



هيئة أبوظبي للطفولة المبكرة
Abu Dhabi Early Childhood Authority



دائرة الصحة
DEPARTMENT OF HEALTH



مركز أبوظبي
للصحة العامة
ABU DHABI PUBLIC



Communicating with Families in Pediatric Healthcare

Empowering healthcare professionals to be more compassionate and empathetic when interacting with parents of young children.





FOREWORD



Few moments carry as much weight and significance as the delivery of news about a child's potential developmental delay or disability to their parents. It is a challenging task that requires a lot of sensitivity, and empathy. The words we choose, the tone we adopt, and the manner in which we convey this information can shape the trajectory of a family's journey, having a lasting impact on their hearts and minds.

This Communication Guide document serves as a resource for healthcare professionals entrusted with the task of delivering difficult news to parents of young children.

Intended as a roadmap for effective communication, this guide is informed by best practices and are drawn from the collective wisdom of experts in the field. The guide explores the different aspects of communication, recognizing that delivery of information around potential developmental delays and disability extends beyond the mere conveyance of information.

It includes the emotional well-being of parents, the importance of active listening, and the fostering of open dialogue that honors the unique circumstances and concerns of each family.

Within this document, healthcare professionals will discover guidance on establishing rapport and trust, addressing parental emotions, and empowering parents to actively participate in their child's care. The guide also emphasizes the importance of ongoing support and follow-up.

This is illustrated with communication examples and scenarios to bring the guide to life and make them more tangible. Healthcare professionals often face limitations due to appointments duration and patient volume, at the same time it is important to follow this guide as much as possible.

We invite healthcare professionals to delve into this document, to absorb the guide presented, and to adapt them to their unique practice settings.

Table of Contents

01

Introduction: Why and how was the Communication Guide developed?

02

Communication Guide for Pediatric Healthcare Professionals



Privacy and Security



Inviting the right people



Communicating clearly



Demonstrating sensitive behavior



Giving time and space



Confirming the understanding



Encouraging engagement



Working together



Providing additional tools

03

Additional resources and training materials





Introduction:
Why and how was the
Communication Guide
developed?

THE COMMUNICATION GUIDELINES WERE DEVELOPED TO SUPPORT PROFESSIONALS WITH PRACTICAL GUIDANCE AND EXAMPLES FOR WHAT TO LOOK OUT FOR WHEN COMMUNICATING WITH FAMILIES OF CHILDREN OF DETERMINATION.



GOAL

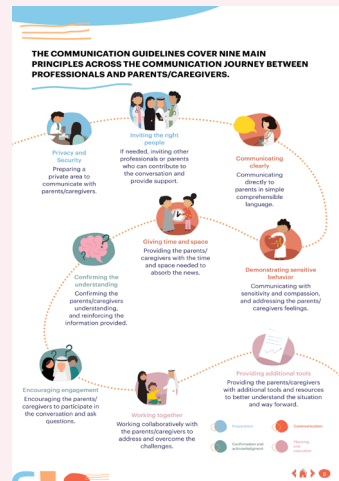
The Communication Guide aims to support Pediatric Healthcare Professionals to communicate and explain their findings to families with compassion and empathy, which will ultimately contribute to an improved overall experience for all parties.

Consultations and detailed input from Pediatric Healthcare Professionals from different hospitals across Abu Dhabi.

HOW?

