

# Supporting Parents at the Time of Their Child's Disability Diagnosis: A Resource Guide for Providers



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Maryland Center for Developmental Disabilities  
at Kennedy Krieger Institute  
*Building Partnerships. Changing Lives.*

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# Overview and Guide Development

**PROGRAM OVERVIEW:** The Community and Professional Development Training Program at the Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute is committed to supporting and enhancing professional development opportunities for professionals and community members, and expanding their knowledge and skills to engage in effective advocacy, in order to improve the quality of life for people with disabilities and their families.

**RESOURCE GUIDE DEVELOPMENT:** This resource guide is designed to help providers find information and guidance for supporting parents and caregivers at the time of their child's disability diagnosis and beyond. The development of this resource guide was supported by an extensive review of scientific literature and available resources that summarize the most relevant research related to supporting parents at the time of their child's disability diagnosis, in consultation with providers and parents raising children with disabilities. Lessons learned are presented in this resource guide.

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**DISCLAIMER:** The views and opinions expressed in this resource guide are those of the authors and do not necessarily represent the views and opinions of the Maryland Center for Developmental Disabilities and Kennedy Krieger Institute. Healthcare professionals and others using this guide should review and apply its recommendations according to their specific practice needs and goals.



# Introduction

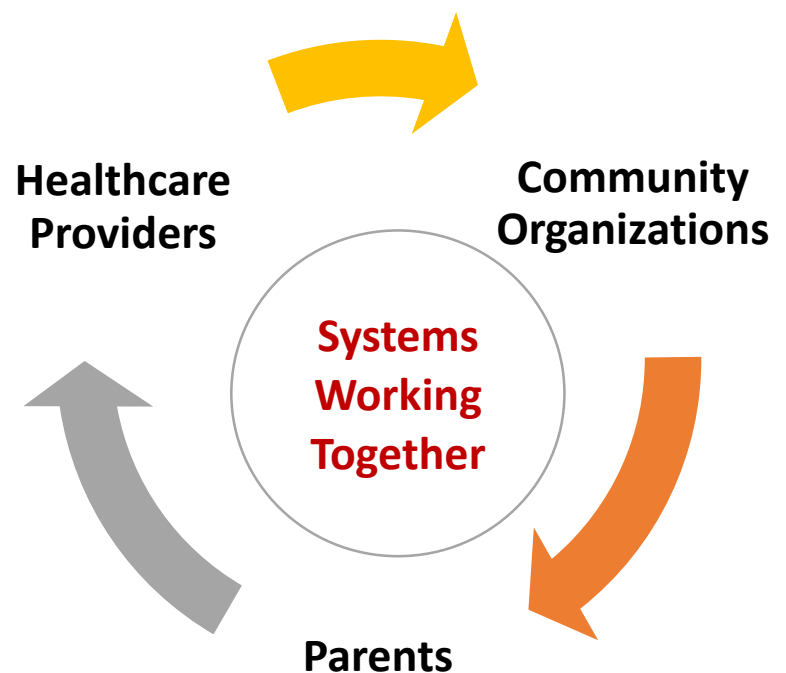
There is strong evidence in the literature on the need to support parents and provide them with accurate and timely information and resources at the time of their child's disability diagnosis. When a diagnosis is delivered insensitively, it increases levels of distress, anger and depression; has a lasting impact on parental coping and increases the risk of litigation (Novak et al., 2019).

During the initial disability diagnosis of a child, parents and families experience different types of emotions, including guilt, uncertainty, rejection and denial. After the diagnosis, they may face many obstacles, including not being able to easily access accurate information from providers. It is important for healthcare providers to have the training and specific skills required to deliver a disability diagnosis to parents and families (Novak et al., 2019; Hill et al., 2003).

Relationships between parents and professionals are vital for the overall health outcome of children with disabilities following their initial diagnosis (Ryan & Quinlan, 2018).

Supporting parents at the time of their child's disability diagnosis requires a multifaceted approach where parents, healthcare providers and community organizations work together.

Presenting information regarding the diagnostic process and prognosis in a way that can be understood is vital. It helps improve the outcome, avoids confusion and distress, and increases the satisfaction of speaking with other healthcare professionals (Sweeny et al., 2007).



## Why Should Providers Review This Guide?

Communicating a child's disability diagnosis to a parent can be stressful for providers, as the diagnosis can have a profound impact on both child and parent health outcomes.

Healthcare providers who adapt evidence-supported diagnosis delivery protocols and culturally responsive care can better support parents at the time of their child's initial disability diagnosis

Showing compassion and providing acknowledgment and support during interactions and diagnosis delivery has a positive impact on parental response to diagnosis delivery (Sweeny et al., 2007).



When physicians communicate the diagnosis in a more comfortable and confident way, parents perceive them as being trustworthy and are more willing to comply with treatment recommendations (Sweeny et al., 2007).

# Consequences of Poor Diagnosis Delivery

## ❖ Impact on Healthcare Providers, Parents and Systems:

### Stress and Anxiety

- Providers feel stressed and anxious while delivering a diagnosis of disability to parents (Sweeny et al., 2007; Aoun et al., 2018).

### Physician/Clinician Burnout

- Lack of training in diagnosis delivery and communication can lead to provider burnout, thus making things more difficult for both the provider and the parents (Chipidza et al., 2015; Sweeny et al., 2007).
- Affects providers' emotional and functional state of mind (Chipidza et al., 2015)



### Complicated Process

- Lack of support during a diagnosis delivery can make the process difficult and leads to a negative experience and lack of collaborative engagement (Aoun et al., 2018; Fitzgerald et al., 2021). It also takes a toll on the mental and physical health of the parents and the child (Gilson, 2017).

### Delayed Diagnosis

- Causes a delay in the diagnostic process, delayed initiation of treatment and leads to disease/symptom progression (Abott et al., 2012; Gautam et al., 2019).
- Leads to a delay in care planning. For example, making choices regarding reproductive health, treatment planning, etc. (Rowland et al., 2013)

### Uncertainty

- Parents feel uncertain about what to expect in the future, and with the lack of a roadmap, they get overwhelmed (Fitzgerald et al., 2021).
- Parents receive confusing, misleading and out-of-date information due to lack of provider knowledge, thus leading to more uncertainty (Hill et al., 2003).

