactions of medications. Most physicians welcome questions to ensure optimal quality of the patient’s healthcare.

It is important to take notes during the appointment so information is accurately shared later with others. During the medical exam, an overwhelming amount of information may be given to the individual and supporter. Taking good notes, helps to prevent important instructions and medical advice from being forgotten. Writing this information down usually provides a more thorough explanation of what the physician’s findings were, as well as what the orders were for prescribing medications, treatments and/or making recommendations.

Asking the physician/nurse if you could summarize verbally what was shared, that may be a good way to determine that you understand what was shared.

Specific questions regarding the individual’s diagnosis, treatment or medication should always be obtained from the physician. If the agency has a nurse, the agency nurse will be able to assist you. The Pennsylvania Health Care Quality Units are also available for general questions.
• It may be necessary to schedule a team meeting to share the information received at the appointment. It is essential to share all information and the next appointment’s date with the other team members. It is important to have certain procedures in place to take care of after the appointment is over. Who should follow up, who makes the next appointment, and who changes the Medication Administration record?

• It is also a good idea to schedule a team meeting prior to the next scheduled appointment so that all information is obtained.

• Many doctors now use electronic file systems, and can print out many resources, as well as the office discharge planning, and other information needed to provide follow up or routine care. It is convenient now too to have e-scripts which is when the physician’s office sends prescriptions electronically to the pharmacies, making things quicker and more convenient.

• Following up with the office manager of the physician’s office after an appointment can be a helpful practice. This person can be a valuable resource to answer other questions later or
clarify issues after leaving the office.
• It is important that whichever physician the person is seeing has all the information.

• This includes sharing all information – from psychiatrist, primary care physicians, urologist, neurologist, gynecologist, etc.

• It is important that the individual’s physician has complete information. This includes sharing information from other physicians and specialists such as the psychiatrist, primary care physician, urologist, neurologist, gynecologist, etc. Direct supporters can help to insure that complete information is shared by updating all physicians.

• Please refer to the Medical Visit Checklist handout. This form can assist in making sure all necessary information has been communicated and shared with the physician.
• Although there are some differences between medical visits to address physical concerns and a mental health appointment, the preparation is the same. Both type of visits require planning and organization. During mental health appointments, it is important to distinguish between challenging behaviors and symptoms of their psychiatric diagnosis. These should be clarified to avoid confusion.

• Information for the psychiatrist should also include the individual’s personal information, diagnosis, a list of his/her current medications and dosages, any allergies to foods or medications, as well as the reason for the appointment. Other information that psychiatrists would find helpful would be a description of the individual’s usual behavior and routine activities, along with any “challenging behaviors” seen. If the individual is exhibiting a challenging behavior, then it is important to only describe exactly what is observed. Behaviors such as aggression, agitation and self injuries should be described as they are observed. It’s important to avoid using “suitcase words” such as aggressive or non-compliant.

• These words mean different things to different people. Explain what
behavior the individual is displaying when the individual is “aggressive” or “non compliant.” This will give the psychiatrist a much clearer picture of what exactly the individual is doing and what their actions may be trying to communicate at these times. Information should also include how often episodes occur, what triggers the behaviors and effective de-escalation techniques.
• In order to make every moment at the physician’s office count, share all the facts. Remember that the physician or other medical specialist’s decisions are based on the information they receive. Complete and accurate Information equals best results. Preparing forms and assisting an individual before, during and after a doctor’s appointment is one of a caregiver’s most important responsibilities in supporting someone with a dual diagnosis.

• Our role is to educate doctors and improve the communication and environment so that our people feel supported and understood. A “typical” appointment is never typical – special attention is sometimes needed, and needs to be highlighted during time of preparation and during the appointment itself. A successful appointment can be achieved with effective
communication between the healthcare provider, staff and the individual. Knowing what is important to document, report to the physician, and for the individual at the appointment, assists in ensuring quality health care for the individuals you support.
Congratulations, you have successfully completed the *Communicating with the Primary Care Physician (PCP) and other Medical Specialists* training.
Thank you for participating in the Communicating with the Primary Care Physician (PCP) and other Medical Specialists presentation.