

# Understanding the Development and Participation of Children with Significant Health Needs

Supporting our statewide vision  
Queensland Child and Youth Clinical Network  
Child Development Subnetwork



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# Feedback from Families





## Executive summary

### Background

In the context of ever increasing evidence regarding the development and participation challenges experienced by children who have significant health needs, this project was initiated as a first step towards optimising the development and participation opportunities for this population of Queensland's children.

The project was initiated by the Queensland Child and Youth Clinical Network's Child Development Subnetwork and funded by Children's Health Queensland. The project builds on the document Act Now for a Better Tomorrow (Act Now), which described how child development interfaces across the continuum of care, identifies core principles for practice for a child development service, articulates the unique position Queensland Health is in to deliver child development supports to specific populations, and details Standards for Clinical Practice for a specialist child development stream of care.

Despite the recognition that the Act Now document gave to the unique capacity of the health system to support the development and participation of Queensland children with complex development needs, services for children who have significant health needs remain ad hoc and lack integration.

### Project aims

The long term goal of this project is to enhance our understanding of the experiences of children who have significant health care needs, with a view to better supporting their development and participation in life.

More specifically, the project aimed to build understanding of:

- the priorities parents of children with significant health needs have for their children,
- parent perceptions of the development and participation experiences of their children with significant health needs,
- parents' experiences of the health and community services, supports and life experiences that either assist or compromise their child's development and participation, and
- the views of parents of children with significant health needs regarding the appropriate role of Queensland Health in supporting the development and participation of their children.

Ultimately, the project findings will contribute to development of clinical service standards and models that more effectively support the development and participation of this population of children.

### Method

The project included parents and carers of Queensland children aged 0 – 16 years who have significant health needs. The method involved an online survey of parents and carers, followed by a series of detailed conversations with parents who expressed an interest in contributing to the second stage of the project.

### Project limitations

As this project needed to be completed in a short timeframe and with limited resources, there were limits to how comprehensively the survey could be promoted to the full population of families to which it was relevant. The professionals and services that engaged most actively in recruiting participants were those providing child development supports. As a result, the group of parents who contributed is likely to be predominated by children who already receive child development supports and may not be representative of the population of Queensland children who have significant health needs.

### Participants

Of the 52 survey responses received, 42 were included in the analysis of findings. The children ranged in age from under 1 year to 16 years, with the majority ( $n = 21$ , 76.2%) aged under eight years. Just over half of the children and their families lived in regional Queensland ( $n = 22$ , 52.4%). For most children, their





health condition began before one year of age ( $n = 37$ , 88.1%). Although the majority of children had a main diagnosis ( $n = 40$ , 95.2%), nearly half of these children had additional conditions that were not explained by this primary diagnosis. For nearly two thirds of children ( $n = 25$ , 59.5%), their health conditions are not likely to resolve with time or intervention, and just over a third ( $n = 15$ , 35.7%) are likely to have the length of their life affected. Nearly half of the children ( $n = 18$ , 42.9%) had experienced five or more hospital admissions in the past two years and nearly one third ( $n = 13$ , 31%) had experienced a single admission of one month or more, and eight (19.0%) had experienced a single admission of three months or more. Nearly half the children ( $n = 19$ , 45.2%) had 10 or more different medical specialities involved in their care in the previous two years. Every child had involvement from one or more medical or allied health professional in relation to their development, with 27 (64.3%) of these children having five or more different child development professionals involved.

Six parents contributed to detailed conversations to expand on the survey findings. The parents were all mothers and their children range in age from one to six years. The six children have a range of different health conditions. Four of the families live in regional Queensland and two in greater Brisbane.

## Experiences of children and families

### *Development and participation experiences of children with significant health conditions*

Each of the 42 children demonstrated some degree of challenge to their development and/or ability to participate fully in activities expected of children of a similar age.

Participation was found to be affected by a multitude of factors. These included, but were not limited to, feeling acutely and chronically unwell; pain associated with the condition and resulting from interventions; avoiding infection risks and ensuring physical safety; sensitivities and/or aversions arising from experiences of the condition and interventions; and time spent in hospital, at appointments and undergoing investigations and interventions.

When parents were asked to rate their children's strengths and challenges in day-to-day activities, on average, 'having fun doing the things they love', 'having fun exploring new things', and 'moving around' were rated as being relatively easier than activities such as 'understanding others and being understood', 'coping with different emotions' and 'joining in sport and physical activity'. Even so, every child demonstrated a unique pattern of strengths and challenges, with parents of five children indicating that their child experiences significant challenges even in the fundamental activity of enjoying activities valued and enjoyed by the child.

Beyond the general impact of a child's health condition and interventions, children were noted to experience significant impacts from lengthy and/or regular hospital admissions. These impacts were said to arise out of the experiences of a highly institutionalised environment; compromised family interactions, social experiences and childhood activities; and missed early childhood education and schooling.

The trauma of specific treatments was identified as having specific, distressing and persistent impacts on children's participation and development as well as their overall emotional wellbeing. The lack of systematic effort for all children to receive supports that proactively minimise these impacts before, during and after traumatic experiences was a great concern for parents.

### *Building understanding of development and participation needs*

Parents stressed how important it is for them to build a comprehensive understanding of their child's development and its relationship to their health. Parents all spoke of their recognition of specific delays in



their child's milestones and recognised the probable impact of their child's health condition and interventions on these delays. Even so, they reported highly varying experiences of how they had been supported to understand their child's participation and development needs. The conversations with parents emphasised that in building their understanding of their child's needs the following issues are of great importance:

- parent input is key to building understanding,
- an integrated, team-based approach makes a difference,
- diagnostic labels alone do not bring understanding and are not enough,
- different family members build understanding in different ways,
- understanding is dynamic must be maintained as circumstances change, and
- parents want transparent and comprehensive information.

### *Access to supports to facilitate development and enable participation*

The challenge of accessing support to facilitate development and enable participation was a strong theme across the survey responses and in every conversation with parents.

Perhaps the single most overlooked aspect of supporting a child's development and participation related to the lack of opportunities and support to engage as widely and successfully as possible in day-to-day life activities both while in hospital and at home. Although some parents expressed appreciation of 'entertainment' activities and therapy support provided in hospital, the lack of opportunities and guidance to normalise day-to-day experiences was seen to be a significant oversight.

All families who contributed to the project were engaged with formal developmental supports in some form or another. However, the recurring story was the lack of a systematic approach to families being proactively provided with information and referrals to access these services in a timely way. Parents spoke about their great frustration at needing to fight for services and supports; the challenge of resources and services being restricted by diagnostic criteria rather than need; the excessive waiting times for services; and in some regional communities the lack of needed supports.

Access to child development supports was further influenced by personal finances. This impact arose out of the cumulative impact of the financial demands of supporting a child with significant health needs and parents' capacity to work being limited by their child's health needs. For families living in rural and regional areas, this challenge was even greater given the additional demands of travel, accommodation and time away from work.

### *Making the difference to children's development and participation*

When exploring the issues and supports parents believe help or challenge their child's development and participation, two of the most important supportive factors were a parent's belief about what their child can and should do and their own knowledge and problem solving. Reinforcing the importance of this finding was the desire for parents to build their knowledge further and become better informed about how to adapt activities to suit their child. Importantly, parents also emphasised the importance of having opportunities to draw on the experiences and knowledge of other parents, rather than relying on professionals who were not familiar with the day-to-day experience of caring for a child with significant health needs.

Parents expressed the need for more opportunities for their child to participate with other children, but noted the lack of community activities suited to their child's needs.

More parents rated their children's therapists as a significant source of support to their participation than any other factor. Even so, when asked about the supports it would be helpful to have more of, a child's medical



team and therapists were only nominated by a very small minority of parents. Parents explained that when interacting with their child and family, health professionals were typically highly sensitive to their child's past and current health needs and experiences. However, parents stressed the negative impacts that resulted when such empathy was not shown.

## Messages for the system

Parents provided many clear messages about what is important to supporting their child's development and participation. This was evident in the priorities parents detailed for their children and the importance of services and supports being offered in a way that respects parents' hopes and aspirations. It was also reflected in clear statements explaining what families valued most about their positive experiences, and the areas where change is needed.

### *Family priorities for their children*

Parent's priorities were wide ranging and mediated by their understanding of their child's current and likely future needs. Individual priorities included parents' hopes for the services their child and family receives and how these services are delivered; their child's short and long term health outcomes; and their long term social, vocational, physical and emotional wellbeing.

A number of parents presented their priorities in general terms, expressing the importance of their child having the chance at the best start in life; a good quality of life; health; happiness; as normal a life as possible; and as a parent – the experience of loving their child.

A number of parents spoke of their different priorities as being interconnected, with each individual priority supporting other priorities, and all accumulating to achieve more significant goals such as attending mainstream school.

### *Key messages from parents*

Across the surveys and the conversations, twelve important messages from parents emerged that are important to supporting children with significant health needs to develop and participate to their potential. These included:

1. Listen to and value the contributions of parents
2. Recognise that children aren't just small adults
3. Respond to a child's needs beyond being clinically stable
4. Establish a systematic approach that responds to the development and participation needs of all children
5. Support the whole child
6. Support parents to understand their child's development and participation needs across their life course
7. Ensure access to information about support and intervention
8. Support children to participate in typical activities of childhood, in hospital and in the community
9. Ensure access to support and intervention, across the life course
10. Facilitate early intervention
11. Integrate and coordinate services to reduce the burden on families
12. Provide supports with awareness of a child's health condition and sensitivity to past and current experiences of the child and their family





## Summary and conclusions

This project, exploring the development and participation needs of children with significant health needs, has surfaced a number of important messages, including:

- the significant development and participation challenges experienced by children who have significant health needs,
- the importance of families having well integrated services to support their understanding of their child's needs,
- the lack of systematic approaches to ensuring access to appropriate supports for child development and participation, and
- the factors that contribute most significantly or act as barriers to the development and participation of children who have significant health needs and their families.

The priorities parents expressed for their children and their specific messages to the service system also provide important direction to guide more systematic service design, development and delivery with the end goal of optimising the development and participation opportunities of children who have significant health needs.





# 1. Introduction

## 1.1. Background

All children have the right to develop and participate in life to their full potential. The benefits of realising this goal are experienced by the child, their families and the broader community of which they are a part. More specifically, a child's development and participation in life is known to have both direct and indirect impacts on their health and wellbeing across their life course.

Recent years have seen increases in both public interest and policy investment in improving universal and population level health and education outcomes. This has coincided with gains in acute health service provision and chronic disease health care and management, resulting in children surviving adverse events and conditions that were previously associated with high levels of mortality and morbidity.

For children who live with significant health conditions, including but not limited to inherited metabolic disorders; childhood cancer; consequences of major heart, gastrointestinal, trachea-oesophageal, or renal defects; and adverse neonatal events; survival has long been the initial goal for families and health professionals. A longer life and improved health status, however, brings new responsibilities to the health care system, particularly in the context of the ever increasing evidence regarding the development and participation challenges experienced by this population of children. *“The fundamental challenge faced by children in our clinics and services involve and concern development – how to become distinct and functional individuals in the face of their conditions and their apparent limitations.”* (Rosenbaum, 2013).

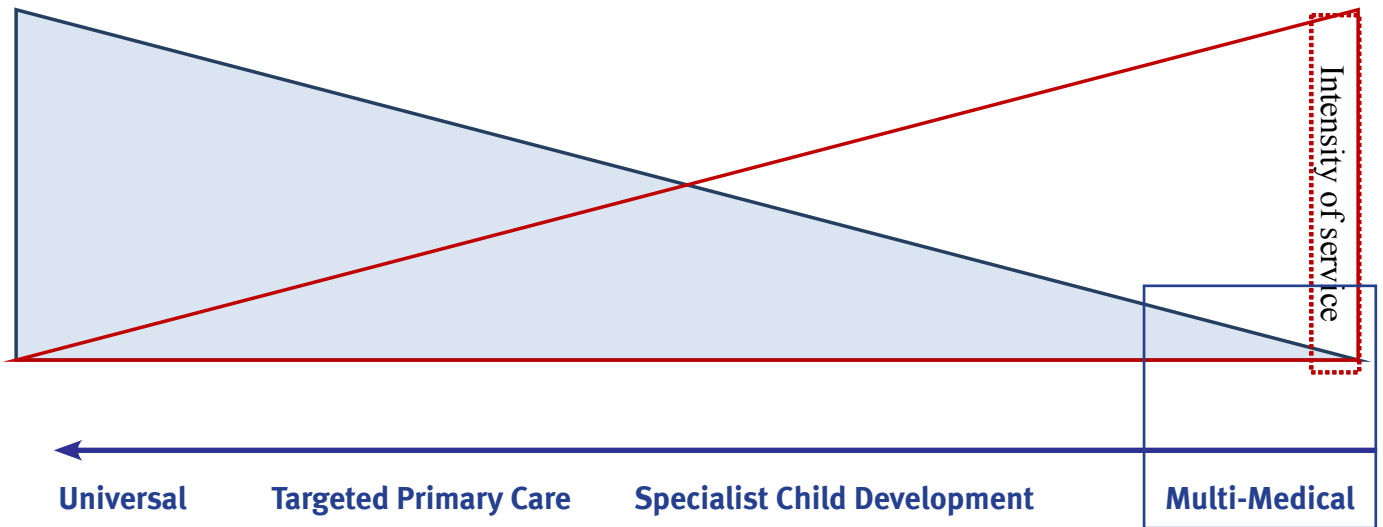
The Queensland Health Child Development Subnetwork (CDSN) was convened by the Statewide Child and Youth Clinical Network (SCYCN) in 2009 following identification of child development as one of four clinical priority areas. The purpose of the group is to provide clear, apolitical advice in a cooperative and collaborative fashion regarding child development services with particular reference to:

- service delivery and standards of clinical care,
- planning, quality, research and clinical-information systems,
- present and future workforce issues, and
- local policy and advocacy as they relate to the above.

In 2013 the Child Development Subnetwork released the document *Act Now for a Better Tomorrow (Act Now)*. *Act Now* describes how child development interfaces across the continuum of care, identifies core principles for practice for a child development service, and details Standards for Clinical Practice for a specialist child development stream of care.

As described in *Act Now*, the Child Development Subnetwork recognises child development services as being provided at many points along the continuum of care. From this perspective, *universal* or *primary* care services are important foundation services to support the developmental health of the wider community. Progressing along the continuum, *targeted primary health care*, or *generalist child development services* are important for children identified as being at risk of non-complex developmental concerns and *specialist child development services* required for children with complex developmental impairments that cross multiple domains, including developmental, biological, psycho-social, cultural, medical, demographic and/or behavioural factors. Finally, there are the children who experience developmental impairments alongside significant medical and/or mental health needs. Typically, these children access their medical care and support from tertiary and quaternary hospitals. The focus of this current project is on the development and participation experiences of these children who have significant health needs.