### Overuse of Services

- Child and the parents visit multiple providers and undergo multiple diagnostic tests to get more satisfactory answers related to the diagnosis (Abott et al., 2012; Aoun et al., 2018). This puts a burden not only on the family but on the system.

### Unwanted Guilt

- Parents feel guilty and think that the disability is their fault due to the stigma and cultural beliefs associated with the diagnosis (Kayrouz et al., 2017).



# Definition of Terms

## What is Support?

- Support is a psychological construct referring to the pattern and intensity of supports necessary for a person and family to participate in activities linked with normative human functioning (Thompson et al., 2009).
- It is a means of providing comfort, encouragement, assistance to help others succeed and achieve their life goals.

## What is an Effective Support System?

- An effective support system is a system that provides emotional, social and environmental support to the individual and family as a whole according to their beliefs and cultural norms (Knapp et al., 2010; Wehmeyer et al., 2016; Selick et al., 2017).
- It is also referred to as a team of individuals, professionals and organizations that comes together to ensure a great quality of life for an individual with disabilities.

## What is Parental Support?

- Parental support is the way parents of children with disabilities are able to find and carry through with care needs in order to enhance their child's quality of life (Resch et al., 2010).

## Who are Keyworkers/ Key Stakeholders?

- Keyworkers or key stakeholders are those who enhance communication between parents of children with disabilities and healthcare providers (Ryan & Quinlan, 2018). For example, psychologists, social workers, educators, case managers, physicians, nurses, clinic staff, parents and families.



# Common Types of Support Services

## Information Support Services

- Services to help parents gather additional information related to the disability (example: providing parents with information about the diagnostic process and prognosis related to the disability) (UNC, 2020)

## Case Management Services

- Defined as “a range of services provided to assist and support individuals in developing their skills to gain access to needed medical, behavioral health, housing, employment, social, educational and other services essential to meeting basic human services” (NASMHPD, 2021).
- This also includes providing linkages and training to the patients for use of basic community resources and monitoring of the overall service delivery (NASMHPD, 2021).

## Social Services Support

- Services that help provide information about various ongoing programs (example: providing information regarding Temporary Assistance for Needy Families (TANF), Head Start, childcare and child support services (HHS, 2020))

## Environmental Support Services

- Services that provide information regarding a child’s daily needs (example: daily medical care or daily living supports) or daily family needs (example: respite care or care for siblings) (Resch et al., 2010)

## Therapeutic Support Services

- These are a set of health services developed to provide rehabilitative interventions to the children and their families who require varying levels of intervention in their homes or elsewhere in the community.



# Why Engage in Self-Reflective Practice?

- Providers should be aware of any biases or beliefs that might influence their decision-making or communicating with the parents during a diagnosis delivery. The “**ouR HOPE**” approach by Racine et al., 2016, can help providers as they engage in reflective practice.
- The five principles of the “**ouR HOPE**” approach are **R**-Reflection, **H**-Humility, **O**-Open-mindedness, **P**-Partnership, **E**-Engagement.

## 1. Reflection:

- Focus on self-examination to consider your own beliefs and attitudes.
- Be open to unexpected parental questions related to their own beliefs.
- Be aware not to impose your own understanding of what is a good outcome for the child.

## 2. Humility:

- Have a modest and non-judgmental attitude.
- Give an honest self-disclosure of the uncertainty of a diagnosis.
- Adjust the communication style and avoid arrogance.

## 3. Open-mindedness:

- Be receptive to the values and beliefs of culturally diverse groups.
- Maintain an open outlook for every case (different people will have different potential narratives).

## 4. Partnership:

- Practice and promote collaborative and family-oriented “shared decision-making”.

## 5. Engagement:

- Be fully engaged with the family during the diagnosis delivery.



# Barriers and Facilitators

## Barriers

- **Cultural Beliefs:** Varying attitudes and beliefs related to disability can impact outcomes (Brown et al., 2017; Fitzgerald et al., 2021).
- **Cultural Awareness:** Parents expressed that there is a lack of cultural awareness among health professionals and organizations (Alsharaydeh, 2019). Some professionals are not aware of traditions and rules within specific cultures.
- **Social Stigma:** Stigma related to disability makes the parents feel embarrassed, ashamed and/or unsure of how to explain their child's diagnosis to family, other relatives and community members (Jacobs et al., 2020). If stigma is not addressed, some parents may avoid accessing healthcare and other social services supports in fear of social exclusion and isolation (Alsharaydeh, 2019).
- **Financial Issues:** The socio-economic status of parents caring for a child with disabilities may hinder their ability to acquire necessary information and services and utilize recommended services. The result is perceived unmet needs (Mendes, 2016; Ryan & Quinlan, 2018).
- **Lack of Collaboration:** Poor collaboration among various agencies further complicates the access to information and resources that are needed by parents to support their children with disabilities (Resch, 2010).
- **Lack of Transportation Services:** Due to regular healthcare appointments, transportation is a challenge (Mendes, 2016).

## Facilitators

- Demonstrate an understanding of cultural health beliefs and use **culturally acceptable intervention** and treatment measures (Brown et al., 2017; Tuffrey-Wijney et al., 2017).



- Provide information related to the diagnosis and the diagnostic process in **"layman's"** language (Brown et al., 2017; Fitzgerald et al., 2021).
- Provide reassurance and help connect families with other parents who have children with similar conditions (Aoun et al., 2018; Jacobs et al., 2020; Racine et al., 2016).
- Offer to explain the diagnosis to other family and community members.
- Assess for financial needs and offer resources that can assist the family with meeting their financial needs. Follow up with family to ensure that they were able to connect with the resources provided.
- Healthcare providers and community organizations should collaborate on how parents can effectively access up-to-date information as they care for and support their child with disabilities
- Ensure that parents can access available transportation services including those provided by the government and other public agencies, for people with disabilities as needed.



# Barriers and Facilitators Cont'd

## Barriers

- **Poor Communication and Educational Needs of Parents:** Communication between parents and clinicians causes stress due to the amount of medical jargon used, and parents have difficulty understanding the diagnosis (Ryan & Quinlan, 2018).
- **Differences in Spoken Language:** Some parents who were not proficient in speaking English considered medical jargon used by healthcare professionals to be incomprehensible. This caused parents not to use necessary support (Alsharaydeh, 2019).
- **Inadequate Session Structure:** Diagnosis delivery over the phone, short sessions and providing a load of information over short sessions (Ahmann, 1998; Abbott et al., 2012; Aoun et al., 2018; Mooren et al., 2014)



- **Lack of Resources:** After the diagnosis delivery, parents were not provided with adequate information and resources to navigate through the system, and little attention was paid to mental health resources for both the parents and the child (Gautam et al., 2019; Gilson et al., 2017; Aoun et al., 2018).

