**Title:** Adaptive innovations to provide services to children with developmental disabilities during the COVID-19 pandemic.

**Article:** Viewpoint

**Running Title:** Children with disabilities during Covid-19

**Abstract NOT FOR PUBLICATION:**

Children with developmental disabilities are experiencing significant challenges to service access due to suspension of in-person assessments during the current COVID-19 pandemic. Telehealth is rapidly becoming the new service delivery model, which presents a unique opportunity for innovation in care that could be beneficial in the post-pandemic period. For example, using a combination of in-home video and telehealth options could form the first step in developmental assessment, allowing children to receive the necessary supports without delay. *Recent telehealth funding is welcome but additional Medicare items for joint consultations between GPs, and paediatric, mental health and allied health professionals is critical.*

**Key words:**

Developmental disability, COVID-19, Telehealth

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Yours sincerely,

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Children with developmental disabilities are experiencing significant challenges to service access due to suspension of in-person assessments during the current COVID-19 pandemic. Telehealth is rapidly becoming the new service delivery model, which presents a unique opportunity for innovation in care that could be beneficial in the post-pandemic period. For example, using a combination of in-home video and telehealth options could form the first step in developmental assessment, allowing children to receive the necessary supports without delay. Recent telehealth funding is welcome but additional Medicare items for joint consultations between GPs, and paediatric, mental health and allied health professionals is critical.

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Manuscript

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Developmental disabilities such as autism and intellectual disability significantly impact the life of affected children, families and their social networks. These and other developmental vulnerabilities account for one in five children starting school in Australia (1). These children require additional services and support for challenges beyond those of parenting typically developing children.
During the COVID-19 pandemic, access to routine but essential services for child health and development, such as well baby checks, developmental monitoring and support services, are limited. For example, publicly funded multi-disciplinary assessment teams and some private specialists have closed their books to in-person assessments, despite waiting lists of up to two years. The impact of these service changes were compounded by the closure of schools and other services that provide formal and informal supports, education, therapeutic interventions, respite care and monitoring. Simultaneously families were dealing with additional stressors including self-isolation or quarantine, infection fears, financial loss, inadequate food and medical supplies, relationship stress and stigma (2). Children are experiencing loss of routines, frustration and boredom, lack of contact with close family members (e.g. grandparents) or friends. Even though restrictions are easing in most states and territories, families are still reluctant to take their children to health facilities for non-urgent issues due to concern about infectious contacts or wishing to minimise burden to stretched services. This in turn is inadvertently limiting opportunities for developmental surveillance for preschool children across the country. This is further exacerbating the “inverse care law” that existed prior to the pandemic in that those children from the most disadvantaged backgrounds and most at risk of developmental disorders are least engaging with and accessing prevention and health promotion programs such as developmental surveillance (3).

Innovative care delivery models must therefore be a focus of health care services and policy initiatives during and following this COVID-19 pandemic. Understandably the initial focus has been on developing readiness for ‘worst case’ infection burden and intensive care. There is now an urgent need to establish alternate support and intervention systems for vulnerable groups, with a recent report suggesting that school- and pre-school children from disadvantaged backgrounds are experiencing significant employment stress in the family (4). In accordance with the WHO call for “keeping each other safe and connected”(5), we examine the potential opportunities to build a service system so that children with developmental vulnerabilities, and their families, are not left behind.

In Australia, telehealth has been used to bridge some gaps in service delivery for those who live outside metropolitan areas, including for Aboriginal population in remote and rural areas [4]. In recent years online health care has also been developed for some chronic
conditions but such programs are not yet readily available for children who are neurodevelopmentally vulnerable and for those with a disability. Further, there are significant challenges in implementing telehealth and other online services for population groups who conventionally have difficulty engaging with the health system, including, but not limited to those from culturally and linguistically diverse backgrounds (6), as adaptations and translations are not always available.