<sup>1</sup> The findings of a rapid review of the literature exploring the development and participation impacts of children with significant health needs is included in Part 2 of this document.



As detailed in *Act Now*, there are a number of factors that place the Queensland public health system in a unique position to deliver child development supports to children with significant health needs, including:

- Understanding the medical, developmental and psychosocial needs of children concurrently through provision of integrated multidisciplinary services delivered by professionals with a specialist skill set.
- Offering a comprehensive analysis of a child’s current and future capabilities, regardless of diagnosis or of that child’s current care arrangements or educational context.
- Partnering with families and other stakeholders throughout the patient journey, from birth across the life course, due to multiple care pathways and entry points to services along the continuum of care. This is particularly important for children with co-morbid health and social complexities.
- Ensuring access to quality assessment, diagnosis and intervention statewide due to equitably located services in regional centres throughout Queensland.

Despite recognising this unique capacity of the health system, provision of support for the development and participation of Queensland children who have significant health needs has been ad hoc and lacking integration.

In this context, this project was initiated by the Queensland Child and Youth Clinical Network’s Child Development Subnetwork and funded by Children’s Health Queensland. It is intended as an initial step in the process of optimising development and participation opportunities for children who have significant health needs.

This report is presented in four sections. The first section provides an introduction to the project, including the project background, aims, method and project limitations. Section two presents a profile of the participants who contributed to the project. This is followed by section three which provides a detailed discussion of the project findings in four broad themes, including a discussion of the development and participation experiences of children with significant health needs; the importance of building understanding of the development and participation needs of children with significant health concerns; the challenge of accessing supports for development and participation; and finally, an overview of the factors that make a difference to children’s development and participation, both within and beyond the formal service system. The fourth and final section offers some key messages to the service system, including a discussion of parents’ priorities for their children and a series of parent perspectives on the issues that need to be responded to if children with significant health needs are to be successfully support to fulfil their developmental potential.



## 1.2. Project aims

The primary aim of this project is to contribute to the long term goal that children who have significant health needs have access to supports that enable them to develop and participate in life to their full potential. More immediately, the aims of the project are to understand:

- the priorities parents of children with significant health needs have for their children,
- parent perceptions of the development and participation experiences of their children with significant health needs,
- parents' experiences of the health and community services, supports and life experiences that either assist or compromise their child's development and participation, and
- the views of parents of children with significant health needs regarding the appropriate role of Queensland Health in supporting the development and participation of their children.

The findings of the project will contribute to the development of clinical service standards and models that more effectively support the development and participation of children with significant health needs.

The project included parents and carers of Queensland children aged 0 – 16 years who have significant health needs.

The project involved two stages – an online survey of parents and carers, followed by a series of detailed conversations with a small number of parents who completed the survey.

## 1.3. Method

The project included parents and carers of Queensland children aged 0 – 16 years who have significant health needs.

The project involved two stages – an online survey of parents and carers, followed by a series of detailed conversations with a small number of parents who completed the survey.

### 1.3.1. Project team

The project team included one independent consultant from Young Futures, one Queensland Health project manager, and one parent advisor whose child's health and development needs met the criteria for inclusion in the project.

The parent advisor provided input to the design and implementation of the project, including specific input to the development of the online survey and the conversation guide.

### 1.3.2. Stage 1 – Online survey of parents

The online survey included questions relating to:

- the child's story,
- the parents' priorities for their child,
- the child's health,
- the child's development and participation in life,
- the services and supports used,
- the contribution the child's health care team makes to supporting the child's development and participation in life, and
- the support received to make sure the child can participate in life to their full potential in the future.





The survey took approximately 30 minutes to complete and remained open for four weeks. A copy of the survey questions are provided at Appendix A.

The project team provided details of the online survey to all Queensland Health child development services and other key health professionals and teams across the State. These services, teams and professionals were asked to invite relevant families to contribute to the survey via an online link. They were also asked to forward the details of the survey to other relevant contacts within their networks. Within the survey, contributing families were invited to forward information about the project and the survey link to others they believed it was relevant to.

In addition to circulating the online link to the survey, one project team member attended the Royal Children's Hospital Outpatient Department for one half day clinic session and provided the opportunity for parents and carers to complete the survey either online or in hardcopy while waiting for a medical appointment.

### **1.3.3. Stage 2 – Conversations with parents**

The second stage of the project involved one-to-one semi-structured conversations with a subgroup of parents who responded to the survey.

Parents who completed the survey in the first two weeks were invited to nominate themselves as possible contributors to these conversation about the experiences of their child and family. A conversation guide was development to inform the broad direction of the conversations. However, to a significant extent, parents were given the chance to lead the path of the discussion. The conversation guide is provided at Appendix B. Families in south-east Queensland were offered the opportunity for their conversation to occur either by telephone or in person at a location of their choosing. Conversations with families in regional and rural areas occurred by telephone.

The conversations were facilitated by two project team members, including the independent consultant from Young Futures and the Queensland Health project manager. Both are experienced in working with children with significant health needs and developmental disabilities and their families.

Each conversation was limited to 60 minutes. All conversations were audio-recorded and professionally transcribed prior to analysis.

In writing this report, careful attention has been paid to maintaining the confidentiality of children and their families. All parents who participated in the detailed conversations were provided the opportunity to review a draft of the report and identify any details they preferred were changed or not included in the final report. These details have been excluded or modified prior to completion of the final report. Pseudonyms have been used in place of these children's names. Where direct quotes have been used from survey responses, careful attention has been paid to excluding information that could potentially identify the child or family.

## **1.4. Project limitations**

This project was initiated to enable an initial exploration of issues relating to the development and participation of Queensland children who have significant health needs. The project was required to be completed within a short timeframe and with limited resources. This impacted on the capacity to proactively promote the project and encourage completion of the survey by the full population of families it was relevant to.





The professionals and services that engaged most actively in recruiting project participants were those that provide child development supports. As a result, the group of parents who contributed to the project is likely to be predominated by children who receive child development supports and may not be representative of the population of Queensland children who have significant health needs.

Despite these project limitations, the project team believes that the findings offer a valuable contribution to initial conversations to guide service planning to better support the development and participation needs of this population.





## 2. Project participants

### 2.1. Survey participants

The survey attracted responses from 52 parents and carers. Responses were included in the project if the child was currently experiencing, or had experienced, a significant health condition that co-occurred with, or could reasonably be expected to contribute to, a child experiencing complex developmental needs. Responses from 42 parents were included.

The 42 children ranged in age from under 1 year to 16 years, with 32 (76.2%) aged under eight years. There were 24 boys (57.1%) and 18 girls (42.9%). The majority of children and their families lived in regional Queensland (n = 22, 52.4%), followed by greater Brisbane (n = 16, 38.1%), and rural Queensland (n = 4, 9.5%). No parents or carers living in remote Queensland responded to the survey.

One parent indicated that their child identifies as Aboriginal. No parents indicated that their child identifies as Torres Strait Islander. Three (7.1%) parents indicated that languages other than or in addition to English are spoken at home.

The age of onset of the children's health conditions was most frequently before one year of age (n = 37, 88.1%) and the onset for all children was before six years.

The majority of parents indicated that their child has a main diagnosis (n = 40, 95.2%), but for nearly half of these children the diagnosis does not explain everything in relation to their child's health. A small minority of children did not have a main diagnosis (n = 2, 4.8%).

As reported by parents, the health conditions of most of the children are not likely to resolve with time or intervention (n = 25, 59.5%), with 15 of these children (35.7%) likely to have the length of their life affected by their health condition. One third of parents (n = 14, 33.3%) did not know whether their child's health condition was likely to resolve. Only three parents (7.1%) indicated that their child's health condition is likely to resolve. Of the parents who indicated they do not know if their child's health condition will resolve, seven (16.7%) said that their child will experience long term impacts from their health condition. Another six parents (14.3%) did not know whether their child would experience long term impacts from their health condition.

Although one in five children (n = 8, 19.0%) had not had any hospital admissions in the past 2 years, nearly half of the children (n = 18, 42.9%) had experienced five or more hospital admissions in this time. Of the 38 (90.5%) children who had experienced hospital admissions at some point in their life, the longest ever hospital admission across the group ranged from one night to 12 months, with nearly one third of children (n = 13, 31%) having a single admission of one month or more, and eight children (19.0%) having a single admission of three months or more.

When considering the involvement of different medical specialities in the past two years, 37 children (88.1%) had five or more specialities involved, and 19 (45.2%) had 10 or more different medical specialities involved. Every child had involvement from one or more medical or allied health professional in relation to their development, with 27 (64.3%) of these children having five or more different professionals involved.



## 2.2. Stage 2 – Conversations with parents

A total of ten parents indicated an interest in participating in Stage 2 of the project. Attempts were made to contact all ten parents and six interviews ultimately occurred. All six conversations occurred with mothers of the children.

**Table 1. Profile of conversation participants**

Name	Age	Location	Primary health condition	Age of onset
Tim	6	regional Queensland	congenital heart condition	< 1 year
Anna	5	regional Queensland	musculoskeletal condition	< 1 year
Stephanie	3	greater Brisbane	respiratory and gastro condition	< 1 year
Ben	2	regional Queensland	undiagnosed syndrome	< 1 year
Emily	1	greater Brisbane	cerebral palsy	< 1 year
Michael	5	regional Queensland	epilepsy	3 years





### 3. Experiences of children and families

#### 3.1. Development and participation experiences of children with significant health conditions

The responses of the parents who contributed to this project demonstrated that each of the 42 children had some degree of challenge to their development and/or ability to participate fully in activities that would be expected of children of a similar age. This was evidenced through responses detailing engagement with developmental therapists, ease of participation in a range of activities, and responses to open ended questions.

Not all children experienced these difficulties as a result of their health condition, as demonstrated by the fact that seven (16.7%) parents indicated that their child's health and/or the treatments they receive do not impact significantly on them participating. Even so, the co-occurrence of significant health conditions and developmental difficulties – both of which are well recognised for placing children at significant risk of a range of secondary impacts – reinforces the importance of attending appropriately to the child development needs of this group of children.

*“We are expected to be super human and cope with the stress of not knowing what the next day will deliver. She might be okay one minute or sick the next.”*

*“Our son's development has always been a problem, but it has often been put aside because of his medical conditions.”*

*“As her parents we have a holistic view about her as a whole person and a member of a family unit and community. We work very hard to make sure as much as we can our medical team and extended team work together for her benefit.”*

##### 3.1.1. Impacts on opportunities to participate

The survey responses and conversations with parents revealed that the opportunities children with significant health conditions have to engage in activities that facilitate development and enable full participation are affected by a range of factors related to their child's health condition and the interventions they receive, including:

- feeling acutely and/or chronically unwell,
- acute and/or chronic pain associated with the condition and resulting from interventions,
- the need to avoid infection for children who are immunocompromised and/or whose health conditions can be significantly exacerbated by infection,
- the need to ensure physical safety,
- limitations to physical strength and endurance,
- sensitivities and/or aversions arising from experiences of the condition and from interventions,
- compromised sensory, cognitive, motor, social and emotional capacity as a feature of the child's health condition or resulting from interventions,
- time spent in hospital, at appointments, and undergoing investigations and interventions, and
- frequent and/or extended hospital admissions.





The impact of these factors is recognised as being two-fold. Firstly, a child's experiences of inclusion and participation in the activities typical of a full childhood are at risk of being significantly compromised. In turn, the reduced frequency and variety of activities likely to be experienced by children with significant health needs has the potential to affect their opportunities to practice and master a range of important skills.

*"We were told our family day-care mum didn't want to care for our daughter anymore because she was too much work. This made it difficult to find opportunities for her to participate with other children. We also spend so much time running around to appointments I often miss playgroup and mothers' group."*

*"We struggle with what is a genuine health issue and what is an 'I can't be bothered'. We don't understand feeling tired 24/7 – he doesn't know any different. (We are) encouraging him to be normal in an abnormal environment."*

Additionally, a number of factors secondary to the child's condition, and external to the child, were also found to impact on their development and participation opportunities. A third of parents indicated that a 'lack of community activities that are well suited to my child's needs (e.g. playgrounds, sports clubs, libraries, theatres)' (n = 14, 33.3%) and 'not knowing how to adapt activities to make it easier for my child to participate' (n = 12, 28.6%) made it more difficult for their child to participate. To a lesser extent, a number of other factors came into play, including:

- lack of equipment or resources my child needs to help them participate (n = 7, 16.7%)
- lack of specific supports to help my child develop skills to participate (e.g. mobility, communicating, feeding, play) (n = 9, 21.4 %)
- lack of time and/or extra support to make it possible for my child to participate (n = 7, 16.7%)
- other people's beliefs about what my child can and should do (n = 6, 14.3%)
- lack of opportunities to participate with other kids (n = 5, 11.9%)
- health professionals not spending specific time planning to support my child's need to participate (n = 4, 9.5%)
- health professionals not paying enough attention to my child's need to participate when they plan my child's treatments (n= 2, 4.8%)
- my beliefs about what my child can and should do (n = 1, 2.4%)

*"Despite all the surgeries and hospitalisations our daughter is a mostly very happy and gregarious little girl who inspires people daily. She is quite bright, although has some global delay particularly with her gross and fine motor skills and with her language. She can read beginner level stories, write her own name and count to 20."*

*"Our son was born with significant heart defects. He had his first open heart surgery at 1 week old and his 2nd at nearly 5 months old. He had to stay in hospital the entire time, he was not allowed to come home. He had to spend a lot of time on his back as a baby as he was recovering from his surgeries. He didn't enjoy being on his tummy until he was about 8 months old. Since being out of hospital we have continued to see specialists to catch him up and continue to address this. From last reports he is very close to where he should be for his age. He is nearly weaned off his tube and enjoying food."*





### 3.1.2. Strengths and challenges experienced in day-to-day participation

Parents were asked to rate how easy or challenging a range of activities were for their child, with 1 being ‘very easy’ and 6 being ‘very challenging’. As shown in Table 2 below, on average, parents rated ‘having fun doing the things they love’, ‘having fun exploring new things’, and ‘moving around’ as being relatively easier than other activities (with average scores of 2.1, 2.4 and 2.7 respectively). In contrast, the activities parents rated as presenting the greatest challenges for children were ‘understanding others and being understood’, ‘coping with different emotions’ and ‘joining in sport and physical activity’ (with average scores of 4.1, 3.9 and 3.8 respectively).