## Facilitators

- Provide **written assessment** reports, preferably in the family's vernacular language and with a pictorial description of the diagnosis, if possible (Abbott et al., 2012; Novak et al., 2019; Portnoy et al., 2011; Racine et al., 2016).
- Follow the parents' lead, emphasize **“shared decision making”** and always try to **“offer additional information”** and not provide information (Abbott et al., 2012; Novak et al., 2019; Portnoy et al., 2011; Racine et al., 2016).
- Appoint keyworkers or key stakeholders who are a point of contact between parents and healthcare providers and will serve to enhance communication.
- Healthcare providers should be present during the diagnosis delivery (Rowland et al., 2013).
- The diagnosis delivery should always be done **in person** (Ahmann, 1998).
- Sessions should be arranged in a quiet place, with no distractions (Novak et al., 2019).
- Provide **multiple sessions** to allow time for information processing and questions, and **invite both the parents and the child** (Abbott et al., 2012; Mooren et al., 2014).
- Provide a list of **accessible resources**, guidance on how to navigate the system, clear information regarding the prognosis of the condition and what to expect in the future (Jacobs et al., 2020; Abbott et al., 2012; Racine et al., 2016).
- Raise awareness about parents joining support groups (Alsharaydeh et al., 2019; Clifford et al., 2016).



# Recommendations for Before & During Diagnosis Delivery

## Session Structure

- Consider when it is convenient, where and how to deliver the diagnosis to the patient and their family.
- Ensure that the diagnosis delivery is done in person and with no interruptions. Allow ample time for the meeting.
- Consider what type of specific information the parents would want at the time of the diagnosis delivery.
- Individualize the diagnosis delivery session by making sure that both the parents/caregivers and the child are present during the session (Hill et al., 2003).

## Advance Preparation

- Prepare for communicating the diagnosis to the parents and show empathy, sensitivity and compassion when giving the information to the parents (Sweeny et al., 2007).
- Give a warning to the family, as it helps to lessen the shock and distress of the news (Porensky et al., 2016)

## Provide Information Packs

- Healthcare professionals involved in providing care to the family and the child should provide resources for parents that include information about the condition, signs of complications and what to expect as the child gets older (Hill et al., 2003).

## Provide Support/Mental Health Support

- Healthcare professionals should offer support and let the parents know that their child's disability was not their fault (Hill et al., 2003).
- Allow the parents to express their emotions after receiving the diagnosis and help them put the situation into perspective (Sweeny et al., 2007).
- Ensure that the parents, child and family are mentally ready to hear and understand what you have to share about the diagnosis (Rowland et al., 2013).

## Provide Clarification

- Look for signs of confusion among parents in understanding the information and proceed to clarify, check for understanding and summarize the information presented (Sweeny et al., 2007).
- Provide information about the likelihood of an intellectual and/or developmental disability early (Strauss et al., 1995).

## Share Positive News

- Share positive aspects of the child along with other information regarding the prognosis (Ahmann, 1998). For example, if the child can participate in sports, attend school, gain employment, or live independently.

## Provide Up-to-Date Information to Parents and Other Care Providers

- Up-to-date information on the diagnosis, treatment options, community resources, and referrals should be available to parents and to other care providers within the clinic as they all play an important role in providing the initial and ongoing care needs of the child (Ahmann, 1988).



# Recommendations for After Diagnosis Delivery

## Advise Parents to Disclose Diagnosis to Child

- A diagnosis of the disability should be disclosed to the child early. Disability diagnosis news can be given to the child gradually over longer periods of time, as it provides the child with developmentally appropriate information and helps the child to understand the information better (Rowland et al., 2013).
- Not disclosing the diagnosis could affect the child's mental health, delay potential future care obligations, reproductive choices and limitations, and create family conflict, which can affect the self-esteem of the child (Rowland et al., 2013).

## Provide Information and Resources

- Parents and families need information about the diagnosis, treatment, healthcare and service plans, daily caregiving needs, equipment needed to provide care, available supports, future expectations, how to explain the disability to others, and the effects of the disability on the child and their family (Novak et al., 2019).

## Disclose Genetic Risks

- Risks related to the disability should be disclosed to both the child and the parents to prevent future problems and misunderstandings (Rowland et al., 2013).

## Provide Timely Referrals

- The child and the parents should be provided with referrals, according to their mental, emotional and physical health needs (Ahmann, 1998).

## Resolve Unwanted Thoughts and Feelings

- Address unresolved thoughts regarding the diagnosis that interfere with parent-child interactions (Schuengel et al., 2009).
- Be aware of elements of resolution, which include recognition of change since diagnosis, assertion of moving on in life, realistic representation of a child's abilities and balanced statements regarding the benefits of the experience (Schuengel et al., 2009)

## Set up a Team of Professionals

- Have a team of professionals such as a pediatrician, general practitioner, gynecologist and geneticist, explain the diagnosis to the family (Hill et al., 2003).

## Appoint Family "Keyworker" or Community Link Team (CLT)

- CLTs provide information, emotional support, and act as a liaison between the family and the provider. Consistent contact with the CLT helps improve knowledge and access to services and resources (Rahi et al., 2004).

## Connect Parents to Support Groups

- Connecting with families who have a child with the same disability has been proven to be very beneficial for both the parents and the child. It provides parents and families with emotional support (Strauss et. al., 1995).



# Role of Culture

## What is Cultural Competence?

- It is defined as “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices and attitudes used in appropriate cultural settings to increase the quality of services; thereby producing better outcomes” (CDC, 2019).

## What are Cultural Attitudes and Cultural Beliefs?

- Cultural beliefs are the beliefs that are learned and shared across a group of people.
- Cultural attitude is the way a person who belongs to a particular society or culture thinks. They have their own formed ways of living and thinking (CDC, 2021).