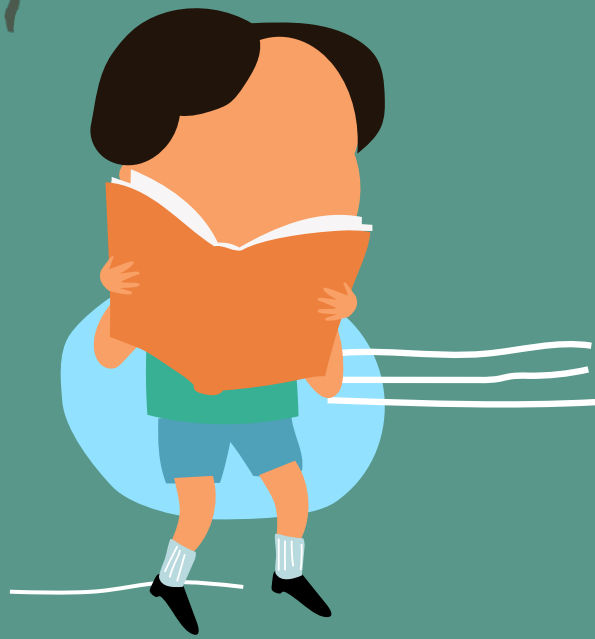
Representative survey with families of young children of determination.

Focus Group discussion with parents of children of determination.



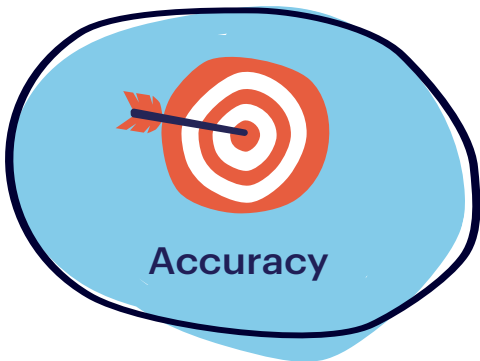
Local stakeholder consultations with public and private entities in Abu Dhabi.

Studied practices in Ireland, the US and the UK as well as international examples of communication guidelines.



Communication Guide for Pediatric Healthcare Professionals

BEING HONEST AND SENSITIVE WHILE TALKING TO FAMILIES OF CHILDREN OF DETERMINATION (ESPECIALLY THOSE WHO ARE NEWLY DIAGNOSED) WILL CONTRIBUTE TO A POSITIVE AND EMPOWERING COMMUNICATION EXPERIENCE.



Communication Guidelines



THE COMMUNICATION GUIDELINES COVER NINE MAIN PRINCIPLES ACROSS THE COMMUNICATION JOURNEY BETWEEN PROFESSIONALS AND PARENTS/CAREGIVERS.



Privacy and Security

Preparing a private area to communicate with parents/caregivers.



Inviting the right people

If needed, inviting other professionals or parents who can contribute to the conversation and provide support.



Communicating clearly

Communicating directly to parents in simple comprehensible language.



Giving time and space

Providing the parents/caregivers with the time and space needed to absorb the news.



Demonstrating sensitive behavior

Communicating with sensitivity and compassion, and addressing the parents/caregivers feelings.



Confirming the understanding

Confirming the parents/caregivers understanding, and reinforcing the information provided.



Providing additional tools

Providing the parents/caregivers with additional tools and resources to better understand the situation and way forward.



Encouraging engagement

Encouraging the parents/caregivers to participate in the conversation and ask questions.



Working together

Working collaboratively with the parents/caregivers to address and overcome the challenges.



Preparation



Communication



Confirmation and acknowledgment



Planning and execution



Privacy and Security



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CREATING A PRIVATE AND SECURE ENVIRONMENT CAN REDUCE PARENTS' STRESS WHEN HEARING ABOUT THEIR CHILD'S DIAGNOSIS

DO



Maintaining eye contact while delivering news in a **private room** with no interruptions to provide a more comfortable environment for the parents/caregivers.



Providing supportive **facilities and amenities** (e.g. water, coffee, tissues, phone...etc.).

DON'T

I am sorry to tell you that your child is diagnosed with autism.



Using a room the parents/caregivers will probably not **visit again** can be helpful to avoid having a **negative association** with the environment.



Distractions such as a phone ringing or physical barriers like computers, desks or crossed arms, **can negatively affect the focus or comfort** of the parents/caregivers. When possible, try to minimize interruptions by technology or support staff.