*“Our daughter is now two years old and is not yet walking or talking, though she is very interactive and communicative.”*

*“Our daughter has Rett Syndrome...All she wants to do is watch movies and be included with the family...She is non-verbal, but has a gorgeous laugh. She relies on the family for full cares.”*

*“Our near term goal is for our daughter to be ready for mainstream prep in 2015...For this to be possible, we have a number of goals and focus areas this year, including around her general health, her eating skills and diet, her communication skills, gross motor skills, fine motor skills, cognitive skills, self-help skills and issues in inclusion settings/education options.”*

**Table 2. Average parent ratings of level of ease or challenge different activities present to their child (1 = very easy, 6 = very challenging)**

Activity	Average	Range	Most frequent response
Having fun doing the things they love	2.1	1 – 5	2
Having fun exploring new things	2.4	1 – 6	2
Moving around	2.7	1 – 6	2
Deciding what things they would like to do	2.9	1 – 6	2
Making and keeping friends	3.1	1 – 6	2
Learning at childcare, preschool or school	3.2	1 – 6	NR
Joining in (with other kids, the family, and the community)	3.4	1 – 6	3
Gradually becoming more independent	3.5	1 – 6	3
Everyday activities (eating, drinking, toileting, sleeping, dressing and bathing)	3.7	1 – 6	2
Joining in with sport or physical activity	3.8	1 – 6	4
Coping with different emotions	3.9	1 – 6	4
Understanding others and being understood	4.1	1 – 6	4

NR = ‘This isn’t relevant to my child’



These averages provide important broad information about the group of children who contributed to the project, however, it is also important to appreciate the diversity of experiences across individual children. Although, on average, children experienced greater ease ‘having fun doing the things they love’, ratings ranging from 1 to 5 occurred across the group, and parents of five children provided a rating of either 4 or 5, indicating significant challenges in the fundamental activity of enjoying activities valued by the child. For each of the other 11 activities, ratings across the full range from 1 to 6 were evident. For 31 children, a rating of either 5 or 6 was scored on one or more activities. For 21 of these children, a rating of 5 or 6 was scored on two or more activities.

### **3.1.3. Impacts from frequent and/or lengthy hospital admissions on development and participation**

Beyond the general impact of their child’s health condition and interventions, parents also raised the specific impacts of lengthy and/or regular hospital admissions on their child’s development and participation, including the broad impacts of an institutionalised environment, environmental impacts on parent – child and sibling interactions, lack of opportunities to socialise across a range of situations, missed early childhood education and schooling, and compromised opportunities to participate in a range of general childhood experiences.

*“Being in hospital means isolation and stress.”*

*“[In hospital] it’s extremely difficult to bond. When you bond at home... we go into her bedroom and hop on the chair and swing back and forward and read a book or sing. That’s quite an intimate time between mother and child. You don’t get that in hospital because you’ve got parents around you, and other people’s children, and lots of visitors and nursing staff. It’s hard to just bond with your baby.”*

*“Since she was 3 1/2 she has spent 1 day a week in hospital...She has also had countless operations which has meant further days off school.”*

### **3.1.4. Impacts from the trauma of health interventions on child development**

Trauma experienced by children when they undergo specific treatments for their health conditions was recognised by parents as having a significant and persistent impact on their children’s development. This was the case whether the experience was a single discrete event (e.g. major surgery) or repeated occurrences of the same procedure (e.g. port needling). Parents expressed significant concern that efforts were not made to prospectively minimise the impact of necessary but extremely distressing experiences. Once the effects of trauma were experienced by children, and the impacts on their development and emotional wellbeing were unfolding, the lack of timely supports further contributed to placing the developmental trajectory of children at risk.

*“Some multidisciplinary coordination early in children’s lives, around traumatic experiences would be great. I don’t know a home TPN child that didn’t scream, vomit and cry in distress for the first few months (and often for years afterwards) when undergoing these procedures which weren’t just for a short course of treatment but were, and are, a lifelong thing. Therapy support from the moment a child has a central line inserted and starts on TPN, with nurses, OTs, play therapists, music therapists etc. just seems like a no-brainer. Part of child development is about not being in a state of constant terror and stress!”*

*“Health professionals don’t think enough about helping children cope with traumatic things, especially from the start of the traumatic experiences compared to months or years down the track when people are called in to treat aversions, trauma, screaming, non-compliance with procedures etc.”*



*“The children, especially the older ones, come home from hospital and they’re not the same kid. They need help emotionally and there’s just nothing.”*

*“From one week being a smiling, happy child talking to everyone, to basically not wanting anyone to poke and prod him again.”*

### **Tim’s story – the impacts of illness and traumatic interventions**

*Our little boy Tim is such a kind, easy going, happy person. He’s a good kid, a really good kid. Rather than loving any one thing in particular, he enjoys everything.*

*Our top priority is for Tim to reach his potential and lead a productive and motivated life.*

*Tim lives with me, his Mum, as well as his Dad and siblings in a regional town in Queensland. Before Tim was born we didn’t know anything was wrong. Within minutes of being born the sirens were pressed and he was rushed away for intubation. Soon he was flown to Brisbane. He had his first heart surgery before he was a day old, his second at one week, his third before he was 6 months, and his fourth a bit before he turned two. For two years he spent a lot of time in hospital – for heart issues and other illnesses he didn’t cope with like a healthy child would.*

*We knew from two months that something wasn’t right. He was very, very slow with his milestones. He was too content. He didn’t cry. He slept all the time. He was too easy-going. That might sound great for some people, but if your baby has been really sick, you think, “No, he’s actually not right.” From the beginning he was vague and unaware.*

*Five years on, Tim is still very vague and delayed in all areas of his development. His needs are complex and he needs significant support. He has very low muscle tone and fatigues very easily. He lays down all day because he doesn’t have the strength to keep sitting up. Now he’s in prep he’s having trouble with that, just sitting all day.*

*After Tim’s last cardiac surgery, he went backwards in his development. It was overnight. He stopped talking for three months. He went backwards with his toilet training. He was still his happy, normal, everyday self, but all of his milestones went back by six months. He screamed every night in his sleep for three months. They give you all the information in the world about wound care, lifting, and that kind of thing, but nothing about how a child copes mentally and emotionally. It took 9 months to see a psychologist. She said he had a post-traumatic stress disorder. He needed help there and then, straight after the surgery, but nobody would help us. How can you prevent a child from having a reaction like that? I’m a member of the Heart Kids Australia Facebook page. When I put the question out there, “Has anybody else experienced this?” there were more than 100 responses. I don’t know what they can do to make it better. They just kind of churn these kids through.*



### 3.2. Building understanding of development and participation needs, in the context of significant health conditions

The importance of developing a comprehensive understanding of a child's development and its relationship to the child's health conditions and interventions was highlighted by parents who were interviewed for the project. Parents all spoke of their recognition of specific delays in their child's achievement of discrete milestones such as toileting, crawling, walking and talking. They each also demonstrated recognition that their child's health condition and interventions had more than likely impacted on their child's development. However, although each of these six children had involvement with one or more developmental professionals and services they reported highly contrasting experiences of developing an understanding of their child's development and participation needs.

Key themes relevant to the issue of building understanding included the importance of:

- including parent knowledge of their child,
- using an integrated, team-based approach,
- extending understanding beyond providing a diagnostic label,
- responding to the different needs of different family members,
- appreciating that understanding is dynamic and needs to be maintained as circumstances change over time, and
- providing parents with transparent and comprehensive information.

*“Nothing is as intimidating as asking questions and requesting alternatives, or getting pros and cons explained better from your child's medical team, who have your child's health (even life or death) in their hands.”*

*“We can't help her if we don't understand what we need to do, or understand where she needs help.”*

#### 3.2.1. Parent input is key to building understanding

The survey and interview findings reveal that respect for and active inclusion of parents' knowledge, observations, and experiences of their child is fundamental to achieving an accurate understanding of a child's development and one that parents trust. Unfortunately, this was not a universal experience for parents and where it did not occur resulted in reduced parent confidence as their sense of an incomplete or sometimes inaccurate picture of their child's capacity and needs resulted. Where parents' perspectives were actively incorporated, they felt included as key members of their child's development team and the result was a much greater sense of confidence to continue to explore and work openly and collaboratively with the team.

*“She started this strange twitching type spasm thing...We were growing more and more concerned because it was happening more frequently. But we were able to just phone the team and they quickly arranged an EEG. You can just ring and say this is what's going on. Just even to give them an update. They love to hear feedback. It's good to have that relationship with them. It gives us more confidence.”*

*“At the end of the day we are her parents and they consult us and say, ‘Okay, we're concerned about this. We think this would help. What do you think about doing with this and this?’”*



*“A few weeks back I said to the therapists, ‘I just don’t feel that she’s progressing. We’ve been in this one spot for such a long time. We want her sitting and she’s so close to sitting but she’s not yet. We’re getting a little disheartened and she’s getting frustrated.’ Straight away, they said, ‘Okay, next week let’s do a regroup.’ So, I put forward my concerns and what I wanted for her. Then they listened, they took it on board. There’s a way about them that makes them so approachable and you feel comfortable. You don’t feel that they’re the professionals and you’re just the parent. It really is a team effort.”*

### **3.2.2. An integrated, team-based approach makes the difference**

Parents who had experienced a highly integrated, team-based process of building understanding of their child’s development, with the combined input of professionals who had specific expertise in the area, could not speak more highly of the process. They explained how the outcomes of this process contributed not only to their understanding of their child but also to how they related to and supported their child across many areas of their life.

Interestingly, although 27 (64.3%) children received supports from five or more medical and allied health professionals with expertise in child development, findings from the interviews suggest that the experience of a highly integrated process achieved an outcome that was far greater than the sum of the parts of input from multiple discrete professionals. This was particularly highlighted by families who originally had an experience of discrete multidisciplinary supports but subsequently had the opportunity of an integrated team process.

One parent spoke of the confusing and difficult experience of medical specialists expressing opinions and speculating about different diagnoses relating to her child’s development over an extended period of time. This occurred without any additional process of referral to medical and allied health professionals with the expertise to undertake appropriate diagnostic assessment and guide access to relevant supports.

*“They’ve helped us more to understand that cognitively she’s average with other children her age, which is absolutely fantastic... They said basically it’s just her body that’s letting her down, which I think really helped us put it into perspective. Whereas we hadn’t had that. All these other people were working with her, but never really went into any in depth the way the (child development service) has.”*

*“Before the (child development service) did their assessment, before we fully understood it ourselves, it was hard. It was frustrating for us not to get cranky at her. She has taken a long time with her toileting, and we didn’t realise that was all part of it, because she just couldn’t sense the feeling of needing to go. Now that we have an understanding of how much this affects her, I think it has helped us a lot. You can be like, ‘Well if you can’t do it that way, we’ll do it this way.’”*

*“Comparing the two [team based approach versus a number of individual clinicians], I think the (child development service) was a stronger route for us because they sat down and worked out together where she’s behind. And they did up a big assessment, which really helped me and my husband understand just how delayed she is and where she’s struggling. I think having it written down in front of us to read, and because it was specific to our daughter. It had information from the speech therapist, physiotherapist, psychologist, occupational therapist. Then there was a summary giving an outline on the overall assessment. I’ve read it so many times now, and I feel a lot more confident in how we can help her and how the child development team can help her, and ECDP.”*





*“Because we’re her only advocates, we have to do what’s best for her. To do that, we have to understand and have options available. The team process has given us the power to be able to do that... We know our options now. Before this, we were flying blind. We were taking her here, there and everywhere, but not getting anywhere.”*

### **3.2.3. Diagnostic labels are not enough**

Some parents related being given a specific diagnosis (e.g. autism) but not being given additional information about what this meant for their child and what their next steps should be to support their child’s development in the best ways possible. Some spoke of being given brochures to read or websites to look at. However, in the absence of additional support, this often proved overwhelming. Parents said that because these resources provided information on the full range of presentations of a condition, they did not clarify the likely path for their child, or how to invest their efforts to support them. They did not know whether their child’s future might be more likely to fit the ‘worst case scenario’ or ‘best case scenario’. Although answers to these questions are not always clear for very young children, parents highlighted the challenge of navigating the information on their own and not knowing how to apply it to their son or daughter.

*“She just said ‘This is what I believe she has. Just go home and Google it.’ That’s what was given to us. We’ve never actually been handed any information. It’s all stuff that we’ve had to research at home, which is pretty hard because it’s sort of linked to so many different things like autism and Down Syndrome and all that. It’s an endless world out there with Google. So it’s very daunting when it throws all this stuff at you, and you don’t know what applies to your child.”*

One parent indicated she was not convinced that her son’s diagnosis of autism made sense in relation to her knowledge of her son’s developmental strengths and weaknesses, his medical background, or her understanding of autism. This highlighted the repeated finding that many parents feel that professionals do not adequately incorporate parents’ understanding of their own child into the clinical process of building a picture of a child’s development and participation skills and needs.

*“Well, he ticks the sensory box when a doctor goes through the autism criteria. He has oral sensitivities and oral aversions. It’s hard to get anything in his mouth, including food and drink. But it’s probably because he’s been intubated and extubated a lot. He’s been tube fed. He’s scared of things in his mouth. So, he ticks that sensory box, but is it because he has autism, or is it because he has negative associations with things going down his throat?”*

### **3.2.4. Different family members build understanding in different ways**

As parents explained their experiences it became clear that processes of building understanding need to be responsive to the individual approaches of different family members and their specific needs across time. Parents spoke of the varying responses between themselves and their partners as they came to understand their child’s development. Although some families navigate this experience successfully, for others it can be a source of very significant stress, in an already challenging situation, that can be just one more contributor to the potential undoing of a relationship.



*“He just couldn’t handle it. I was watching him break down slowly...”*

*“I felt that she would eventually get there, but my husband wasn’t really happy with the paediatrician giving us that. He’s the type of person that just wants answers, no matter what. There’s got to be a reason. Whereas I felt that she was continually progressing. She wasn’t going backward...But my husband was like, no, there’s got to be something wrong. There’s got to be something more. I think he struggled a lot.”*

*“It has taken my husband and I a long time to digest our son’s diagnosis. I am being treated for depression and feel immense guilt all the time. I am scared for his future.”*

*“He gets on Google and starts looking at these things and saying ‘I think she’s got autism’, and ‘I think she’s got this.’ And I tell him ‘You need to stop doing that. It’s not helping you, is it? It’s stressing you out’”*





### 3.2.5. Understanding is dynamic and must be maintained as circumstances change

Parents expressed a clear appreciation of the likely changing needs of their child through time. In this context they explained that it is not enough to build understanding about their child at the initial point of connection with the health system and not have the opportunity to revisit this as their child develops, as their health needs change, as the circumstances of their family evolves, and as the services available at different ages and stages of development come and go. They expressed the feeling that it would not be at all helpful to provide an initial opportunity for assessment and understanding, but no access to ongoing therapy, problem solving, and guidance regarding appropriate supports.