## What is Meant by the Health Belief Model (HBM)?

- The HBM suggests that a person’s belief in an illness or disease, together with a person’s belief in the effectiveness of the recommended health behavior or action, will predict the likelihood that the person will adopt the behavior related to the desire to avoid illness or the belief that a specific health action will prevent, or cure, illness (LaMorte, 2019). The six constructs of the HBM are:
- **Perceived susceptibility** - This refers to a person’s subjective perception of the risk of acquiring an illness or disease.
- **Perceived severity** - This refers to a person’s feelings on the seriousness of contracting a disease or illness.
- **Perceived benefits** - This refers to a person’s perception of the effectiveness of various actions available to reduce the threat of illness or disease (or to cure an illness or disease).
- **Perceived barriers** - This refers to a person’s feelings on the obstacles to performing a recommended health action. The person weighs the effectiveness of the actions against the perceptions that it may be expensive, have side effects, painful, time-consuming, or inconvenient.
- **Cue to action** - This is the stimulus needed to trigger the decision-making process to accept a recommended health action.
- **Self-efficacy** - This refers to the level of a person’s confidence in his or her ability to successfully perform a behavior.





# Role of Culture in Diagnosis Delivery

## What is the Role of Family in Providing Culturally Competent Care?

- During the delivery of a disability diagnosis, it is appreciated when both the parents and the child are present.
- Family members can help with (AASW, 2016; HHS, 2020):
  - **Capacity Building** - Work with healthcare professionals to help understand the needs and challenges of the family and the child with a disability.
  - **Service Management, Care Coordination and Case Management** - Coordinate support, engage with multi-disciplinary teams and help in effective decision-making.
  - **Advocacy** - Help advocate on behalf of the child with a disability diagnosis.
  - **Counseling and Therapeutics** - Help adjust plans related to the disability and therapeutic requirements according to the family dynamics.
  - **Health, Cultural and Personal Beliefs** - Family members help understand beliefs that might affect health-seeking behaviors.

## What is the Importance of Culturally Competent Care in Diagnosis Delivery?

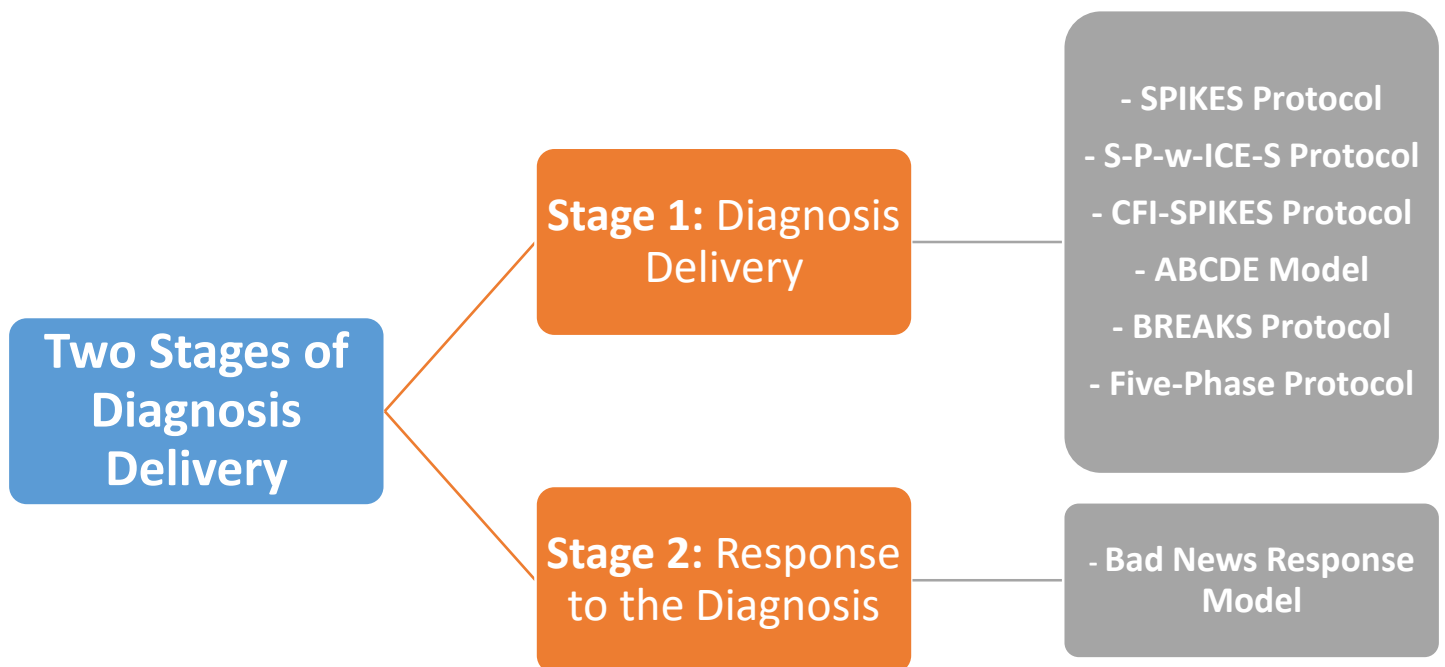
- To improve the accessibility and effectiveness of healthcare services for people from various racial/ethnic backgrounds (Truong et al., 2014)
- To improve the quality of healthcare and the diagnosis delivery (Truong et al., 2018)
- To be able to demonstrate an understanding of individual cultural health beliefs and practices during a diagnosis delivery (Brown et al., 2017; Tuffrey-Wijney et al., 2017)
- To be able to build a stronger parent-clinician relationship
- To have collaborative engagement and shared decision-making (Abott et al., 2012)
- To be able to provide culturally sensitive and family-centered treatment options

## Considerations for Providers While Providing Culturally Competent Care

- Acknowledge the presence of family members.
- Organize sessions with family members at regular intervals (Gautam, 2019)
- Be considerate of the cultural values and beliefs of family members before planning intervention and treatment (Abott et al., 2012; Brown et al., 2017)
- Help bridge different views related to the disability (Gautam, 2019)
- Understand and address the barriers that arise due to cultural beliefs and lack of understanding (Abott et al., 2012; Brown et al., 2017)
- Help with culturally competent care coordination and case management (Brown et al., 2017)

# Evidence-Based Practice Models

- The following evidence-based models were identified during the scientific literature review, which can be further divided into two stages:
- **STAGE 1:** Models for diagnosis delivery
  - The first stage involves giving the diagnostic news using the diagnosis delivery models (Novak et al., 2019).
- **STAGE 2:** Model for response to diagnosis
  - The second stage involves guiding the parents toward the desired response of “active change” and “acceptance” of their child’s disability diagnosis using the Bad News Response Model (Novak et. al., 2019).