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INVITING THE RIGHT AND NECESSARY PEOPLE WHO WILL CONTRIBUTE TO THE CONVERSATION AND PROVIDE SUPPORT TO THE PARENTS/ CAREGIVERS

DO



When communicating the news, **both parents** must be present. In the case that one parent is not available, it is recommended to have **another individual (close relative or friend)**. Also, if the parents/caregivers are **very young**, it might be appropriate to invite **older close relatives**.



Giving the opportunity to parents/caregivers to **visit** the baby **as soon as possible** after the news in case the baby is in the **ICU**.



Delivering the news by a **trained staff member**, preferably by the **doctor leading** the intervention with whom the family is **familiar**.



Minimizing the number of persons present.



Depending on the **developmental age** of the child, it **may not be appropriate** for the child to be **present** when news of the disability is being shared with the parents.

DON'T



When delivering the diagnosis news **close to child's birth**, it's crucial for parents or caregivers to have already **seen the baby**, if possible. This allows them to establish a connection with their infant **as a child first**. Additionally, it's important to **prevent any misunderstandings** that may lead parents/caregivers to believe that their child has **passed away or is in a critical condition**. If the baby **cannot be physically present**, it is advisable to **sensitively reassure** the parents/caregivers that the forthcoming news does not indicate the child's death.



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سنعمل معك ومع فريق محترف لوضع خطة لطفلك. ستصف الخطة كيف نتوقع أن يقدم طفلك وكذلك متى وأين وكيف سيتم تقديم خدمات.

The plan will describe how we expect your child to progress as well as when where and how services will be provided.

We will work with you and a professional team to develop a plan for your child.

I want to make sure that I explained things clearly. Can you please explain to me what the next steps are for your child?

DO

AS SIMPLE AS POSSIBLE - PARENTS/CAREGIVERS ARE NOT NECESSARILY HEALTHCARE PROFESSIONALS



Understandable and **honest** communication between the professionals and parents/caregivers.



Keep it simple and to the point - Avoid using complex medical terms and provide **explanations that simplify the message** using visual tools when possible. This approach helps parents/caregivers better understand the information without compromise its actual meaning.



Assessing the knowledge of the parents/caregivers early and taking into consideration the parents/caregivers **linguistic abilities, social, cultural and religious factors** in future communications.



Having an **experienced interpreter** to facilitate the conversation in the same factual and empathetic way as the doctor in case the parents/caregivers are more comfortable in another language.

DON'T

Next step is to develop an IFSP?

Any idea what that means?

I am too shy to ask what it means.



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DEMONSTRATING EMPATHY AND SENSITIVITY AND ACKNOWLEDGING PARENTS/CAREGIVERS FEELINGS, VERBALLY AND NON-VERBALLY.

DO



Delivering news **verbally**, and later communicating in **writing (in the preferred language of the parents/caregivers) as a reference.**



Delivering the news with **empathy, sensitivity, honesty, respect, compassion and understanding.**



Referring to the child by **their name** rather than the disability they have.

DON'T



Awareness of **body language** and how it can be **interpreted** by the parents/caregivers, **avoiding whispering** or non-verbal **signals that could raise concerns** for the parents/caregivers, and conveying **positive, realistic and hopeful** messages.



Acknowledgment of parents/caregivers **reactions, listening attentively, supporting** them, and **understanding** that parents/caregivers might have different coping mechanisms.



Avoiding the use of **dismissive, impatient, aggressive or judgmental** language with the child or parents/caregivers.



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I will give you some privacy but I will be right outside if you need anything.

Please do not feel in a rush, and take your time. Whenever you are ready we can discuss this further.



DO

GIVING PARENTS/CAREGIVERS THE TIME AND SPACE THEY NEED TO ABSORB AND COPE WITH THE INFORMATION.



Giving parents/caregivers some **time alone** with their loved ones to **absorb the news**, and having a **staff member in easy reach** in case needed.

DON'T

Here is the situation, your child will need a 2-year intervention plan we will start in around 1 month, then we will see.