One parent spoke of the experience of her son's development being routinely 'monitored' by her son's paediatrician. However, she saw this as offering little value given that it was not paired with detailed discussion about the implications of the findings or exploration of possible recommendations and actions for the future.

*"If you've had the assessment, then keep on going with it. Otherwise you'd have to go back to all those ones individual professionals. You'd just be back to square one, I think."*

*"None of us asked to have a child with a disability, and most of us wouldn't change it for the world. But it is really hard in day-to-day living for all involved... We love him to bits, but his future still holds a level of uncertainty – including for him – as he comes to understand his syndrome fully and how that will affect his future."*

*"As she's getting older we're realising how in depth it's going to be, like with her speech and her language. When she was really little, her fine motor skills didn't seem to be a problem. I took her to an OT and they said, no, she's fine, she doesn't need follow up. Now she's a bit older, it's more apparent that she obviously needs a lot of OT. She does struggle in those areas now."*

*"They have been focused on both – his medical needs and his development needs. But mainly they do an assessment, compare that assessment to where he was six months ago, and then say, 'See you in six months.' You know what I mean? Not really give you any kind of direction."*

### 3.2.6. Parents want transparent and comprehensive information

Parents stressed the need to hear honest, transparent and comprehensive information about their child's development from professionals with appropriate expertise. However, they also emphasised that this must be paired with proactive guidance and support to access the full range of relevant services in a timely way, and in the right combination at a particular point in time, to ensure their child has the best chance to develop to their full potential.



*“We have therapists that are really approachable and that want us to be comfortable and understand, but not give us false hope. They’d never do that. I’ve said straight out to our therapists, ‘Do you think she might walk?’ They say, ‘We can’t answer that. But we can tell you that, so far, she’s doing really well.’ They will give us the positives, but they’re not going to sugar coat it for us, which is good. They’re realistic, but gently realistic.”*

### **Stephanie’s story – a difficult path to understanding**

*Our little girl Stephanie has this little ninja personality. She’s just amazing – so resilient and so happy, despite being unwell and in pain. But she wasn’t always like this. She was an unhappy, unsettled baby. She vomited a lot and failed to thrive. For a long time she cried and whinged for many hours every day. She didn’t grow or gain weight for nearly a year. She was diagnosed with gastroparesis before she was one and bronchiectasis just before she turned two. Although Stephanie has all the symptoms of cystic fibrosis, she apparently doesn’t have CF. She’s been in hospital more than twenty times in the past two years.*

*We don’t really know Stephanie’s prognosis. One doctor said, “She’s got the lungs of an 18 year old CF kid.” Kids with CF have CF, then they get bronchiectasis, then they die. She’s gone straight to bronchiectasis. That’s where we started going, “Hang on. Is this essentially what kills the kids with CF, and you’ve already got it, and you’re only three?”*

*I was worried about her hearing and her speech from very early. I had to fight her paediatrician for a referral. The paediatrician said there was nothing wrong but my ‘mummy intuition’ knew something wasn’t right. The hearing test showed she could only hear the loudest sounds. That’s when she got her first grommets. And they said a speech therapist would only tell me stuff I already knew. But when I went I found it really useful. It was helpful to know I was doing the right thing. It wasn’t therapy for Stephanie so much, it was good advice for me.*

*Last year the medical team said she had an intellectual impairment. I think this was because of her behaviour and the distressed sounds she made when she was in pain. Later I heard they also thought she had autism. But then her development exploded and the doctor said “Oh goodness, I’m not worried anymore.” None of this was based on assessments by people who are experts in these things. Then they said to go back to our paediatrician to monitor her development. The paediatrician wrote and told them Stephanie didn’t have an intellectual disability, but they still referred to it. She definitely has a severe communication delay and gross motor delay. She continues to track and maintains the same delay, she’s not catching up or getting worse.*

*No-one has spoken to us about how, what, or why about Stephanie’s development. To me – if she didn’t grow for nearly a year, probably nothing grew. That explains some of it. And the speech and language is explained by the hearing and to some extent by low muscle tone. Her receptive language is really quite good. And the physical stuff is probably because she’s unwell and in pain a lot. This is just what makes sense to me.*

*People talk in vague terms. I want to be told, her speech is at 18 months. Her gross motor is at two years. Her fine motor is whatever. I’d know where to focus if people were honest. Our priorities now are to understand Stephanie’s health and development, get intensive early intervention, and give her the chance for inclusion.*



### 3.3. Access to supports to facilitate development and enable participation

The project has revealed that parents experience a complex mix of issues that influence their access to opportunities to support their child to achieve their developmental potential and participate fully in life. These factors included inadequate proactive, systematic processes to:

- guide parents to support children’s development through day-to-day activities in the context of their health conditions and interventions, and
- support access to formal child development support, within and beyond the health system, for children with, or at significant risk of, complex child development needs.

#### 3.3.1. Supporting development and participation through day-to-day life

Developing and participating optimally by taking part in day-to-day activities in ways that successfully accommodate children’s health and interventions was a significant challenge for families both while their child was in hospital, and while at home and in the community generally.

##### 3.3.1.1. Development and participation through day-to-day life in hospital

Some families of infants who experienced lengthy hospital stays spoke very highly of the team-based allied health developmental therapy and support they received and valued this enormously. Despite this targeted intervention that some families received, no-one experienced proactive, systematic efforts to make sure their child’s development and participation needs were met as part and parcel of the day-to-day experience of an extended hospital stay.

*“In a hospital, people think about supporting children’s development in terms of therapy, but less so in terms of everyday experiences to offset the abnormal hospital environment.”*

The value of ad hoc entertainment, activities and events while a child is in hospital were acknowledged. However, parents saw this as different to normalising children’s lives by having the chance to participate in day-to-day experiences and routines in ways that give their child the best developmental opportunities within compromised circumstances.

*“Health professionals in hospital underestimate (or forget about?) the value of everyday things, and forget that children who’ve spent their life in hospital since infancy have never even seen every day things, and need to see sunlight, grass, dogs, trains, cars, stars, the moon, babies and children as part of their development.”*

Parents spoke of having to use their own initiative to seek opportunities that might be supportive of their child, such as finding the means to play music, seeking a pass to go outside, and attempting to establish and maintain routines more typical of life at home. None of the parents interviewed indicated that they were given any guidance on the things that might be options for their child in the hospital environment and in the context of their health needs. These parents expressed great concern for other children whose parents did not have the skills or confidence to be proactive in an environment that most find very intimidating.





*“I’d love to see them have a pamphlet to give parents for children that are in hospital. Because it’s long and it’s draining, and sometimes you’re a complete zombie and you’re not thinking. While in the back of your mind you’re thinking, ‘I want to have a normal relationship with my child, I want to do normal things’, you don’t know how to put it into play.”*

*“In EVERY admission I have to be proactive in negotiating day passes, or leave to go down to the front lawn to see daylight/visit Ekka activities etc. No one ever suggests it. Why is this? And what about parents who are too nervous about their kids to think of this as an option. Half an hour on the grass breaks up a boring day in hospital like you wouldn’t believe.”*

*“In HDU when we could pick her up and move her around, we’d hold her and sing to her, and read stories to her. But none of that was recommended by the hospital. They didn’t say you can do this or you can do that. We had to bring things in and then ask if we can do them, on the off chance they said yes.”*

*“Our daughter was in PICU for a long time and although therapy dogs couldn’t come into PICU, it was only that I asked if we could go out into the corridor to meet a dog...As it turns out, she hated the dog, but I was glad she had the chance to see it anyway – the point was having the experience.”*

### **3.3.1.2. Development and participation through day-to-day life at home and in the community**

Although the importance of providing opportunities for children to develop and participate to the full extent possible while in hospital cannot be underestimated, most children only spend a small proportion of their time as inpatients.

As detailed above regarding the impacts of health conditions on children’s opportunities to participate, there are many factors that can limit the participation of children with significant health conditions within the community. Examples include, the risk of infection, the need to ensure physical safety, impacts of pain and chronic ill-health, limitations to physical strength and endurance, as well as factors external to the child including lack of community opportunities that respond to the specific needs of the child. Most parents indicated that they receive little or no guidance or direct support services to overcome these challenges and assist their child’s engagement in important life experience and developmental opportunities in their daily activities.

The need for supports within childcare centres and schools to facilitate optimal participation stood out as a particularly important issue. This was the case in relation to both the knowledge and skills of childcare workers and teachers, as well as resources to provide direct support and assistance to the child to firstly enable a child to attend at all, and secondly to gain the most they can from the experience.

*“[it would be valuable] to have a respite carer to help with going to group activities where I have both girls [with disabilities] to take.”*



*“If the teachers understand why they’re like that and where their weaknesses are, then they can help build on those...It’s not their responsibility to do everything, but just contribute in some little way. Just even understanding would go a long way...Next year when she starts school, if her teachers have got concerns and we’re not sure, it would be good to be able to go back to that same team and say, look, this is where she’s struggling. How can we deal with it?”*

*“Because he’s so easy-going, he doesn’t raise any red flags. He’s not challenging, so he just gets put to the sidelines all the time. We’ve had this all the time...We could go to day care and leave him playing with a toy. We’d come back a couple of hours later and he’d still be sitting there with the same toy. But because he wasn’t challenging, the staff never gave him any additional assistance.”*





## Emily's story – supporting development through every day experiences

*Emily is perfect just the way she is. She's beautiful. What happened to her was devastating, but she's our little girl. She's doing amazing things! I sit back and go, 'Wow! I don't know if I'd have the strength to do what she's doing.'*

*Emily had a life threatening illness when she was very young and this resulted in significant brain damage. She was on life support for a few days. When we got the MRI they said it was really bad. They said she may not smile, she may not do anything. Not long after, she smiled for the first time. We thought it was a fluke, but she's been smiling ever since!*

*She's very switched on. She's meeting all her milestones cognitively. She rolls over. She's standing at the bath by herself. And this child is so noisy. She's always chattering away.*

*While she was in PICU we read stories to her. We had one of her first teddies with her. We asked for a CD player from the music therapy department. It was difficult, because we couldn't pick her up, but we wanted to make sure she knew we were here. So hearing our voice and holding her hands and that kind of thing. None of that was recommended by PICU, so you go in there blind. They didn't say 'You can do this, or you can do that.' But if you know the resources that are there, you're going to put your hand up. Parents are going to say, 'Wow! That sounds great. Can we get a hold of this? Can we do this?' It was kind of bring it in and ask, on the off chance they said yes.*

*In HDU when we could pick her up and move her around, we'd hold her and sing to her, and read stories. Once she was getting better no-one offered that we could go for a walk. Her first time outside the ward was when her siblings came. We went down to the playground outside. After we'd been in hospital for ages, someone mentioned the Wonder Factory. We took her there for a walk with her siblings. It was nice to get out of the ward. Being outside did her good. Fresh air and seeing different things. We didn't know if her eyesight was affected or her hearing or anything. We just wanted to keep doing normal things until we knew different. And it is all sensory. Light, sounds, the feeling of the grass. It is extremely important. People, especially in hospital, need to do that. They don't have that normal stuff and they need that normal stuff. Because kids become, for want of better words, institutionalised. I think it helps with their development to feel, to see, to hear. I would love for the hospital system to say to parents, you know, try this. What about some music? Go for a walk outside. If they're stable enough, why not? Why keep them cooped up? Give them the option. Obviously there's rules. You can't take them off the hospital grounds.*

*It might just be that difference between giving a parent that is losing their mind that little bit of sanity. They've gone, 'Wow! There's something outside of the norm that we can do.'*

*While she was in hospital we asked several times about early intervention. We know how important it is. We had to really be quite forceful and push for it, because nobody was doing anything about it. Eventually we got referred to the (child development service) and they are just wonderful. She wouldn't be where she is today without them.*

*As much as the therapy needs to be done, we need to incorporate the normal things as well. Because kids need that. They need routine. They need to know what is normal.*

*We're definitely guided by our therapists. While they're concentrating on Emily, they explain it and show us in a way we can understand, and then we can supplement it at home. Rather than doing therapy we*





*try to incorporate it with a song or game or get the other kids involved. We want the other kids to see her as normal as well. So we just do normal games, as we would have done with them, and include the other kids so it's not always Emily! We don't say Emily is doing therapy, they're just playing games with her, and it's helping her through a normal family activity. We made a big circle not long ago and we all had shakers and were singing with her. So I think there needs to be some sort of normality there. By getting the other kids involved, it takes away the 'having to do it' kind of feeling. Our therapists tell us that we're good at doing things naturally and not even realising it.*

*Our top priorities for our daughter are to work closely with the therapists to give her the best chance at a normal life and developing any skill that she's capable of. We want her to be the best that she can be.*

### **3.3.2. Supports for complex child development needs**

One of the strongest and most consistent themes within the project related to the challenges accessing formal child development supports, within and beyond the health system, for children with, or at significant risk of, complex development needs. A number of interacting issues were identified, including:

- lack of timely information and referral to formal child development supports,
- excessive waiting times for formal child development supports within the community,
- the need to fight for services,
- access to supports based on diagnostic criteria rather than need, and
- the impact of personal finances on access to child development services and supports.

All children involved in this study were accessing formal supports to assist their development and participation. This universal access to child development supports should be interpreted with some caution as the professionals and services that engaged most actively in recruiting project participants were services that provide child development supports.

The formal supports to child development and participation being accessed included:

- services from public and private allied health professionals and developmental paediatricians,
- allied health support from Education Queensland and Disability Services Queensland,
- a range of supports from non-government services such as Montrose Access, the Cerebral Palsy League of Queensland, Hear and Say Centre, Mamre, and Xavier Family Support Services, and
- special education support in public and private preschools and schools.

*“We not only had issues accessing services via QHealth but also hit brick walls with EdQld and Disability Services. I firmly believe my daughter would be ‘further along’ had she been able to consistently access the recommended and required support services.”*



### 3.3.3. Lack of timely information and referrals to formal child development supports

Of concern to parents was the lack of timely advice to ensure families are routinely able to consider and make informed choices about the range of options available to support their child's development and participation, in the short and long term – whether these supports be within or beyond the public health system.

Two parents involved in the project presented highly contrasting experiences in relation to accessing information and referrals to relevant child development service. One parent spoke of needing to persist for over a month once her child was medically stable in order to access information about child development supports that were immediately available within the hospital where she was an inpatient. This occurred in the context of having been given a grave prognosis for the likely developmental trajectory of her child, but no guidance regarding opportunities to facilitate the best outcome possible. In contrast, a second parent explained how she was provided with comprehensive information about service options and support from the outset of her child's health concerns. This parent described an experience of being well supported throughout and, having observed the contrasting experience of many other families, expressed a desire that all families were afforded the same opportunity.

