

VIEWPOINT

Coronavirus tool kit may aid families with autistic children during lockdown

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On 17 March, France went on lockdown to slow the spread of the coronavirus, joining many other countries in Europe.

French authorities ordered residents to stay at home and closed schools, as well as institutions that provide care and support for autistic children and adults. The lockdown included our institution, the Center of Excellence for Autism Spectrum Disorders and Neurodevelopmental Disorders (InovAND), in Paris.

Lockdowns are challenging under any conditions. In large urban areas, including Paris and its suburbs, families often must remain isolated in cramped apartments, an experience that is particularly difficult for the community we serve — families with one or more children who have autism or other conditions of brain development.

To help these families cope with the sudden loss of professional support precipitated by the lockdown, we have created more than **30 instructional modules** designed to provide resources, counsel, information, lessons, schedules and overall aid to families confined to their homes.

Each module features evidence-based techniques adapted to the conditions of the lockdown. The resources integrate general cognitive and behavioral strategies, as well as specific practices drawn from the Early Start Denver Model and the Preschool Pediatric Autism Communication Therapy.

The modules also provide concrete guidance, along with specific examples and worksheets for structuring days, tasks and activities, and tips for behavioral management and self-care.

An urgent need:

The need for a solution like our tool kit became apparent after the shock of the first week of confinement had worn off.

During the lockdown, many parents of children with autism or other conditions lost most or all their institutional, educational and therapeutic support, leaving them to independently manage the daily and hourly issues related to their child's condition, ranging from helping children focus on homework to managing their meltdowns.

Most families will have had experience handling these problems, but not all day and all week, with no opportunity to go outdoors.

News reports about the pandemic have also increased **anxiety**. Some parents of autistic children with immune or heart problems, for example, worried that a coronavirus infection could prove fatal for their child. Autistic children expressed increased separation anxiety at bedtime, an increase in obsessions and compulsions (particularly rituals linked to the fear of being contaminated), or states of acute stress disorder.

Parents who themselves have a chronic condition such as diabetes, high blood pressure or obesity grew concerned about their own fate or that of their elderly parents. The death of a parent or a grandparent could rob an autistic child not only of a primary, stabilizing bond but also of their strongest advocate, causing intense stress.

Strategies that our team had patiently helped families learn over days, weeks and months unraveled within a matter of days.

We also heard that progress with prosocial behaviors slowed, and associated conditions such as hyperactivity, attention deficit and impulsivity became more prominent.

Scale and breadth:

We had our work cut out for us. We developed individual modules for parents of children who have autism or a range of related conditions from attention deficit hyperactivity disorder to speech and language delay or Phelan-McDermid syndrome.

Other modules focus on topics such as stimulating the cognitive development of a child younger than 2, psychomotor therapy, managing screen use and dealing with oppositional behavior.

Modules also address the needs of parents, such as how to prevent passing on anxiety about the pandemic to children, how to help children when a loved one dies and how to practice self-care while caring for others.

Word spread quickly about the tool kit, with the landing page soon receiving some 20,000 visits daily. French government websites, as well as hundreds of organizations serving parents of children with these conditions, have published some of the modules.

Other countries have published sites that mirror our tool kit or have published translations in English and Spanish. Parents also may choose to translate the pages using free online services such as Google Translate.

Our research partners at the Institut Pasteur and other institutes are helping us refine the tool kit. Collaborations with clinicians, researchers and autistic people and their families will help us develop ways to improve the everyday lives of the families.

We have heard people say that things will improve after the pandemic ends. But in our community, we can see that some things have already changed for the better. Unlike the pandemic, these relationships and partnerships will endure.

Richard Delorme is head of the Center of Excellence for Autism Spectrum Disorders and Neurodevelopmental Disorders at Robert Debré Hospital in Paris. Benjamin Landman is chief resident at the center.