Anyway, your appointment is about to finish do you have any questions?



Not rushing the appointment, and dedicating **enough time** to communicate and answer questions creates space and time for the information to be absorbed.



Avoiding **overloading** parents/caregivers with information, prioritizing what **has to be** communicated at the time, and conveying the more detailed information at the **right moment**.



Ordering, Directing, Commanding

Power-based communications like *“you must...”, “you will...”* often lack empathy and acceptance of the parents/caregivers and their perspectives.



Using logic, Arguing

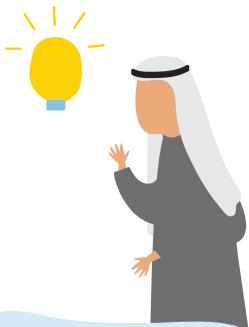
“The fact is...”, “Here is where you are wrong”, make parents/caregivers feel inferior to the professional, and provoke instructing and teaching kind of communication.



Analyzing, Interpreting, Diagnosing

Messages like *“I see what you are trying to do here”, “you are trying not to be like your own parents/caregivers”* make the parents/caregivers feel embarrassed and exposed.

Some communication styles might result in roadblocks



Advising, Giving Solutions, Suggesting

“What I would do...”, “Why don’t you...” might not be easily identified as roadblocks, however, in some situations these messages might demonstrate lack of trust in parent judgment or thoughts, and may discourage them from seeking solutions and ideas themselves.



Praising, Agreeing, Supporting

“You are the best parent I have ever seen”, exaggerated or inadequate positive evaluation might have a negative effect on the parents/caregivers. It might evoke denial or make them heavily dependent on your praising.



Reassuring, Sympathizing, Consoling

Even with the intention to make others feel better, saying phrases too often like *“It’s just immaturity, and your child will grow out of it.”, “The young brain is so resilient, your child will make a remarkable recovery”* might minimize the seriousness of the situation.



Claiming, Assuming

Messages like *“Your child is too young to determine if they have a disability”* or *“Your child will never walk or talk”* eliminate hope and discourage parents from seeking appropriate intervention or support services.



Criticizing, Judging, Blaming

“You are not thinking clearly”, “I couldn’t disagree more” these messages make the parents/caregivers defensive, or feel inadequate or unworthy. Judging them might eventually turn into them judging themselves.



Questioning, Probing, Interrogating

“Did you do as I told you?”, “Are you sure you did everything possible?” these messages might be interpreted by parents/caregivers as careless or irresponsible, and focus more on the issue rather than the solution.

While other habits always act as roadblocks to communication with parents/caregivers



Moralizing, Preaching, Shoulds and Oughts

“What you really should do is...”, “It is your responsibility to...” not only demonstrate lack of empathy, but trigger resistance.



Misleading, Discouraging

“What can you do about it anyway? There is no cure for your child’s disability” diminishes their sense of optimism and resilience, potentially hindering their ability to explore alternative approaches to support their child.



Avoiding, Diverting, Ignoring

“Relax, do not worry about it”, “just have a glass of water, and you will be fine”, do not acknowledge parents/caregivers concerns which might be valid.



Privacy and Security



Inviting the right people



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Demonstrating sensitive behavior



Giving time and space



Confirming the understanding



Encouraging engagement



Working together



Providing additional tools

PACKAGING THE INFORMATION AND REPEATING IMPORTANT POINTS OVER TIME, WHILE VALIDATING THE PARENTS/CAREGIVERS OVERALL UNDERSTANDING

DO



Reiterating the information more than once and at different points to ensure the parents/caregivers have absorbed the key points correctly.

DON'T



Asking parents/caregivers to confirm **full and clear understanding**.



Communicating news with the appropriate **context** and connecting it with any previous communication.



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ENCOURAGING PARENTS/CAREGIVERS TO ASK QUESTIONS AND EXPRESS THEIR CONCERNS, ADDRESSING THESE AND FOLLOWING UP

DO



Encouraging parents/caregivers to **ask questions and participate** in the conversation, and always listening to them.