*“We’re very proactive parents who think, ‘Let’s not stick our head in the sand. Let’s get on top of it. We want to start.’ We weren’t giving up on the therapy side of things. We eventually did get referred to the (child development service) after about a month of asking for something.”*

*“Yeah. I was lucky. I had a wonderful social worker who was like, hey, there are all these wonderful services to get in touch with.”*

A number of parents recounted recognising a delay or difference in the development of their child from an early age, and spoke of their efforts to address these questions and concerns with their doctors. In most instances their doctors did not actively support them to address these concerns but rather sought to minimise the parents' concern and provided advice such as not comparing them to their siblings or to 'give them time'.

In order to facilitate timely access to services, parents spoke about the importance of a holistic view of their child's needs that considers their physical, developmental, social and emotional wellbeing simultaneously and at every step along the way. This contrasted to their typical experience of a singular, discrete focus on physical health for an extended period of time before other issues are responded to.

*“I don’t think, just because a child is clinically stable, that they should go, ‘Okay, out on your own.’ I think they’ve always got a responsibility to look after that child...Even if they’re clinically stable, don’t dismiss them. Just because your child’s clinically stable, doesn’t mean they don’t have extra needs that need attending to.”*

*“Nobody was willing to listen to me saying ‘There’s something wrong with his eyesight.’ I’d say it to many people and they were like, ‘It’s too early to check.’ I’m like, ‘No, seriously! You wave in front of him and he’s not looking.’”*





Five of the six parents interviewed explained that on the most part their access to services arose out of highly proactive efforts on their own part to find out what exists. They indicated that they found out about services through extensive personal research, by accident, or through speaking with other parents. Some parents explained that other families offered them far more valuable information than professionals – in relation to service options as well as in relation to ways to support their children in their development and participation. Where parents were aware of specific services that may be an option for their child, or when they assumed relevant services must exist, a strong and recurring theme arose regarding the need to ‘fight’ for more specific information and then for a referral to access the service.

The suggestion was made by some parents that the reason some medical specialists do not actively facilitate parents engaging with child development services is that they don’t believe they offer any particular value. This was a source of significant disappointment for families who, once they had engaged with the services they were seeking, reported significant benefits to both their child and themselves. The survey findings reinforced this finding, with parents nominating therapists as a key source of support more frequently than any other option provided (n = 31, 73.8%).

*“I actually think the doctors don’t think it’s that beneficial, which is a shame. If they took the time to come in and follow a child’s story, for instance our daughter’s story... You follow the story and you think, “Okay, this is where she was. We know this is bad. This is where she’s gone to.” Every month that she’s been in therapy, how much of a difference it’s made. Compare that to a child who has had no intervention whatsoever. There’s a massive difference. I think if they were more informed about what therapists are doing and how it helps, I think their opinion would be a lot different.”*

*“Disability Services got a written discharge from the girls at (community health service). They looked at what they’ve been doing and they pretty much picked up where they left off... Even in the two appointments so far you can tell that they’re looking at his underlying needs. His medical needs. Not just the fact that he is slow... It’s been a good transition for him.”*

### **3.3.4. Fighting for services and supports**

Parents spoke with great distress at the additional unnecessary demands that ‘fighting for services’ placed on them in the context of an already extremely demanding role meeting the daily needs of a child with significant health concerns. This distress was borne not only out of the energy required to access services, but also the challenging realisation that their child was missing opportunities to develop to their full potential whilst navigating a path to service access. Parental knowledge of the importance of early intervention further compounded this impact when long, and seemingly unnecessary, delays were experienced. Parents found this process exhausting and expressed their disbelief at the fact that it should be necessary. One parent raised the need for an advocate or support person to assist in navigating the system and ensuring each child has the opportunity to access services that are available and relevant to their needs.

Parents explained that given that most of what they access for their child is as a result of significant effort and without any particular support from the formal systems around them, they were left with concerns about children and families less able to advocate for themselves. Some families gave specific examples of children they know who receive little if any appropriate supports relative to their child’s development and participation needs.



*“Our son is a very complex child with a lot of medical and special needs issues. Because he is a quiet and well behaved child, he falls through the cracks. We have noticed this a lot in different settings. Our son needs significant support.”*

*“Families need an advocate because you get sick of having to explain yourself, trying to find out the services that he’s allowed to get to...a ‘go-to’ person, to say, ‘I don’t know what I’m meant to be doing. What’s the process? When do we come back? Who do we have to call?’*

### **3.3.5. Access to supports based on diagnostic criteria rather than need**

A strong and recurring theme across the interviews was the significance of diagnosis rather than need serving as the ‘entry card’ to a wide range of supports and financial assistance. Parents repeatedly detailed the great sense of unfairness arising out of a support system built around ‘ticking diagnostic boxes’ rather than responding to recognised need. This was particularly the case for children with specific and significant health conditions that had major consequences for their development and participation but are not considered as ‘disabilities’ for a range of funding and service supports from the Commonwealth Government and State Government (e.g. congenital health conditions, epilepsy). For some children their need for support is so great, and the support options so few, that even a diagnosis that is not a ‘good fit’ for a child was an outcome to be celebrated given the opportunities it would open up. Others didn’t want their child to have a diagnosis simply so they could receive funding, but were well aware of the opportunities that would be available and the decisions they could make if their child’s needs were appropriately recognised.

*“Our son has a disability, but in comparison to other disabilities he appears mild. Because he is so active his [disability] is almost a hidden disability and people just think he is a naughty child not realising that he as a PEG, a diagnosis, etc. His syndrome receives no Government funding (i.e. Better Start) and we are relying on second jobs, parents and tight budgeting to provide him with the weekly speech therapy and private access to gastro and ENT services.”*

### **3.3.6. Excessive waiting times for formal child development supports in the community**

A proportion of children whose health needs result in frequent and/or lengthy hospital admissions receive comprehensive, well-coordinated multidisciplinary child development support from their treating hospital during their infancy. However, parents described mixed experiences of transitioning to community based services provided by Queensland Health, other government departments, or non-government organisations once their health condition was more stable and the hospital environment was no longer the most appropriate service option for their child’s development needs. A minority of parents described a smooth transition to community based services, with minimal if any waiting times, and an effective handover process. A number of parents described extended wait times with long periods of no support, restricted support options in terms of the mix of professionals any one child could access, significantly reduced intensity of intervention, and loss of the value of a highly integrated team based approach.



*“I can’t get enough therapy. Plain and simple. When we were exited from the (hospital team) to the (community health team) we needed physio, OT and speech. I could get heaps of OT, physio about every 6 weeks, and I was told the wait for speech would be over 2 years, so don’t even bother. In the 6 months it took to transfer from (community health) to Disability Services (FECS) we had NO SPEECH THERAPY. And now FECS only offer us speech approximately once a month. All the therapists agree my daughter is making progress and CAN LEARN, and more therapy will be beneficial...The combined appointments [at the hospital] were absolutely invaluable. A huge amount of my stress comes from having to explain and re-explain and pass on information from one therapist to another in an endless cycle. Not to mention driving to three appointments a week instead of one. The TEAM APPROACH at the (hospital) was highly beneficial for my child, and much less stressful for me.”*

*“He has had delayed speech and required support from speech pathologists which is ongoing, he also had a balance problem and had physio and occupational therapy, but when we moved out to (regional town), he went on the waiting list, and then we had to move a year later to (regional town) and still did not get support, another year in (regional town) and no support for physio, speech or occupational...We eventually just moved back to Brisbane to try get back into the system only to be told it was too late as he was turning 5.”*





### 3.3.7. Impact of personal finances on access to child development supports

The issue of the impact of personal finances on service access recurred throughout the project. When a child has high support needs and experiences extremely vulnerable health, and therefore is not in a position to attend childcare, there is an immediate impact on a family's earning capacity. This impact occurs on top of the additional cost of caring for a child with significant health needs and the lost income of a working partner arising out of attendance at appointments. For families living in rural and regional areas the costs of travel, accommodation and even greater time away from work, this impact is even more significant. Each of these factors has an impact on the entire family, as well as on the capacity to access the formal and informal supports that may benefit the child. Where circumstances allowed, parents who had maintained employment, to the extent that was possible, noted the additional opportunities the extra resources opened up for their child.

*"We both work in professional roles. Had we had to give up our work to care full time for our daughter her options would have been far worse and most likely her outcomes to this point. This is because of the financial burden."*

*"...Parking [at the hospital] is at a premium, there is no street parking and I pay up to \$24 a day in parking fees alone. I now drive a minibus because (we have a large family) but there is no parking available for high vehicles so I have to take my son and his siblings on the train and the bus which not only takes extra time but costs extra money as well. People with autism seem to have no problem accessing thousands of dollars of funds for extra support whereas I can't even drive to an appointment."*

*"I'm not sure what it's like for people with actual diagnosed syndromes, but at this stage we get no funding support for her, or anything like that. Everything is out of our own pocket."*

#### Michael's story – the challenge of accessing supports

*My husband and I live in regional Queensland with our son, Michael. When Michael was born, everything was fine. I had him checked out when he was 11 months because he wasn't crawling, but they said he was still in the normal range. He crawled just after he was one, then walked by 16 months. By two years, he was just like all his peers.*

*Just before Michael turned three, over a period of just a couple of weeks, he went from being perfectly fine to having 70 seizures a day. It was such a difficult time. I don't know if it's from a regional point of view, but families need an advocate...a 'go-to person', to say, 'I don't know what I'm meant to be doing. What's the process? When do we come back? Who do we call?'*

*It was so difficult to get the services we needed. Once you get into a service the doctors, specialists and allied health are wonderful but everything you access has a long waiting list, it takes an emotional toll on your family and child. It is heart wrenching to watch your only son suffer. My son is the bravest person I know. My son is on a Ketogenic diet. He has to eat at specific times and can only eat three meals and two snacks a day. It's intense, but it's been the only thing that's helped. His epilepsy is considered to be drug resistant. Before this we were desperate. Because of limited places due to funding it took a*





*long time. We're probably at the best place we've been in a year and a half. That's because of food. But some days I spend a minimum of four hours cooking, and that's just for Michael.*

*About a month into things he started wearing a helmet that the hospital issued, because of the drop seizures. We were very cautious of going out anywhere. We tried to do playgroup, but it wasn't safe. He'd go there and have a seizure – so you kind of stop. We stopped going out from a safety perspective and from an illness perspective. If he gets ill, it brings on seizures, so it is very isolating.*

*Michael's development has been affected, probably from a lack of experiences because he's been so unwell and because of his medications. One of the medications stops him from sweating, so he overheats and when he overheats he has a seizure. So the medication limits what you can do, the food limits what you can do. His seizures limit what you can do. He's not toilet trained yet because you couldn't leave him on the toilet because of the seizures. Because of having seizures around the time he was eating, you have to monitor what he eats and how he eats it, and because the diet is high fat, I don't know any child that would eat high fat food without fuss, so I have to feed him. His speech and this thought processing have been affected by the medication he's on and his uncontrolled seizures. And his fine and gross motor skills are not the best, he has no strength. We're trying to get him some support through the Early Childhood Development Program, through Education Queensland.*

*We have access to OT and a physio and a speech therapist through the hospital, but it's just getting into the services that's a big issue. There's lots of different models like the Better Start program – but my son's epilepsy does not qualify him for this funding.*

*Now the seizures have improved a bit Michael goes to kindergarten. They have an aid for him from 9:30 to 11:30. Otherwise I'm there with him. I can see the benefit of him going, so I go with him. He needs one-on-one time. I find it difficult that the Government don't define epilepsy as a disability. It has been very stressful and complicated process applying for a grant through the government so that he has aide for a few hours a day. I worry about him going to school next year. He's not considered severe enough to just 'tick' the box. He only has to have a seizure and cause himself a significant head trauma, and then terrible things will happen to him, and then he'll qualify for something. It's terrible.*

*It would also be really helpful to have a group, a peer support service, in regional areas, almost like a playgroup-support group.*

*There aren't any services to look after Michael, so I had to give up work. It's had a big impact financially. Our hopes for Michael are that he becomes seizure free, that we can keep him safe from his seizures, reduce his medication, and hopefully try to catch up his developmental delays so he can go to kindergarten and prepare for mainstream prep. I also hope we can normalise the epilepsy and give him good social interactions.*





### 3.4. Making the difference to children's development and participation

The survey sought to understand the range of issues and supports parents currently believe help or challenge their child's development and participation.

An important but not surprising finding was the critical contribution of parent's perceptions and personal knowledge in relation to enabling their child's development and participation. The factor most frequently nominated as helping a child's participation was 'my belief about what my child can and should do', with just over half the parents identifying this as an important influence (n = 22, 52.4%). Similarly, a parent's personal knowledge and problem solving was the second most frequently identified source of support (n = 28, 66.7%). Reinforcing the importance of building the confidence and knowledge of parents was that when considering the supports parents would like more of, one third of parents selected 'knowing how to adapt activities to make it easier for my child to participate' (n = 15, 35.7%) and nearly a quarter of parents selected 'my own knowledge and problem solving' (n = 10, 23.8%). Additionally, the value that a significant proportion of parents place on being able to draw upon the support, knowledge and experiences of 'other families with a child with similar needs' was clearly evident, with over one third of parents seeking additional engagement with other families (n = 15, 35.7%).

*"Other parents of sick kids have been more important to me than any other source of support, in inspiring me to normalise my daughter's life, showing me what was possible. Basic stuff like how to transport a child hooked up to three different devices – not letting that stop. Encouraging me to think laterally. When other people not living this life make suggestions I often feel quite hostile, but if other parents living this life show me what they've done I pay attention."*

*"I've got a friend whose little boy has severe, severe autism. And she says, 'I love you,' and 'You get it more than any mother I know,' she said. No one gets it like another mum whose kid is at the same level."*

The value placed on engaging in everyday activities and social interaction was evident through one third of families indicating that 'opportunities for my child to participate with other kids' (n = 14, 33.3%) was helpful to their development and participation. However, the 'lack of community activities that are well suited to my child's needs (e.g. playgrounds, sports clubs, libraries, theatres)' was recognised as a significant barrier for one third of children (n = 14, 33.3%) and was second only to the impacts of the child's health condition and intervention.

*"She had to stand on the edges. Still in the pool, but at the side. Her swimming instructor was very understanding...So she was really, really good with her...But it was hard because she wasn't really getting anything out of the lessons. She really needs it more from a physio point of view, rather than Learn to Swim, at this stage."*

The important contribution of health professionals to a child's development and participation was also demonstrated. Three quarters (n = 31, 73.8%) of parents indicated that their child's therapists were currently serving as a significant source of support to their child's development and participation. Importantly, this was the most frequently nominated support to participation. More generally, just over half the parents noted the value of 'health professionals pay attention to my child's need to participate when they plan my child's treatments' (n = 22, 52.4%) and to a slightly lesser extent, 'health professionals spend specific time planning to support my child's need to participate' (n = 17, 40.5%).