# Diagnosis Delivery Model I: SPIKES Protocol

The **SPIKES** protocol was developed by Bailey et al. (2000) as an oncology-based protocol for the delivery of a cancer diagnosis. It is a **six-step** protocol for providing information to patients and their families (Novak et al., 2019; Porensky et al., 2016; Aoun et al., 2018).

## S- Setting up the Interview

- **Secure** a quiet environment, with at least two face-to-face sessions, where both the parents and the child are present (Novak et al., 2019; Mooren et al., 2014).
- Provide positive feedback and personalized and individualized information.

## P- Assessing the Family's Perception

- Try to assess the family's perception and ask open-ended questions to determine how much they know about the diagnosis, answering questions about the unknown.
- Parents want honest, specific information, and to be involved in the management of care.

## I-Obtaining the Family's Invitation

- Provide an invitation to respond to parents' requests regarding more information.
- State that, as the healthcare provider, you are willing to listen to parents' questions now and later, and will answer openly and honestly.

## K-Giving Knowledge and Information to the Family

- Provide knowledge about the diagnosis, prognosis, support and healthcare services during the session.
- Use simple and jargon-free language in a hopeful, empathetic and supportive tone and provide written information so that the diagnosis can be easily reviewed.

## E-Addressing the Family's Emotions with Empathic Responses

- Allow the parents to discuss their feelings/emotions and respond empathetically, observe and name the emotions, and identify the reasons for the emotions.
- Parents report better coping and more satisfaction with the disclosure process when they discuss their feelings with the provider.

## S-Strategy and Summary

- Work together with the parents and focus on "shared decision-making" (Portnoy et al., 2011; Racine et al., 2016).
- Check with the family and see if they are ready to discuss and start formulating treatment plans, and support plans to promote long-term coping.
- Provide family support and ways to navigate the healthcare system as a part of the treatment plan.
- Appoint keyworkers to help families navigate the service system.

## Diagnosis Delivery Model II: S-P-w-ICE-S Protocol

During a diagnosis delivery, challenges faced with the clarity, order of protocol components (e.g., Invitation) and flow of managing the encounter led to the S-P-w-ICE-S protocol, a revision of the SPIKES protocol. This protocol is also suitable for a diagnosis delivery via phone or video (example: during the COVID-19 pandemic) (Meitar et al., 2021).

Twelve tips for healthcare providers/clinicians are as follows:

### Tip 1- Prepare Yourself

- Before the diagnosis delivery, pay attention to the information being delivered.
- Be mindful of the emotions of the parents.
- Reflect on your past experiences, attitudes, beliefs, culture and biases that might impact communication.
- Reflect on your emotional challenges, information gaps and the choice of strategy to deal with the challenge.
- Adjust the timing of the conversation, wording and who will be present along with the provider (social worker, nurse, etc.).

### Tip 2- Prepare the Patient

- A diagnosis delivery is not a single encounter, and the process begins when symptoms appear and lab results require further investigation.
- Begin early to understand the preferences and communication style that is suitable for the family.
- Be mindful of new preferences expressed verbally and non-verbally during sessions.
- When circumstances are not favorable for a diagnosis delivery, S-P-w-I-C-E-S protocol **tips 3-10** are helpful.

### Tip 3- S- Setting

- Make the parents and the child feel cared for and respected.
- Provide a quiet setting, allocate enough time without interruptions, sit down at eye level with tissues at hand, etc.
- During a diagnosis delivery in a hectic ER environment, via phone or telemedicine conversations, be aware and pay attention to detail. For example, when sharing the news by phone, you should check the whereabouts and situation. People are sometimes engaged in activities inappropriate for receiving a diagnosis (e.g., while driving or caring for a baby or frail person).
- Do not assume that the presence of loved ones is the preferred option.
- Identify the legal guardian of the child and be sensitive to other family issues that possibly affect the decision of who receives the medical information of the child.

#### Tip 4- P- Preparation to Identify Gaps

- Create a safe environment by building trust at the beginning.
- Understand the perceptions regarding the medical condition and its possible present and future implications, which helps to identify gaps between how the patient/family perceives the medical situation versus the actual condition and its implications.
- Adjust the quantity and quality of information conveyed, tone, chosen words, pace and gestures.
- Repeat important pieces of medical history, test results or issues previously discussed, to help the family make sense of the course of events.

#### Tip 5- w- Warning Call & Pause

- A transition stage, from listening and gathering information to sharing the diagnosis. In this stage, the news is **not actually shared yet**.
- Choose the words for the warning call carefully; prepare the recipients, mentally, emotionally and physically that news related to the diagnosis is coming; and capture attention without overwhelming the parents and the family members.
- The warning call is a point of no return and carries a short message/warning.
- A short pause must follow the warning call, allowing time to brace for what is coming next.

#### Tip 6- Ongoing Juggling between Providing Information, Clarifying and Dealing with Emotions - ICE

- The next three stages require sensitive juggling.
- The stages occur concurrently: providing **Information**, **Clarifying** informational needs and cognitive and emotional availability and dealing with **Emotions**.
- Make frequent shifts in the ICE component order, according to the patient's and family's reactions and needs.

#### Tip 7- I- Providing Information

- Use simple, clear words; avoid jargon; and use a step-wise approach that will help families absorb the information better.
- Use a flexible pace, and space for silence breaks to allow for questions and the expression of emotions.
- Share information regarding the name of the disease or condition and its connection to the symptoms or the meaning of the lab/imaging results.
- Explanatory words, drawings, sketches, pictures or images should be adjusted to individual family needs, with an option to record the conversation for future reference.
- Be mindful that everyone has a limited ability to absorb new information at any given time, especially when they feel emotionally overwhelmed.

### Tip 8- C- Clarifying Information and Needs Comprehension

- Provide clarification and regularly check-in with families to ensure that they understood what was shared about the diagnosis.
- Allow for cognitive digestion.
- Adjust the amount and content of information given to the needs of all those present during the session, and assess the need for more clarification and understanding.
- Give invitations to ask questions.

In the original SPIKES protocol, “**Clarification**” was referred to as “**Invitation**” and was located earlier in the protocol before sharing the news. Physicians found this confusing, since it is impossible to address information needs before giving any indication of the topic of discussion.