DON'T



Recognizing the concerns of parents/caregivers, taking them **seriously**, and **consistently** following up as needed.



Keeping parents/caregivers **up to date** all the time, even in times of uncertainty, and keeping them **engaged to build trust and give confidence** to share with you.



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WORKING COLLABORATIVELY WITH PARENTS/CAREGIVERS.

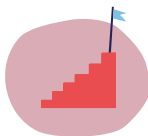


DO



Scheduling a follow up appointment before ending the current discussion or conversation.

DON'T



Clarifying the next steps and future plan, and answering any related questions about what can be done next.



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DO



PROVIDING PARENTS/CAREGIVERS WITH ADDITIONAL RESOURCES AND THE OPPORTUNITY TO JOIN SUPPORT GROUPS AND MEET OTHER PARENTS WHO FACED SIMILAR CHALLENGES.



Providing **multiple communication channels** for parents/caregivers to reach out for consultations or ask follow-up questions as needed.



Providing **guidance on resources** with **relevant and accurate** information on the child's specific case.



Providing information on **support groups** (relevant to the child's case).



Providing parents/caregivers with the opportunity to **meet other parents/caregivers** of children with similar cases.



DON'T



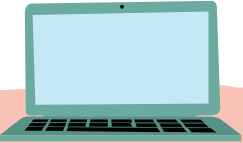


Additional resources and training materials

LOCAL RESOURCES AND TRAINING MATERIALS

Overview 	Source	Links 
Training, Awareness and Education Platform	Abu Dhabi Public Health Center	https://www.adphc.gov.ae/en/Public-Health-Programs/Training-Awareness-Education
Healthcare Guidelines	Department of Health, UAE	https://www.doh.gov.ae/en/resources/guidelines
Clinical Training Program	Department of Health, UAE	https://www.doh.gov.ae/en/programs-initiatives/meed/intermediate-training-program/Clinical-Training-Program
Abu Dhabi Early Intervention Guide	Abu Dhabi Early Childhood Authority	https://eca.gov.ae/explore-resources/abu-dhabi-early-intervention-guide/

INTERNATIONAL RESOURCES AND TRAINING MATERIALS

Overview	Source 	Links
Training videos on communication	Academy of Communication in Healthcare	https://www.aachonline.org/Resources/ACH-Resources/Videos
Articles on empathy & compassion	Academy of Communication in Healthcare	https://www.aachonline.org/Resources/Academic-Articles/Empathy-Compassion
Relationship-centered communication: Communication skills training	Academy of Communication in Healthcare	https://rccskills.org/#section-004108d-1
Transforming Healthcare Through Relationship-Centered Communication	Academy of Communication in Healthcare	https://www.aachonline.org/Resources/Communication-RX
Faculty-in-training: a learner-centered professional development program	Academy of Communication in Healthcare	https://www.aachonline.org/Programs/Faculty-in-Training-Program

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- 2 ECA (2023). Consultations and detailed input from Pediatric Healthcare Professionals from different hospitals across Abu Dhabi. Several rounds of consultation via online workshops were conducted in August and September 2023.
- 3 ECA (2023). Focus Groups with Parents of Children of Determination. Conducted in September 2023.
- 4 Levetown, M., & American Academy of Pediatrics Committee on Bioethics (2008). Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics*, 121(5), e1441–e1460. ([Link](#))
- 5 National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability. (2007). Informing Families Guidelines. ([Link](#))
- 6 Gordon Training International (n.d.). The Roadblocks to Communication. Gordon Model. ([Link](#))
- 7 UNICEF, ECARO, & ISSA. (2022). Module 10: Caring and Empowering - Enhancing Communication Skills for Home Visitors. ([Link](#))





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The Abu Dhabi Early Childhood Authority is committed to the highest standards and we have young children and their families at the heart of all we do. If you have any suggestions or feedback on how the content in this guide could be improved, please get in touch.

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