Interestingly, when asked about the supports it would be helpful to have more of, a child's medical team and a child's therapists were only nominated by 14.2% (n = 2) and 11.9% (n = 5) of parents, in contrast to other supports already noted above and the additional supports of 'my child's childcare centre/school/TAFE' (n = 12, 28.6%) and 'general community groups not specifically related to my child's needs' (n = 11, 26.1%). These findings reinforce the important issue of needing to identify the specific goals most important to an individual child and family, and their preferred path to fulfilling these goals, including understanding the preferred and most appropriate contribution of formal service supports to these goals.

When considering the issue of formal service supports, parents spoke about the way different child development professionals related to their child and how this impacted on the experience of intervention. Most parents spoke of experiences of allied health professionals being highly sensitive to their needs as parents and their child's needs in the context of their child's past and current health and development.

However, parents stressed the negative impacts when this did not occur and were surprised that professionals who knew their child's story and history might not have a greater appreciation of the issues of past or current experiences of pain, trauma, illness and compromised opportunities for participation. Their responses reflected the significance of such sensitivity to successfully establish and maintain a relationship conducive to effective support and intervention – for both their child and their parents. Through the online

*“With hydrotherapy they said, ‘Has she gone under the water yet?’, and I said, ‘No!’ It was just a question and straight away I was saying, ‘Whoa!’ And they didn’t push it. They knew I felt uncomfortable and I was clear, ‘I don’t want to put my baby under the water.’ We compromised and we did it in front of her, we got little splashes on her face and that kind of thing. Then we went from that to putting a bit of water on top of her head. Now – she puts her head in! She goes face first into the water now! At the time I was not comfortable at all. They knew that and they didn’t push at all. Whereas, my other children, when they go to see their therapist, they will push.”*



## **Ben's story – responding to a child's needs in the context of their health condition**

*Ben is my youngest boy. His two brothers get along really well with him. Having me and his two brothers around, that's what he loves. He gets kind of anxious if I'm not close to him. He does well with music and just loves it when we sing and play with him. And the remote control! He's trying to steal it from the boys all the time, and just laughs.*

*We realised Ben probably had health problems when he was a couple of days old. At first they weren't quite sure what was wrong, but after doing some investigations they found there were a number of health issues. He possibly has (syndrome), but he doesn't quite meet all the criteria. Ben is also legally blind. About 90 per cent of what I understand about Ben's needs comes from my own research. My paediatrician doesn't really go into a lot of stuff.*

*After Ben was born he didn't come home for a few months, so I expected him to be slightly behind. And from very early the professionals said he would probably have a developmental delay, even though he was still on track at that time. While he was in hospital no-one talked about anything around his general development or ways to stimulate it. People were constantly focused on his weight and bottles!*

*I didn't think about his development much either. We were just so overwhelmed with trying to get him home, and the only reason we couldn't was because of bottles! We weren't really focused on anything else. I started to become concerned about his development at eight months. At about seven or eight months he started clapping, and then after that we went downhill. He rolled from back to front on time, but he never liked being on his stomach and he didn't like sitting up because he was so sick with reflux. He'd just throw himself back in pain and scream. He's slowly progressing, he hasn't stopped. He's 21 months now and rolls everywhere. But he does get up on all fours and do the rocking. And he can sit without help for one or two minutes. When he wants to!*

*He had physio, OT, speech, at the hospital from very early. Later we changed to (the community based child development service). Ben did really well there. He loved his OT and speechy. They didn't push Ben too hard. With some other professionals Ben sees he screams for them to go. He's just like, 'Get out the door.' When they leave he sleeps for three hours. I get what they're trying to do, but when he basically signs for them to stop, and they won't. So he knows when they walk in the door – he's not happy they're here. Ben just likes the others because they're nicer to him. The way they speak to him and the way they hold him. A lot of people, especially his paediatrician, skim past the fact he can't see. Where his OT and physio were very aware he cannot see properly. So they worked his therapy around this. And they wouldn't force him to sit up when he had the reflux problem because they knew he'd be in too much pain. They were quiet with him, and reassuring. He felt safe. The most important thing is that he feels safe. I'm realising it's because of his sight that he gets quite anxious.*

*It was like, "I don't want to leave you guys." They didn't tell me what to do, they worked with me. Unfortunately there wasn't a choice – at a certain time you need to move to Disability Services. So now we've moved to Disability Services and we've been approved for Better Start funding. In a short period of time we've changed services three times. But it's been a good transition for him. It hasn't been that bad. Even with just two appointments so far you can tell they are looking at his underlying needs. They pretty much picked up where the other team left off.*



*If I was designing my perfect service it would involve someone that can work with the parent. They've got to be able to work with me, and Ben has to feel comfortable. They need to be able to understand his health issues. What I really love about my therapists is they provide really clear information about what I need to do and write it down so I remember everything. And it's more about the fun bit for Ben. He doesn't like doing physio much unless it's fun!*

*He does really well at the Education Queensland Early Childhood Development Program playgroup. He loves it. It's almost like a physio and OT thing for him with painting, swings and other things. That's where he shines the most, when we can go there and do his physiotherapy with all that stuff.*

*I'd like the changes of services to stop. I want to be able to settle him down. He was lucky, he did have the same OT and physio for about nine months (at the child development service). So he did get lucky there. I think it's best not to swap them around so much. I'd wish I'd gone straight to disability services so I didn't have the change now.*





## 4. Messages for the service system

### 4.1. Family priorities for their children

Through the online survey parents were asked about their priorities for their children. The responses to this question were wide ranging, including priorities relating to the services they receive and how these services are delivered, their child's short and long term health outcomes, as well as their broader priorities for their child's long term social, vocational, physical and emotional wellbeing.

A number of parents presented their priorities in very broad terms, expressing the importance of their child having the chance at the best start in life; a good quality of life; health; happiness; as normal a life as possible; and as a parent – the experience of loving their child.

Not surprisingly, for the absolute majority of parents, their priorities were mediated by their understanding of their child's current and likely future needs.

Although the discussion regarding parent priorities presented below is presented under discrete subheadings, for most parents these priorities are interrelated and each one is supportive of the others.

#### 4.1.1. Priorities for health

Parents raised a range of priorities around their child's health. For one parent, in the context of a highly complex, life limiting and life threatening condition, survival was the starting point upon which a range of other priorities were then built. Similarly, other families of children with health conditions that impact significantly on day to day life expressed priorities to maintain the health and safety of their child by avoiding infections (e.g. when immunosuppressed or when infection will exacerbate an existing condition), avoiding anaphylaxis (e.g. in the context of severe environmental and food allergies) and protecting their physical safety (e.g. in the context of epilepsy).

For others, the successful management of specific chronic health needs such as incontinence, seizures, constipation, sleep, and gaining weight was an important focus.

Recognising the impacts of specific interventions, for some children a significant priority is to achieve the maintenance of optimal health with as little pharmaceutical intervention as possible was an important issue.

A number of parents expressed a particular priority to support their children to understand and progressively manage their health needs with greater independence over time.

*“To maintain his immunity, avoid infections and keep him active and healthy.”*

#### 4.1.2. Priorities for development and participation

Children's development and participation also featured strongly in parent priorities for their children. Parents spoke in general terms about their children reaching their potential, but many also articulated the importance of their child developing skills in specific developmental domains, including communication, feeding, social skills, managing their emotions, and mobility.

A number of parents expressed their desire for their child to have access to opportunities for participation, inclusion, and socialising. More specifically, one parent explained the importance of surrounding her daughter with people who could see her abilities rather disabilities.

The opportunity to attend school full-time, successfully participate in mainstream education, and have teachers who understand their child's health condition and needs were specific goals relating to participation in education.





*“Mobility and participation in the community and at school. To grow and learn as much as she can in a normal learning environment.”*

*“To be able to communicate and participate in more activities that other children do.”*

#### **4.1.3. Priorities for how services are delivered**

How children and families experience the services that are provided was also raised repeatedly as an important priority. In particular, the need for highly personalised care from all parts of the health system was emphasised. Parents also stressed the significance of having timely access to appropriate types and amounts of information, assessment and intervention for the full range of health, development, and social and emotional needs of their child and family. The importance of these services being well coordinated was also emphasised to improve quality of care and reduce unnecessary demands on families.

*“Timely access to specialists...Good coordination of specialists...Availability of the same specialist for each visit...Access to specialists in-between visits (i.e. via phone/email).”*

*“Be seen to quickly. Be seen as a patient and not as a number. Receive a consistent level of care regardless of which department, ward or specialists are seeing my child.”*

#### **4.1.4. Priorities for emotional wellbeing**

The priority of a child’s emotional wellbeing was raised by many families. The happiness of their child was a critical goal. As an important element of this, parents spoke about the importance of their child being able to successfully manage and maintain their emotional wellbeing and remain positive in the context of their health needs and the impacts of the interventions they receive. One parent explained the importance of her child having the chance to ‘enjoy being a child.’

*“For him to remain positive despite his health. To never give up on life. To return to normal life at the end of treatment with no adverse side effects. To learn from this and pass on to others.”*

#### **4.1.5. Priorities for the long term future**

Parents’ priorities also included their hopes for their child’s long term future. Here aspirations were expressed for their child to get a job they enjoyed, to have a family, achieve independence, and learn from their experiences. More specifically, parents expressed the importance of preparing for the relevant long term supports their child would need, starting with planning for adolescence and young adulthood.

*“To have him live as independent a life as possible and hopefully hold down a job and have a family.”*



#### 4.1.6. Priorities to open up functional opportunities and life experiences

In sharing their priorities for their children many parents reflected on the specific functional opportunities and life experiences that would be available to their child if their priorities could be met – improved mobility would give a young child the chance to independently explore their world; improved communication would support a child’s emotional wellbeing and their capacity to participate socially; and successfully managing chronic illness and maintaining their child’s health would support greater participation in school and other important childhood activities.

*“...Being as well as possible so our child can go to school, see friends, enjoy life, and participate in hobbies like ballet or art or circus classes...”*

### 4.2. Key messages from parents

Parents provided a number of important messages they believe need to be heard and responded to if children with significant health needs are to be successfully supported to fulfil their developmental potential.

#### 4.2.1. Listen to and value the contributions of parents

*“First of all, I think the health system needs to listen to the parents...When you’re meeting a child for the first time, your impressions are exactly what’s in front of you. You’ve got a parent that’s with this child 24/7...Just because they don’t have a degree doesn’t mean they shouldn’t be listened to. Parents have a lot of valuable information.”*

*“We have learnt the most life changing things and health changing advice from other parents. Parents are the untapped potential in the medical system. They are PhD qualified (professors even) – in their children.”*

#### 4.2.2. Recognise that children aren’t just small adults

*“Children have needs that are unique to them. They’re not little adults emotionally, physically, mentally. Things need to be more kid friendly. The environment they’re in, the way that – I was going to say the way they’re spoken to, but not really. People do get down to their level in hospital. But just that they’re not little adults. They’re kids.”*

#### 4.2.3. Respond to a child’s needs beyond being clinically stable

*“I think the hospital has an obligation to a child, whether it be development or medical...Even if it’s just to outsource them to somebody else, like a community organisation or finding information for them. They need to be the ones that say, ‘Look, you don’t have to do this alone. There’s this organisation. Or we can refer you to this therapist.’ When a child is under their care, they have a duty of care to that child.”*



#### 4.2.4. Establish a systematic approach that responds to the development and participation needs of all children

*“There IS no systematic response to support the participation and development of children who have complex health needs. There are various interventions, programs, initiatives, services and volunteer programs that are offered seemingly without coordination and without prioritisation in relation to children that receive them, and that are often received serendipitously rather than through a planned, systematic approach!”*

*“Every child is unique. My child is wonderful but he is not perfect and when he is your only child you want the best for them. If you live in a developed country, it shouldn’t come down to money. The only thing I can say is, come and live my hell. That’s what it is, really, some days. Come and do everything we do to save him on a daily basis, I have become his carer first and then his mother. Our children are the future...I hope my son grows out of it. His idol at the moment is being a doctor, so what’s that say about his life? He plays doctors a lot. To me, that’s a big tell. That’s his life.”*

#### 4.2.5. Support the whole child

*“I never thought I’d say this, but I think they just need to look at wellness. It’s almost that whole social, emotional stuff. They have their little bit that’s their favourite bit, but they need to look at the whole picture and understand the whole picture...All they are worried about is her lungs. They’re not looking at her.”*

*“In our experience a lot of medical teams and allied health specialists (in particular) focus on their specific speciality only and do not consider the whole of the child. This includes considering their part in a family unit. If the family is not supported (parents, siblings), the child by default will also not be supported or have as good an outcome.”*

#### 4.2.6. Support parents to understand their child’s development and participation needs across their life course

*“The support that the occupational therapist, physiotherapist and speech therapist have given (and continue to give) our daughter is amazing, but they have also been just as important to us as the parents to reassure us and guide us and explain things to us in a way that helps us reduce our anxieties and better understand what they are doing for our child and why.”*

*“For our child to develop and progress it’s important to be able to access information and support services to help us understand her and her disabilities. It has only been recently that we’ve been able to access a team of specialists at (child development service). This service is absolutely wonderful and we are so grateful to be able to have their assistance and guidance for our daughter’s overall development...In her early years we weren’t really given any information or offered any assistance and had to go home to ‘Google’ what things mean.”*



#### 4.2.7. Ensure access to information about support and intervention

*“I just wish everyone had the same experience as me, really. I wish they were knowledgeable about the things that are available to them, basically. I think there maybe needs to be a bit more information about it so parents don’t feel so overwhelmed when they find out they’ve got a sick child.”*

#### 4.2.8. Support children to participate in typical activities of childhood, in hospital and in the community

*“Development can be aided by therapeutic interventions but I assume most development happens from everyday living and creating opportunities for children to enjoy new experiences.”*

*“It is hard because she needs extra support in her activities, like in swimming, to help with her development...So I think maybe if there was any way that the therapies or the health system can help with that...Give those services assistance in understanding how your child needs help. I guess as she gets older and wants to do more things, like dancing and things like that, she’s going to struggle. We haven’t had a lot at this stage where she can’t participate. It’s only been swimming where they haven’t been too accommodating to her.”*

#### 4.2.9. Ensure access to support and intervention, across the life course

*“There is not enough therapy available to parents with children who don’t have funding. It’s so expensive to have private sessions which delays the help the child needs.”*

*“There are many services that may have been of benefit to our son when he was little but we were unable to access these as the waiting lists were very long and unfortunately it is extremely difficult to get carer allowance and then try to pay for these services privately. He was unable to access speech therapy at school and in order to access it through the hospital a lot of travel and cost was involved.”*

#### 4.2.10. Facilitate early intervention

*“Early intervention is the key! We are so grateful to the (child development service) and all the work they do because when doctors saw our daughter’s MRI they didn’t hold much hope for her. But to see what she has accomplished and still is accomplishing is a direct result of the (child development service). They have given our daughter the greatest gift of all... the opportunity, through their wealth of knowledge and guidance, to have the best life that our daughter can... You’ve got an amazing resource... It’s helping the children now, it’s helping them later in life, but it’s helping the health system as well. How many children are out there that have injuries that don’t get the therapy? Then they try to make up for it later on in life.”*



#### **4.2.11. Integrate and coordinate services to reduce the burden on families**

*“There is no one to hold all the information together. I find I’m having to co-ordinate everything, as I only see the paediatrician every 6 to 12 months, and therefore he has no idea what is going on. I’m unable to see the doctor often enough to keep him up to date, so it’s me constantly trying to find out what his issues are and have them seen to. So to date there are lots of unresolved issues...but I do what I can. The hospitals and doctors/specialists don’t offer me a co-ordinated approach. This makes it difficult and I feel I am failing my child.”*

*“I have twin girls with (disability). One is more severe than the other. The worse of the two is high dependant. They get seen through different government agencies which makes juggling appointments that bit harder. We have access to funding for one but not the other.”*

#### **4.2.12. Provide supports with awareness of a child’s health condition and sensitivity to past and current experiences of the child and their family**

*“And they wouldn’t force him to sit up when they knew he had that reflux problem, because they knew he’d be in too much pain. So they worked with him really well. Where (health professional) will just sit him up. She still thinks it’s all in his head.”*

*“The hospitals have also been hard at times with staff overriding what we think as parents to be best for our boy, it’s very distressing for us.”*





## 5. Summary and conclusions

This project was undertaken as the first step in a process of working towards optimising the development and participation opportunities of Queensland children who have significant health needs. Although small in scale, the diverse experiences and perspectives offered by parents who have contributed to the project offer insights of enormous value.