### Tip 9- Exploring Emotions and Providing Empathy

- Emotions and their expression differ among people and may take various forms, and emotional expressions are very much culture dependent.
- Identify, explore and actively address emotions during the entire diagnosis delivery session, as part of relationship building and trust.
- Be aware that the diagnosis delivery will evoke strong emotions, even if they are not expressed.

### Tip 10- Share Possible Strategy, Summarize and Support

- Focus on planning for the near future.
- Clarify whether the parents and the family members are ready to proceed to discuss treatment options or defer the discussion to a different session.
- Impose treatment option discussion at this point only if it is a medical emergency requiring on-the-spot decisions.
- Assess the parents’ and the family’s decision-making ability and if their current emotional state will allow for effective discussion.
- Provide a clear, general picture of what life will look like in the near future, and a clear understanding of the current, realistic, possibly achievable goal/s.
- Provide support to families as they think through how to break the news to the child or other family members in the near future or refer them to another staff member who can better support them during this process.

### Tip 11- Document the Conversation and Update

- At times, conversations take unexpected turns and issues planned for discussion are not always discussed. This requires documentation, including the documentation of important topics to raise next time.
- Helps prevent other health professionals from mentioning topics as yet unknown to the parents and the family

### Tip 12- Reflection, Processing and Setting a plan for the next encounter

- A diagnosis delivery takes an emotional toll on everyone involved in the process, including the breaker of the news (healthcare providers/clinicians), who must allow themselves time and space to reflect critically on the encounter. This process is necessary for continuous professional growth and for maintaining their own well-being.

## Diagnosis Delivery Model III: CFI-SPIKES Protocol

The DSM-5 Cultural Formulation Interview (CFI) and SPIKES protocol were integrated to create the **CFI-SPIKES** protocol, which is helpful for communicating a disability diagnosis to parents from culturally and linguistically diverse (CALD) backgrounds (Kayrouz et. al., 2017).

- The CFI-SPIKES protocol helps the CALD patient and the practitioner to address the stigma associated with communicating a diagnosis, ensuring patient engagement and informed shared decision-making.
- The CFI is applied at step 2 in the SPIKES protocol (**P**- Assessing the Family's **P**erception) to obtain a thorough understanding of the patient's stigma associated with the illness.
- The CFI helps the provider to access the following:



- Cultural definition of the problem
- Cultural perceptions related to the diagnosis
- Stressors and supports that make the prognosis worse or better
- Role of cultural identity that makes the situation worse or better
- Cultural factors that affect self-coping and help-seeking
- Barriers to accessing treatment
- Cultural factors that affect help-seeking and treatment preferences



# Diagnosis Delivery Model IV: ABCDE Model

The ABCDE model, by Rabow and McPhee (1999), focuses on how clinicians can deliver the diagnosis more effectively, with a focus on the setting, words used and attitude.

## A-Advance Preparation

- Decide what words to use.
- Prepare emotionally and practice news delivery.
- Arrange for the presence of a support person/family members.
- Ask the parents what they already know about the diagnosis.

## B-Build a Therapeutic Environment/Relationship

- Arrange a quiet place without interruptions.
- Provide adequate seating for all.
- Reassure about pain and suffering.

## C-Communicate Well

- Be direct.
- Do not use jargon or euphemisms.
- Ask them to repeat their understanding of the news.
- Provide the diagnosis in writing.
- Allow for silence.

## D-Deal with Family Reactions

- Listen actively and empathetically.
- Assess physiological reactions: flight/fight, conversation/withdrawal.
- Assess cognitive coping strategies: denial, blame, intellectualization, disbelief.
- Assess affective responses: anger, rage, guilt, sadness, helplessness.

## E-Encourage and Validate Emotions

- Reflect back emotions.
- Evaluate the effects of the news and explore what the news means to the family.
- Offer to deliver the news to other family members on their behalf.
- Process your own feelings.
- Arrange follow-up meetings and provide timely referrals.
- Address the immediate needs of the family and the child and work on the near-term plans and treatment choices.



# Diagnosis Delivery Model V: BREAKS Protocol

After the ABCDE and the SPIKES diagnosis delivery models, another protocol called “BREAKS” was proposed by Narayanan (2010). See BREAKS protocol description below.

## B-Be Aware of the Family and the Disease Background

- The clinician must be aware of the family background, education level and support system at the time of the diagnosis delivery.
- Be considerate of the cultural and ethnic background, as thinking and actions greatly depend upon cultural beliefs .
- Be aware of the child’s disease status, family’s emotional state and education level, coping skills and the support system available.

## R-Build a Good Rapport with Family

- Having a hostile attitude has a bad outcome on the parent-clinician relationship.
- Allow the parents to inquire about the diagnosis through open questions and try to respond to the questions without any jargon.

## E-Explore What the Family Already Knows

- Try to explore what the family already knows about the diagnosis and start from there.
- Explore family history, what the parents think about the diagnosis, and the potential conflicts between the parents’ beliefs and the diagnosis, family dynamics and coping mechanisms.
- Do not jump to premature offer of reassurance, which occurs when a physician responds to the parents’ concerns with reassurance before exploring and understanding the concerns.

## A-Announce and Give a Warning Shot

- Give a warning shot before the disclosure of a diagnosis and get consent before a diagnosis delivery.
- The announcement of the diagnosis must be in straightforward terms. Avoid medical jargon, elaborate explanations (a rule of thumb: do not give more than three pieces of information at a time).

## K-Kindling

- Ensure that the parents listen to what is being said, because people listen to diagnosis delivery differently and provide supportive space for emotional expression.
- While trying to kindle the emotions, care should be taken not to mention any unrealistic treatment options.
- Be aware of differential listening; at times, parents will listen only to information that they want to hear.

## S-Summarize the Session

- Summarize what was discussed and concerns expressed by the parents during the session.
- If possible, provide summaries in writing and reassure parents of your plan to actively participate in their child's ongoing care plan.



# Diagnosis Delivery Model VI: Five-Phase Protocol

The Five-Phase protocol was designed to help physicians facilitate the process of a diagnosis delivery (Fine, 1991).

## Phase 1-Preparation

- Establish appropriate space.
- Be sensitive to the parents' needs.
- Be sensitive to cultural and religious values.
- Be specific about the goal (Monden et al., 2016).

## Phase 2-Information Acquisition

- Ask parents what they already know.
- Ask how much they want to know.
- Ask what they believe about the condition (Monden et al., 2016).