**Service opportunities**

**Parents:** Parents are their child’s greatest resource for wellbeing and neurodevelopment. Parents should be actively engaged through anticipatory guidance and ongoing developmental monitoring of their child. *Raising Children’s Network (RCN)* ([https://raisingchildren.net.au](https://raisingchildren.net.au)) and the ‘Learn The Signs Act Early’ (LTSAE) program ([https://www.cdc.gov/ncbddd/actearly/index.html](https://www.cdc.gov/ncbddd/actearly/index.html)) are examples of resources available for parents, professionals, and early childhood educators. The LTSAE program comprises age appropriate developmental checklists available in different languages from birth to five years. It has been incorporated in the *My Personal Health Record* (PHR) ‘Blue Book’ as part of the NSW State universal developmental surveillance program and is available electronically. Translations of the Blue Book are available for 19 most commonly spoke languages in NSW. The developmental checklist, along with embedded anticipatory guidance, is an effective way of engaging parents to monitor their child’s developmental achievements and identify differences or delays. Building on this program in NSW and as a further innovation, an online *Watch Me Grow (WMG) developmental surveillance platform* ([https://is.gd/wmgdevcheck](https://is.gd/wmgdevcheck)) has been developed to engage parents to complete the LTSAE ‘red flag’ developmental checklist. Those who indicate a concern on ‘red flag’ items are then guided to seek more detailed assessments by a health professional. The weblink also provides age appropriate anticipatory guidance for each parent using online resources such as RCN as applicable to the respective age of the child. Further, once the parents engage with the weblink, the WMG platform sends reminder emails at the recommended ages and stages for developmental checks in order to allow ongoing developmental monitoring until the child turns five.
Primary care: Primary care professionals can offer parents tier two assessments and several resources are available through the Health Pathways for GPs (7). In addition, there are freely available developmental measures, such as the Survey of Wellbeing in Young Children (SWYC) (www.theSWYC.org) [7] for general assessment of development and behaviours, or the Modified Checklist for Autism in Toddlers (MCHAT)(8) for identifying early features of autism. Children identified in the primary care setting can receive appropriate referrals and recommendations for care, or relevant early interventions including free to access online parenting programs (e.g. Parent Works (https://parentworks.org.au/#/) or those delivered by therapists using telehealth (e.g. internet -Parent Child Interaction Therapy (IPCIT) (9, 10).

Specialist care: Prior to COVID-19, common problems for specialists including Paediatricians, and allied health professionals caring for children with developmental disabilities, included prolonged wait times and difficulty accessing information from other key professionals such as mental health specialists. During a pandemic and in the post-pandemic period, these issues are exacerbated but need to be overcome. Telehealth can be effectively used in developmental assessment (11) which can enhance access, timeliness, and quality of care by supporting uniform implementation of best practices, processes and protocols. It can also save costs, including travel time and be a more efficient use of health professionals’ time and skills.

Innovations have commenced with emerging evidence. A coaching service is being investigated in Victoria to assist families while waiting for assessment services. In a randomised pilot study, parents reported being as satisfied with online interactions as face-to-face. Coaching to identify key goals for each child was possible and service advice was able to be provided (12).

To improve access for children most in need of specialist services, a recent pilot study, conducted in five Victorian GP practices found that integrated GP-paediatrician care, consisting of co-consults, case-based discussions and email and telephone support, upskilled
GPs to be able to better identify those children who needed specialist support for developmental concerns versus those whose development was within normal limits [11].

Telehealth is also being increasingly used as a way of providing care in regional and remote Australia. This has now been extended to metropolitan settings. Evidence from the USA suggests that multi-disciplinary remote assessments, using versions of telehealth, are feasible, acceptable and effective in accurately diagnosing children with ASD. Further, high level agreement has been found between reference standard, in-person assessments versus ASD assessment protocols conducted via video [12, 13] with a brief, online developmental history followed by clinically-guided in-home video recordings capturing different scenarios of the child’s day-to-day interactions and problem behaviours [14]. In Australia, a combination of in-home video and telehealth could be used as the first step in assessment, allowing children to receive the necessary supports (e.g. through NDIS) based on functional needs, to be then followed by more comprehensive assessments later.

**Options for telehealth billing:** To enable timely care, and to avoid longer waiting times funding is critical for health professionals to work, such as Medicare-rebated telehealth subsidies. Recent funding of specialist telehealth provision is welcome. However, without additional Medicare items to allow GPs and specialists to work as a team, and with mental and allied health professionals, easily remediated behavioural and developmental difficulties will be exacerbated. Vulnerable children will not be given the opportunity to reach their potential and families will face additional stress in the short and long term, incurring imminent and future health, well-being and financial costs.

**Conclusion:** The COVID-19 pandemic represents a ‘transformative shock’ [15] to our healthcare system. We can choose to learn from it by embracing technological solutions and creating true partnerships between parents, GPs and specialist care services. Significant opportunities exist to expand the telehealth offerings for child health and development, with suitable subsidies for all health professionals. Without timely intervention, children particularly from disadvantaged (due to socioeconomic, geographic or cultural and linguistic) backgrounds will miss out as valuable time is lost when routine universal services are mostly
closed due to the pandemic, leaving limited opportunities for prevention and health promotion programs such as developmental surveillance to take place. The opportunity must however be seized to engage all parents of preschool children through the General Practitioner, Child and Family Health Nurse programs, Early Childhood Education Centres or Aboriginal or Out of Home Care support workers etc. using any opportunistic routine contacts that these professionals have with the parents. This will allow for better engagement with parents alongside integration of primary and specialist care for children with developmental disabilities. Post pandemic, many of these initiatives might prove as effective and more cost-effective than current practises.

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