These insights relate to:

- the significant development and participation challenges experienced by children who have significant health needs,
- the importance of families having well integrated services to support their understanding of their child's needs,
- the lack of systematic approaches to ensuring access to appropriate supports for child development and participation, resulting in the need for parents to 'fight' for the assistance they recognise their child needs, and
- the factors that contribute most significantly or act as barriers to the development and participation of children who have significant health needs and their families.

The project has also offered important perspectives on the priorities parents have for their individual children, which serve as a reminder of the critical importance of every child and family having the opportunity for their supports to be shaped by their unique goals and aspirations.

Finally, the specific messages from parents to the service system provide explicit direction to help guide more systematic service design, development and delivery that optimises the development and participation opportunities of children who have significant health needs.

# Literature Overview





## Literature Overview

### Understanding the development, function and participation of children with Special Health Care Needs and/or Chronic Health Conditions.

#### Introduction:

Children in Australia benefit from social and political contexts that both value and invest in robust health and education systems and practices. While most Australian children are medically and developmentally well, there is a small but significant number who have chronic conditions (across physical, developmental, behavioural and/or emotional domains) that require health and related services of a type or amount beyond those required by children in general. These children are commonly described as having 'special health care needs' (SHCN) (Farooqi, et.al, 2006; Newacheck, et.al, 1998).

The incidence of children with SHCN has been estimated as being between 10% and 22% of the paediatric population, yet this group consumes services valued at about two thirds of annual health care expenditure for children (Nageswaran, Silver & Stein, 2008; Turkel & Pao, 2007). The health conditions children experience vary in terms of diagnosis, severity, and impact on day to day function and participation. Children with SHCN who experience functional limitations are more likely than those who don't to have frequent and intensive interface with the health care system (including emergency department presentations, hospital admissions and long hospital stays), delays in access to appropriate care, unmet health care needs, uncoordinated care, problems with referrals, and difficulties accessing services along the care continuum (Nageswaran, et.al., 2008). Yet our health care system generally focuses on the health condition rather than on the raft of functional and developmental problems faced by children and their families (Lollar, Hartzell, & Evans, 2012).

The purpose of this paper is to better understand the developmental implications of the experiences of children with SHCN, particularly those who have functional and developmental impairment with medical co-morbidities; and to explore how Queensland's public health care services might better support these children and their families to improve development, function and participation, and ultimately better life outcomes. This overview both informed and was shaped by a parallel consumer engagement strategy that explored the lived experiences of children with chronic health care needs who frequently interface with the health care system.

#### Children in Australia:

In June 2013, there were about 4.36 million children aged 0-15yrs in Australia, comprising about 19% of the total population (ABS, 2013). The Australian population is generally concentrated around capital cities and major regional centres, and the distribution of children follows this trend. However, it is important to note that some remote Queensland communities and larger regional areas have amongst the highest distribution of children as percentage of the population in the country. Children living in remote Australian communities are more likely to have compromised health and developmental outcomes.

The majority of Australia's children are medically well and developmentally on-track (ABS, 2007; Australian Government, 2013). Death rates for children have halved over the last 20years, and diagnosed disability sits at about 8% (increasing from 4% at 0-5years to 10% at 5-14yrs). Vaccination coverage has continued to improve, albeit more slowly than in the past, with 91% of one year olds and 84% of six year olds fully vaccinated in 2005. About 63% of children participate in organised sport outside of school and the proportion of children physically active has increased, although obesity levels and sedentary behaviours also continue to rise. Leading causes of hospital admission include respiratory concerns, prematurity, and conditions of the ear, nose and throat (ABS, 2007). In 2004-05, 41% of children had a long-term health





condition, encompassing concerns such as compromised respiratory function (19% of all children), limited vision (10%), and mental and behavioural concerns (7%) (ABS, 2007). These children may or may not have compromised development and participation.

A small but significant number of children in Australia live with a chronic disease that requires special care or management to ensure optimal function and wellness (AIHW, 2005). This includes both congenital and acquired conditions such as diabetes, cancer, epilepsy, cystic fibrosis, allergies and musculoskeletal disorders. The Australian Institute of Health and Welfare recognises that chronic disease can seriously threaten a child's trajectory of development, impact across the lifecourse (in terms of education, participation and health outcomes) and compromise family function. Chronic disease, so often associated with adult health, has begun to dominate the health care landscape for children.

### Children with Special Health Care Needs:

The experience of childhood for children with a chronic condition or SHCN must be understood to be different to those of their peers. Advances in medical treatment for acute and chronic paediatric health conditions have resulted in children surviving disease and congenital disorders that were previously associated with high rates of childhood mortality and morbidity (Berry, et al, 2010; Eagleson, et.al, 2013; Mickley, Burkhart & Sigler, 2013; Turkel & Pao, 2007). However, that survival has brought new morbidities, and there is increasing awareness of the impact of early experiences and environmental influences on emerging brain architecture and long term health (Shonkoff & Garner, 2011). Our hospital, health and education systems have not necessarily evolved to consider the impact that serious health conditions and their treatment/s might have on a child's development and participation; or on how systems must work together to enable these children to become active participants in childhood and optimally functioning adults.

Children with SHCN are not a homogeneous group. Some children are born with a known condition that is likely to require a significant interface with the health care system; others have congenital conditions that become apparent over time; and still others experience adverse events or acquire a condition during childhood that alters their life trajectory. Studies that explore the impact of SHCN on children's function and participation indicate that up to 85% of this group experience at least one functional difficulty, within and across domains such as learning, attention, anxiety, and communication (Lollar, et.al, 2012; Nageswaran, et.al. 2008). Emerging evidence indicates that it is the children who have functional limitations associated with their SHCN (rather than the SHCN in and of itself) that have more frequent and less satisfactory engagement with the health care system (Nageswaran, et.al, 2008). However, predicting co-morbidities is not easy. Health conditions and a child's functional difficulties may often be aligned but are complex, and difficult to address (Lollar, et.al., 2012).

Chronic health conditions and SHCN are not evenly distributed across the population. There are groups of children who are known to be particularly vulnerable to certain conditions, and who experience both a higher burden of disease as well as poorer health and life outcomes than others with a similar diagnosis or condition (Berry, et.al, 2010). These disparities are often associated with socio-economic, cultural and geographic factors. It is also known that the characteristics of a child's functional impairment is likely to change over time, in response to age, interventions and other life experiences, irrespective of the course of the health condition (Lollar, et.al., 2012). So even if their diagnosis is stable, a child's function and participation can, and will, change and impact in different ways on that child's health and their family outcomes. Our public health care system has an important role to play in both understanding and better managing inequities, and the ever-changing impact of health care needs on development, function and participation.





While the focus for many children with SHCN is on the treatment and management of their health conditions, there is a growing recognition that development and functional capabilities might be a better indicator of outcome once survival is no longer the primary concern (Forrest et.al., 2011; Lollar, et.al., 2012). For example, long-term health conditions do not necessarily affect school performance, but functional limitations and poor developmental outcomes invariably do (Forrest et.al., 2011). With chronic disease rates increasing and the dynamic nature of these conditions becoming better understood, at-risk children need to be identified early, and health and education professionals need to work together to ensure developmental and functional needs are understood, supported and monitored over time (Forrest et.al, 2012; Mickley et.al., 2013; Van Cleave, Gortmaker, & Perrin, 2012). Table 1 offers an overview of the broad impact that SHCN may have on a child and their family, with a focus on how it shapes their experience of health care services and school.

Subsequently, children with SHCN require an individualised approach that transcends their diagnosis and encompasses a sophisticated and integrated understanding of the nature of their condition, the impact of the treatment of that condition on the child and their family, the child’s functional capabilities, and their family’s capacity to support that child across sectors and contexts (Lollar et.al, 2012, Turkel & Pao, 2007).

**Table 1: Generalisable impacts of Chronic Disease/SHCN on a child and their family**

Health Services Utilisation (i)	Impact on Schooling (ii)	Impact on Self (iii)	Impact on Family (iv)
More Emergency Department presentations	Lower academic achievement	More days in bed	Financial impact (costs of treatment and resources)
More outpatient department appointments	Lower motivation at school	Higher incidence of emotional, behavioural, mental health and psychiatric symptoms	Need to provide active caring role
More hospital admissions	More disruptive behaviours at school	Trauma associated with medical treatment	Need to stop or reduce paid employment or other activities
Longer length of stay per admission	More frequent experience of bullying	Impacts of medication	Altered interactions with health care providers
Delays in accessing appropriate services due to focus on acute health care needs	More school absences	Altered and/or delayed path to independence	Altered relationships within the family (including parent-child relationship)
Poorly coordinated care between teams	Reduced opportunity for peer interactions	Compromised confidence to participate in everyday activities/social withdrawal	Altered social relationships and extended family relationships
High levels of unmet health care needs	Adverse impact on participation in extra curricular activity	Compromised ability to participate in everyday activities	High levels of family stress and parental mental health
High levels of dissatisfaction with health care services	Increased utilisation of learning support and special education services	Infection risk and other medial implications of participation across contexts	Overprotective behaviours and parental anxiety

(i) Bebbington, et.al., 2013; Lollar et.al., 2012; Nageswaran, et.al., 2008; Newacheck, et.al., 1998; Turkel & Pao, 2007.

(ii) Forrest, et.al., 2011; Lollar, et.al., 2012; Mickley et.al., 2013; Newacheck, et.al., 1998; Turkel & Pao, 2007.

(iii) Lollar et.al., 2012; Newacheck, et.al., 1998; Turkel & Pao, 2007; Wray & Radley-Smith, 2004.

(iv) Lollar, et.al., 2012; Mickley, et.al., 2013; Nageswaran, et.al., 2008; Turkel & Pao, 2007; Wray & Radley-Smith, 2004.



## A Snapshot of Conditions:

Chronic illness in infancy and childhood compromises development across multiple domains. While there are generalisable learnings across contexts and conditions, significant variation exists in the progression of each illness specifically, the treatment that is required, and the way that a child and their family may respond to these factors. Table 2 provides a snapshot of data in regard to four conditions that are known to have impacts on child development and functional participation. These are not the only conditions that developmental clinicians are required to understand and plan to support. Other groups may include children with musculo-skeletal conditions, cranio-facial conditions, respiratory conditions, metabolic and endocrine conditions, those with significant sensory impairments, and syndromes associated with multi-organ involvement.

**Table 2: Profiling Four Populations**

<p><b>Adverse Neonatal Events (including Extremely Low Birthweight and Extreme Prematurity)</b></p>	<ul style="list-style-type: none"> <li>• There has been a significant increase in preterm births (prior to 37weeks gestation) in recent decades (now about 13% of all live births in the US) (Johnson, 2012).</li> <li>• This group, particularly those born very early and very small, experiences higher levels of significant neurodisability as well as higher levels of low severity functional impairments associated with communication, behaviour and schooling – up to three times higher than normal birthweight children (Farooqi, et.al, 2006; Hack et.al., 2005; Marlow, et.al., 2005; Pritchard, et.al., 2013).</li> <li>• Chronic disease rates are significantly higher for children born preterm and extremely low birthweight, and the difference in incidence increases when multiple comorbidities were considered (extremely preterm children 2.5 times more likely to have a single chronic disease, but 10 times more likely to have three or more) (Farooqi, et.al., 2006)</li> <li>• These children have a higher utilisation of health care services (including allied health and multimodal specialist services) and educational support services (67% of children born &lt;27weeks require additional educational support, compared with 22% of controls) than do their full term peers (Farooqi, et.al., 2006)</li> <li>• Periventricular brain injury, chronic lung disease and retinopathy of prematurity are associated with greatest risk for functional and developmental impairment (Hack, et.al., 2005)</li> <li>• Chronic conditions are stable in older childhood, with about 75% of extremely low birthweight survivors at ages 8 and 14years identified as having a chronic condition (compared to 37% &amp; 47% of controls) (Hack, 2011).</li> <li>• There is poor uptake of early intervention services, particularly for socio demographically vulnerable children (Pritchard, 2013)</li> <li>• Early intervention is more likely to be offered to those with perinatal risk factors (Pritchard, et.al., 201)</li> </ul>
<p><b>Childhood Cancer</b></p>	<ul style="list-style-type: none"> <li>• Childhood cancer survival rates have improved from 68% to 82% since the 1970s (Youlten, et.al., 2011).</li> </ul>