## Phase 3-Information Sharing

- Re-evaluate your agenda and teach (Monden et al., 2016).

## Phase 4-Information Reception

- Allow for assessing the information reception.
- Clarify any miscommunication.
- Handle disagreements courteously (Monden et al., 2016).

## Phase 5-Response

- Identify and acknowledge the parents' response to the information.
- Close the interview (Monden et al., 2016).





# Response to Diagnosis: Bad News Response Model

- After the first stage of a diagnosis delivery using the evidence-based protocol, the second stage is to guide the parents toward “active change” and “acceptance” using the Bad News Response model (Novak et al., 2019).
- The **Bad News Response model** suggests how parents can respond to news of a diagnosis, with the goal of fostering long-term adaptive responses (Novak et al., 2019).

## Watchful Waiting

- Clinicians and parents “wait and see” if the child develops a disability (Novak et al., 2019). Parents should be aware of the risks of waiting.
- Emotion-focused coping methods create distraction from the diagnosis.
- New evidence suggests that child outcomes can be improved by harnessing neuroplasticity, and it is time for a shift from watchful waiting to active change.

## Active Change

- Teach and show parents how to actively adapt to the diagnosis, provide information about evidence-based treatment options (Novak et al., 2019).
- Establish a support network, raise awareness about the child’s needs, empower families’ decision-making, connect recipients to other families with similar diagnoses.
- Take steps to prevent a deterioration of the condition.
- Instigate treatment and create routines to improve the child’s development.

## Acceptance

- Accept the disability diagnosis and “spend the energy moving forward” (Novak et al., 2019).
- Share information, help the family accept their social reality, elicit support from friends and family.
- Accommodate and incorporate the child’s diagnosis into daily life, adjust for the future, help build relationships with healthcare professionals.
- Listen to the family’s concerns, openly discuss hopes and goals, focus on ways to help the child, avoid labeling the child and refer to the child by name.

## Non-responding

- Four forms of non-responding include denial (disagreement with the diagnosis), disbelief (confusion related to the diagnosis rather than denial), deferral (avoidance of the diagnostic news), and dismissal (anger toward the healthcare provider) (Sweeny et al., 2007).
- Denial is a defense mechanism (disagreement when evidence is clear).
- Deferral is avoidance as a result of inadequate resources to cope.



# Helpful Resources

## ❖ **American Association of Family Physicians: How to Deliver Bad News**

This article offers evidence-based tips and methods that review the best ways to deliver and discuss bad news with patients and their families.

<https://www.aafp.org/afp/2018/0715/p99.html#:~:text=When%20delivering%20bad%20news%2C%20respond%20to%20patients%27%20emotions,courses%20to%20improve%20skills%20in%20delivering%20bad%20news>

## ❖ **CDC Disability and Health Information for Caregivers**

This page discusses caregiving and self-care tips for people taking care of children with disabilities. <https://www.cdc.gov/ncbddd/disabilityandhealth/family.html>

## ❖ **CDC's Guide on Helping Children in the Rural Areas**

This webpage discusses the unique challenges that families with a child with a disability face in rural communities. It also explains the best ways to alleviate these challenges and provide support for these families.

<https://www.cdc.gov/childrensmentalhealth/features/rural-health.html>

## ❖ **CDC's Tips for Talking to Parents: A Teacher's Guide**

Contains tips and examples about how educators should speak to parents about developmental concerns in their students

[https://www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/tipstalkingparents.pdf](https://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/tipstalkingparents.pdf)

## ❖ **Center for Parent Information and Resources**

Offers a quick roadmap to the disability world and helps to locate disability resources on this website and beyond. <https://www.parentcenterhub.org/new-to-disability/>

## ❖ **Department of Human Services, Maryland**

The Temporary Disability Assistance Program (TDAP) is available to help low-income, disabled Marylanders through a period of short-term disability or while they are awaiting approval of federal disability support. <https://dhs.maryland.gov/weathering-tough-times/temporary-disability-assistance/>

### ❖ **Disability Benefits Help**

An organization committed to helping claimants across the United States receive approval for disability benefits [https://www.disability-benefits-help.org/cpc/general?utm\\_source=bing&utm\\_medium=cpc&utm\\_term=state%20of%20Maryland%20disability&utm\\_content=disability%20services%20for%20parents%20in%200maryland&utm\\_campaign=SSD+-+Phrase+State&\\_egma%5bMatchType%5d=p&\\_egma%5bDevice%5d=c&\\_egma%5bCreative%5d=77721773901370&msclkid=e68ca2f2e7de15f67c90c22b81bf7c03](https://www.disability-benefits-help.org/cpc/general?utm_source=bing&utm_medium=cpc&utm_term=state%20of%20Maryland%20disability&utm_content=disability%20services%20for%20parents%20in%200maryland&utm_campaign=SSD+-+Phrase+State&_egma%5bMatchType%5d=p&_egma%5bDevice%5d=c&_egma%5bCreative%5d=77721773901370&msclkid=e68ca2f2e7de15f67c90c22b81bf7c03)

### ❖ **Disability Rights Maryland**

This non-profit organization is Maryland's designated Protection and Advocacy agency that helps to advance the civil rights of people with disabilities.  
<https://disabilityrightsmd.org/>

### ❖ **Family Resources Centre for Disabilities and Special Needs (Parent Manual)**

Promotes opportunities for learning, inclusion and empowerment for individuals with disabilities and special needs, their families and the community through education, advocacy and outreach <https://frcdsn.org/resources/>.

### ❖ **Guide to Special Education Acronyms**

This guide breaks down common acronyms that are used across disability communities and special education environments. <https://www.ppmmd.org/wp-content/uploads/2021/01/Alphabet-Soup-SPED-1.2021-1.pdf>

### ❖ **Learning Disabilities Association of America**

Provides a wealth of information on understanding learning disabilities, negotiating the special education process, and helping your child and yourself  
<https://ldaamerica.org/parents/?audience=Parents>

### ❖ **Overview of Early Intervention**

Discusses the process and benefits of early intervention for babies and toddlers with intellectual or developmental disabilities <https://www.parentcenterhub.org/ei-overview/>

### ❖ **Parent to Parent Maryland**

Offers parent-to-parent support as a core resource for families with children who have a special healthcare need, disability or mental health concern  
<http://www.thearcmd.org/programs/parent-to-parent-maryland/>

❖ **Parents Support Groups**

This article explains the wide variety of support groups for parents of children with disabilities as well as their benefits and where to access them.

