

SchoolKit Family Timeline

| | Parent/Carer Perspective | School Support |
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| 4 Years to 11 Years | <p>Students enter school with an earlier medical diagnosis of 'global development delay' (carrying the connotation of a student 'catching up') which is now changed to an intellectual disability as the student enters a specialist school or support class for students with an intellectual disability. The changing of this label means parents are faced anew with the prospect of their child having a life-long disability. This creates:</p> <ul style="list-style-type: none"> • A fear of the future as parents encounter a range of students with differing disabilities of all ages at school for the first time • A sense of denial that their child will develop idiosyncratic behaviours • Shock that their child is not going to a Kindergarten Class in their local primary or parent's school of choice • A 'future reality check' and facing for the first time what the future may in fact hold • A perception of 'parental failure' that they do not have a 'normal' child • A need arises for parents to 'let go' of their child and to begin to share the responsibility for care and education with the school. <p>Social Isolation occurs for some families once the Allied Health Professionals that delivered services up to 7 years of age begin to pull out. This leads to:</p> <ul style="list-style-type: none"> • A loss of relationships and trust with important services • A loss of advocacy from others as they transition into school • The beginning of new relationships with school staff which take time to develop via meetings and phone contacts. <p>The family unit is stressed in a variety of ways. This leads to:</p> <ul style="list-style-type: none"> • A need for more support for the family unit as there may be possible breakdowns in family relationships. <p>A period of calm begins as primary school gets underway. Trust is built with school staff as teachers support the parents with learning and behavioural strategies and help the family to access services outside school like respite and organise medical clinics to support the student and family.</p> <p>Parents are learning how to talk about disability with family and friends and helping their children explain to their school friends (as often they attend different schools).</p> | <p>Entry to school</p> <ul style="list-style-type: none"> • The school enrolls 'the whole family' not just the child with an intellectual disability and complex health needs • Teachers provide support via telephone calls, communication books and PLSP meetings with 'non-judgmental' listening • Focus on students developing leisure skills both in the school program and in skills that will generalise to the home like going out to cafes to eat with the class culminating in a restaurant visit as they graduate. This helps them in developing socially appropriate behaviour in a range of public settings which supports families. <p>Primary Years</p> <ul style="list-style-type: none"> • Executive staff and school counsellor provide support as needed and assist the family unit in recognising the needs of all members of the family unit. • Functional learning approach • Child centred approach • Helps build connections with new Allied Health personnel and professionals in different agencies • Helps families continue to develop trust and connections with medical services (School Clinics) • Parent support group with agenda to provide connectedness and other assistance. <p>School counsellors complete cognitive and adaptive assessments and share the results with parents and carers helping them to understand more about disability and providing psychoeducation. Preparing parents for future decisions about secondary placements.</p> |
| | 12 Years to 18 Years | <p>Earlier unresolved issues from the time of diagnosis become more acute and impact on the teachers and school as the student transitions from primary into secondary school and begins to enter puberty. This leads to:</p> <ul style="list-style-type: none"> • Worries about siblings and their future • Parental guilt over lack of time to balance all the family needs • Loss of support occurring especially if the student changes schools and school relationships • Older siblings begin to separate from the family unit and pursue their own interests and there is less support for both parents and other children in the family • Puberty is a challenge and new strategies are needed for managing behaviour as their child undergoes natural physical maturation and is larger • New technologies are a challenge for some parents • "Blinkers" come off as the reality of an unchanging condition continues as the end of school looms and dreams of a different future are irrevocably over • Years 11-12 are the beginning of transition to adult medical services. Can be a confronting time for parents as they re-experience shock, loss and grief • Development of new relationships as students and parents move into adult services with the assistance of school transition clinics • Fears of what the future holds: <i>What will happen when I die & who will look after my child?</i> |

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