## Survivors

- Tumor type, site, age of diagnosis, treatment type, length of treatment and treatment dosage are all associated with variations in outcome (Barrera, et.al., 2005; Mitby, et.al., 2003). Repeated and prolonged absence from school and other functional activities also has a significant impact on participation and development.
- Tumors of the CNS, leukaemia, and neuroblastomas in particular were associated with difficulties learning and interacting with peers (Barrera, et.al., 2005).
- Childhood cancer survivors are twice as likely to access special education services as their siblings and significantly less likely to graduate from high school (Mitby, et.al., 2003)
- Increasing interest in medical community about the late effects of treatment for long term survivors of childhood cancers (Geenen, et.al., 2007; Oeffinger & Robinson, 2007) with emerging evidence indicating:
  - o High burden of disease and associated impact on daily life in young adulthood for this population (about 75%) (Geenen, et.al., 2007) including post-traumatic stress disorder (Skinner, Wallace & Levitt, 2006a)
  - o While the condition is increasingly ‘cured’, survivors experience health and participation problems as a result of the type of the tumor a person had, the treatment they received, and factors pertaining to lifestyle and genetics (Oeffinger & Robinson, 2007)
  - o Radiotherapy (particularly cranial radiation) is the treatment associated with the highest rate of adverse events in the long term (including cardiovascular, endocrine, neurologic, second malignancies, and psychosocial and cognitive events) in comparison with chemotherapy or surgery, although all have associated impacts along the lifecourse (Geenen et.al., 2007)
  - o Long term follow up and care is variable (Skinner, Wallace & Levitt, 2006b)

## Congenital Abnormalities requiring Surgery (focusing on Congenital Heart Disease)

- Survival to adulthood is increasingly an outcome for many children with severe congenital anomalies who require surgery. Ninety five percent of infants born in New South Wales requiring newborn surgery for major birth defects will survive (Lang et.al., 2011).
- While many of these children have good developmental outcomes there is a high prevalence of neurodisabilities amongst survivors, with up to 50% of the infant who undergo cardiac surgery having a congenital or acquired cerebral insult (Ballweg, Wernovsky & Gaynor, 2007; Laing, et.al., 2011; Marino, et.al., 2012; Newburger, et.al., 2012; Robertson, et.al., 2004; Snookes, et.al., 2010)
- This population of children are also frequently preterm and/or have an associated genetic syndrome, both of which pose additional challenges to the child’s development and participation (Wray & Radley-Smith, 2004)
- Some conditions require immediate surgery (or surgery during infancy) for survival and optimal outcomes, while others are required to wait, sometimes for a number of years. In both of these instances, children are at-risk of developmental impairment (Newburger, et.al., 2012; Snookes, et.al., 2010: Wray & Radley-Smith, 2004).
- Adverse neurodevelopmental outcomes include impairments of: cognition, attention and executive function, visual-spatial and visual-motor skills, communication and behaviour. These deficits may only be evident later in childhood and may or may not be modifiable depending on the cause of the impairment and patient specific factors. (Ballweg, et.al., 2007; Shillingford, et.al., 2008)



### Congenital Abnormalities requiring Surgery (focusing on Congenital Heart Disease)

- There is a critical period between 6mths and 4years during which hospitalisation has been found to have a particularly detrimental effect on children (Wray & Radley-Smith, 2004).
- Factors that have been attributed to adverse developmental outcomes for this population of children includes repeated general anaesthetic, frequent and long hospitalisations (unstimulating physical environment, frequent changes in caregivers, separation from family), experience of painful and traumatic treatments, comorbid syndromes and other genetic factors, compromised nutrition in early childhood, prenatal factors, long duration of illness, cyanotic lesions and hypoxia (Ballweg et.al, 2007; Marino, et.al, 2012; Newburger, et.al., 2012; Shillingford, et.al., 2008; Wray & Radley-Smith, 2004)
- Brain injury is the most common long-term complication of congenital heart disease requiring surgery in infancy (Snookes, et.al., 2010) and a high percentage (nearly half) will require additional learning support at school (Shillingford et.al. 2008).

### Epilepsy

- There is a childhood prevalence of seizure disorder of about 1%, with associated medical, developmental and educational implications that are likely to persist into adulthood due to significant rates (>50%) of developmental and learning impairments (Russ, Larson, & Halfon, 2012)
- Known developmental comorbidities include: depression (8%), anxiety (17%), ADHD (23%), conduct problems (16%), developmental impairment (51%) and autism spectrum disorder (16%). Limitations to function and participation are also reported as are social competence and parental aggravation (Russ, et.al., 2012).
- While epilepsy in adults occurs in the context of a developed and relatively stable cognitive state, children present with the additional complication of dynamic cognitive and brain development (Herman, et.al., 2008). Subsequently the combined and accumulative effects of the condition, the treatment, the child's pre-morbid state, and environmental factors will shape that child's developmental and their functional potential and outcomes.
- There are a vast number of epilepsy syndromes, many of which start in childhood. These syndromes will follow variable pathways in terms of prognosis and treatment (Besag, 2006) so clinicians supporting optimal development need to understand these variations and their implications.
- There are cognition implications in both the short and long term for children with epilepsy. While there is concern about the progressive cognitive impairment that may result from chronic medication resistant epilepsy, or from the medications themselves, there is evidence that diffuse mild cognitive impairment is evident close to onset, and that changes to function may be evident even prior to a child experiencing seizure activity (Herman, et.al., 2006)
- About 70% of childhood epilepsies will stabilise due to successful medication or spontaneous resolution within 2years of onset (Ostrom, et.al., 2005)
- Parenting behaviours have a strong influence on educational participation and outcomes in children whose seizures have resolved, with this factor influencing outcomes beyond medical variables (Ostrom, et.al., 2005).



Conversely, it is known that children with pervasive developmental disorders are more likely than their peers to have medical comorbidities and interface more frequently with the health care system (Kohane, et.al., 2012, Levy, et.al., 2010). For example, Autism Spectrum Disorders (ASD) has a prevalence rate of about 1%. Children with ASD have a substantial interface with specialist medical services outside of developmental clinics, and this interface increases as they get older (Kohane, et.al., 2012). It is known that children with ASD have significantly higher incidences of bowel disorders, CNS anomalies, respiratory condition, epilepsy and psychiatric disorders, as well as a much smaller chance that these conditions will resolve (Kohane, et.al., 2012; Levy, et.al., 2010; Schieve, et.al., 2012 ). The presence of ASD can both mask and be masked by the presence of other medical conditions (Close, et.al., 2012; Kohane, et.al., 2012; Levy, et.al., 2010), and this group of children has unusually high rates of hospitalisation and emergency department presentations (Bebbington, et.al., 2013). These factors indicate that children with ASD and other pervasive developmental impairments are particularly vulnerable in terms of their long term health and social participation outcomes. Subsequently, the current healthcare system must be better equipped to care for this growing population of vulnerable children (Bebbington, et.al., 2012; Berry, et.al., 2010).

### Opportunities for Action:

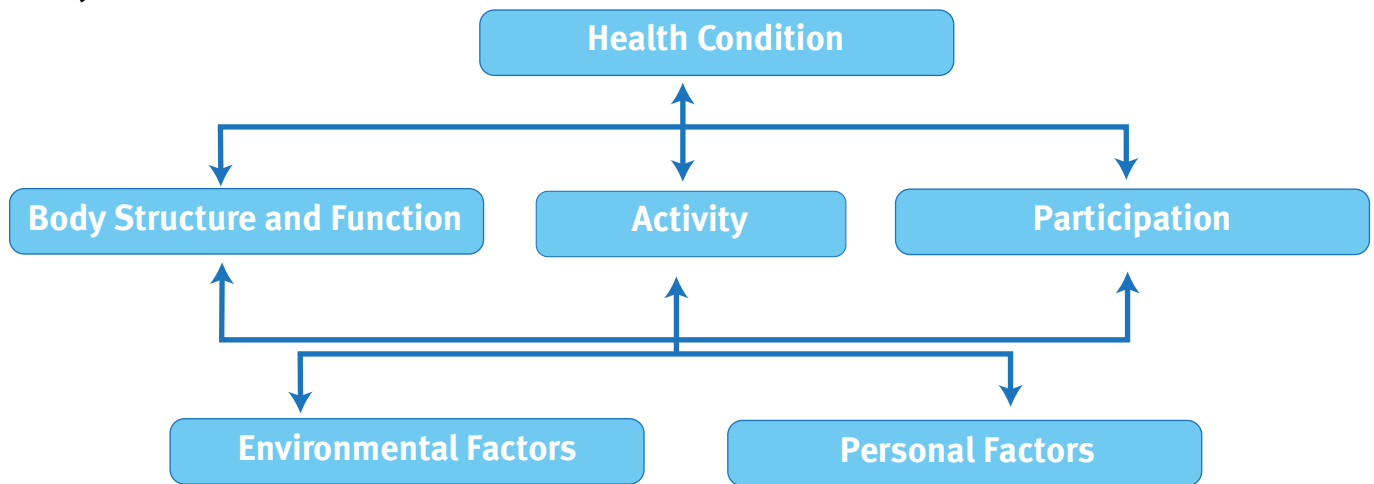
This brief review of the literature clearly identifies that children with significant health care needs are particularly at-risk of developmental and psychosocial impairment that may impact on their function and participation across the life course. We know that there are common understandings we can apply in regard to the impact of chronic illness on children and their families, and we also know that children are dynamic beings who are shaped by a complex and individual interplay between their biology and their environment, including the condition/s they have and the treatments they receive. Once a child is medically stable or an acute phase of treatment has passed (and even during active treatment phases in many instances), there is a clear role for the public health service to facilitate an understanding of that child's current state and likely developmental trajectory, and to support others to optimise the child's development, function and participation (Wray & Radley-Smith, 2004).

The World Health Organisation's International Classification of Functioning, Disability, and Health (ICF) challenges traditional practice models that hold biomedical factors as the primary consideration in planning an individual's care (see Figure 1) (Rosenbaum & Gorter, 2011; So, 2013). The ICF framework consists of a set of factors, all of which influence other aspects of a person's system in an interconnected and interdependent way. This reorientation of our conceptualisation of health and wellbeing is particularly important within the context of a child growing up with a chronic disease or special health care need and reinforces the notion that an integrated and holistic approach to care is required. It is no longer the case that health professionals can depend on diagnosis alone to guide treatment (Bebbington, et.al., 2013; Lollar et.al., 2012)





**Figure 1: The International Classification of Functioning, Health and Disabilities framework (WHO, 2001)**



Child Development does not fit well in a biomedical model of care (Rosenbaum & Gorter, 2011; Rosenbaum, 2013). The notion that a right and specific diagnosis can and will be made, and that the condition can be treated or even ‘fixed’ just does not apply within this clinical service area. Developmental diagnoses are often imprecise, and describe a heterogeneous group of conditions that may impact on function in a wide variety of ways (Lollar, et.al., 2012). Conventional treatments often manage symptoms rather than cure the biomedical underpinnings of the condition, and even then the treatment may not impact on function. Given that children develop quickly and in response to a wide array of factors, detecting casual connections between an intervention and an outcome is very difficult to do (Rosenbaum, 2013). Emerging concepts of development and function that align with the ICF framework have the potential to reform this clinical service area, and change both the scope and purpose of the business of specialist developmental services.

In line with the ICF Framework is the concept of a tiered approach to the identification of developmental need and the provision of support (Marino et al, 2012). Universal developmental surveillance is a widely endorsed concept that is perhaps even more pertinent to children with medical comorbidities. Surveillance for all enables the health care system to identify parental concern, maintain a record of a child’s

developmental history, directly observe that child, and identify potential risk and protective factors (Marino, et al, 2012). Universal surveillance forms the foundation for the provision of screening and formal evaluation processes, which may happen independently or in sequence, depending on the resources that are available and on the child and family context.

In addition to integrating a child’s emotional and cognitive development with their biomedical health care needs (Mickley et.al., 2013; Rosenbaum & Gorter, 2011; So, 2013; Turkel & Pao, 2007), health professionals need to understand the role and capacity of the child’s family, and collaboratively formulate strategies to aide a child’s development and participation (Rosenbaum, et.al., 2013; Turkel & Pao, 2007). Participation and function need to drive support and intervention in a way that is determined by the context of that child and their family and that allows both adaptation of everyday activity and variation to the ‘normal’ developmental trajectory. Importantly, there needs to be opportunity to partner with a child and their family over time to adjust the collective understanding as required given the dynamic nature of childhood and adolescence, the changing impacts of health conditions and surgical and pharmacological interventions, and the evolving context of the child in their world (Mitby, et.al., 2005; Newburger et.al. 2012; So, 2013,).



It is these partnerships with families that are the key to enhancing participation in the home, at school, and in leisure and recreation activities (Piskur et.al, 2012). This leads to a focus on health care autonomy, whereby parents, and eventually the child themselves, understand that child's developmental capabilities so they can make and evaluate opinions about development, participation and function; make informed decisions about their care including defining their developmental goals; and finally develop and evolve strategies to meet these goals over time (Beacham & Deatrck, 2013).

Specialist Child Development service providers are uniquely positioned to work with others to facilitate improved developmental and participation outcomes for children with significant health care needs and chronic disease. Specialist Child Development Services are provided by multidisciplinary teams across medical and allied health streams that operate in a transdisciplinary way according to a family centred practice model that holds function and participation at its core. Specialist Child Development Services have the capacity to integrate medical, biological, psychosocial and developmental factors and build and support necessary links between families, health, hospital and education service providers. This includes a particular focus on partnerships with primary care, including both general practice and child health; and with education providers across the public, catholic and independent sectors. Specialist Child Development Services can value add to the quality of life, health and wellbeing of children who frequently interface with our health care system, and in doing this add value to both the system itself and to the communities in which we all live, work and grow.

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Recommendations:





## Recommendations:

Following feedback from families and this overview of the literature, the Queensland Child and Youth Clinical Network's Child Development Sub Network makes the following recommendations:

- I. Improve awareness of the developmental needs of children with special health care needs and/or chronic disease, driven by Queensland Health and directed at families, clinicians and service partners beyond the public health care context.
- II. Advocate for the application of the ICF Framework by all subspecialties (in partnership with general paediatrics) as a means of integrating developmental, functional, participation, and biomedical understandings of an individual child
- III. Advocate for and support the growth of developmentally enriched inpatient environments and experiences
  - a. Generally, to improve the experience of short term inpatient stays, to reduce adverse impacts on the neurodevelopment of children who spend time in hospital settings, and to empower caregivers (both families and staff) to facilitate improved developmental health
  - b. Specifically, to understand and then meet the developmental needs of children who experience long inpatient stays, including the identification of particularly at-risk children and the development and implementation of individually determined Developmental Enrichment Plans
- IV. Establish pathways to enable prioritised access to specialist developmental services for children with identifiable and complex developmental concerns co-morbid to significant health care needs
- V. Develop linkages to support transitions across HHS, including between the new Lady Cilento Children's Hospital and metropolitan, regional, rural and remote services, as well as between regional HHS
- VI. Progress targeted workforce development strategies:
  - a. Across subspecialties and along the continuum of care, including service partners in sectors such as Education
  - b. Specialist CDS workforce