<https://www.parentcenterhub.org/parentgroups/>

❖ **Participating in Your Child's IEP Meeting**

This fact sheet offers tips and guidance for parents working with their child's educational team to create an IEP. <https://www.ppmmd.org/wp-content/uploads/2019/03/Tips-for-Participating-in-Your-Child%E2%80%99s-IEP-Meeting-Factsheet.pdf>

❖ **PATHFINDERS For Autism**

A resource center that serves Maryland's families by providing timely, accurate autism-specific information and resources, responding personally to inquiries via phone, email and Facebook, and distributing monthly "PFA Tips" articles on a variety of topics

<https://pathfindersforautism.org/about-pathfinders-for-autism/our-mission-programs/>

❖ **Pathways to Effective Communication for Healthcare Providers and Caregivers**

Provides information on how to prepare and what questions to ask during an appointment with a clinician

<https://www.caregiver.org/resource/pathways-effective-communication-healthcare-providers-and-caregivers/>

❖ **People on the Go of Maryland (POG)**

Offers to advocate, educate and legislate on behalf of individuals with disabilities, parents and caregivers about the importance of choice and freedom

<https://www.peopleonthegomaryland.com/>

❖ **Resources from Parents' Place of Maryland**

This resource page on the Parents' Place of Maryland website offers a variety of guides with important information about topics pertaining to special education, virtual learning, bullying, advocacy and more. <https://www.ppmmd.org/resources/>

❖ **Self-Care Tips for Parents**

Suggests different self-care practices that parents of children with disabilities can try to relieve stress <https://childrenfirst.com/special-needs-parenting-self-care/>

❖ **Self-Care**

Explains the importance of self-care for parents and caregivers, as well as tips and activities that can be stress-relieving and relaxing <https://www.ppmmd.org/wp-content/uploads/2021/02/Self-Care-TIES-1.pdf>

❖ **Sibling Support**

This organization was founded specifically to support siblings of individuals with disabilities. Offers support groups, articles and other helpful resources  
<https://siblingcenter.org/>

❖ **Support for Siblings of People with Disabilities**

Offers a variety of support groups and other resources for siblings  
<https://disabilityinfo.org/fact-sheet-library/parent-sibling-resources/support-for-siblings-of-people-with-disabilities/>

❖ **Support for Families**

This organization offers support groups, workshops, recommended resources and special events to support parents and families of children with disabilities.  
<https://www.supportforfamilies.org/>

❖ **Support Center Resource Guide**

This contains a list of resource and support groups for parents, families, caregivers and children with disabilities. <https://www.supportforfamilies.org/find-support>

❖ **Special Education Resources Database**

Provides a variety of educational resources and a database of educators that includes tutoring, virtual learning, therapy and more <https://www.iser.com/founders.html>

❖ **Special Need Alliance (SNA)**

Provides resources that help cover the finances needed in supporting a child, ranging from cash payment to healthcare plans.  
<https://www.specialneedsalliance.org/blog/government-programs-for-children-with-disabilities/>

❖ **Support Groups for Parents of Children with Special Needs**

Provides support and guidance to families raising a child with special needs  
<https://blog.bayada.com/be-healthy/eight-support-groups-for-parents-raising-children-with-special-needs>

❖ **Supernova Momma**



Helps black and neurodiverse parents break generational curses from systemic racism and ableism and raise children in a mutually loving, empathetic and respectful environment <https://supernovamomma.com/mission/>

❖ **The Arc Baltimore**

Provides family support via organizing support groups for parents and siblings <https://www.thearcbaltimore.org/programs/family-services/family-support/>.

❖ **The Individualized Family Service Plan**

This guide explains what an Individualized Family Service Plan (IFSP) is as well as tips for implementation and utilization of the IFSP. <https://www.ppmid.org/wp-content/uploads/2020/12/The-IFSP-EC-12.2020.pdf>

❖ **The Office of Special Education and Rehabilitation Services**

This office of the federal government outlines the programs and resources available for special education for people with disabilities of all ages. <https://www2.ed.gov/about/offices/list/osers/aboutus.html>

❖ **Vital Talk**

Demonstrates the use of the SPIKES protocol and incorporates many articles and videos that describe and illustrate each step <https://www.vitaltalk.org/>

❖ **When you learn that your child has a disability**

Describes the journey that many parents go through after learning that their child has a disability, and offers support and resources for the process. <https://www.parentcenterhub.org/journey/>

## **Media Resources**

❖ **Breaking Bad News- When the child is seriously ill**

Stephen Liben, MD, Associate Professor in the Faculty of Medicine of McGill University and Director of the Montreal Children's Hospital Pediatric Palliative Care Program shares strategies for telling parents their child has a life-limiting illness. <https://www.youtube.com/watch?app=desktop&v=KBrmMW9c8g>

❖ **Caring for children with disability- Mini parenting master class by UNICEF**

How can I support my child with a disability? How can I play with my child with disabilities? Child development expert Professor Maureen Samms-Vaughan answers these and other questions. <https://www.unicef.org/parenting/child-development/children-with-disabilities-class>

❖ **Delivering Bad News: What not to do**

A short video by the University of Texas Health Science Center at San Antonio on what not to do while delivering bad news

<https://www.youtube.com/watch?app=desktop&v=HWAZnhCuAeE>

❖ **Delivering Bad News: An excellent encounter**

A short video by the University of Texas Health Science Center at San Antonio - a better way to deliver diagnosis to patients during an encounter

<https://www.youtube.com/watch?app=desktop&v=uOS7hfKkVI>

❖ **How should providers deliver bad news?**

Dr. Michael Haglund, Professor of Surgery at Duke University Medical Center, demonstrates a bad example and a good example of how providers deliver bad news. The video is based on the work of Dr. Neil S. Prose and filmed with actors playing the role of the parents of a young child.

[https://www.youtube.com/watch?app=desktop&v=qHGvjv\\_7PLU](https://www.youtube.com/watch?app=desktop&v=qHGvjv_7PLU)

❖ **Video: Self-care**

This video by the Parents' Place of Maryland describes the importance of self-care and important self-care tips and routines to alleviate stress for parents and caregivers.

[https://www.youtube.com/watch?app=desktop&v=q1jsu9S4I\\_E](https://www.youtube.com/watch?app=desktop&v=q1jsu9S4I_E)

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