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Parents' views of an optimal school life: Using Social Role Valorization to explore differences in parental perspectives when children have intellectual disability.

Glenys Mann, Karen Moni, and Monica Cuskelly

Abstract

Children with disability continue to experience disadvantage in their school lives, thus, the question of what makes up an optimal school life, and whether this is different for children with disability, becomes critical. This paper reports on research into parental views about an optimal school life and the usefulness of Social Role Valorization theory as a framework for exploring this issue. Six focus group interviews were used to collect data from 30 parents. Children of a variety of ages, with and without disability, were represented. All groups were similar in the aspects they regarded as optimal in a child's school life. These fell into five categories: being connected, growth, personhood, basic needs, and happiness. Despite this similarity across groups, there were some notable differences in the detail; for example, parents of children with disability had a stronger focus on children being wanted, high expectations, and being seen as an individual.

Keywords: disability; school life; Social Role Valorization; parental views; intellectual disability; intellectual impairment

Research tells us that people are more likely to lead impoverished lives when they have a disability (e.g., Mithen, Aitken, Ziersch, & Kavanagh, 2015). This is true at all life stages, including the school years (e.g., Gilmore et al., 2014). If the disadvantage experienced by students with disability is to be addressed, then the question of an optimal school life is important as it turns attention to what children with disability *should* be experiencing as an alternative to what they are experiencing now. What does it mean to have an optimal school life? Is there a common understanding of what is optimal? Is an optimal school life different for children with disability? This paper reports on research into what parents of children, both with and without disability, perceive as optimal, and the differences in views when children have a disability. Social Role Valorisation (SRV) (Wolfensberger, 1998) is used to explore the connection between a disability diagnosis and views of what constitutes an optimal school life.

Current understandings of the school lives of children with disability

In spite of international agreements such as the Convention on the Rights of Persons with Disability (United Nations, 2006), anti-discrimination legislation, and policy reform, research confirms the considerable difference in how education is experienced if a student is categorized as disabled. For example, some children with disability experience exclusion (McMaugh, 2011); access to inclusive education is unreliable (QPPD, 2011), or is denied (Anderson & Boyle, 2015). According to Boyle and Sharma (2015), many countries continue to categorise and separate children with disability from typical educational experiences. Parental reports attest to the educational marginalisation that is more likely to be associated with a disability label (e.g., Wendelborg & Tossebro, 2010). Specifically, students with disability are more likely to experience academic failure (Kelly et al., 2014), social isolation (Carter, Sisco, Chung, & Stanton-Chapman, 2010), and limited long-term prospects (Haber et

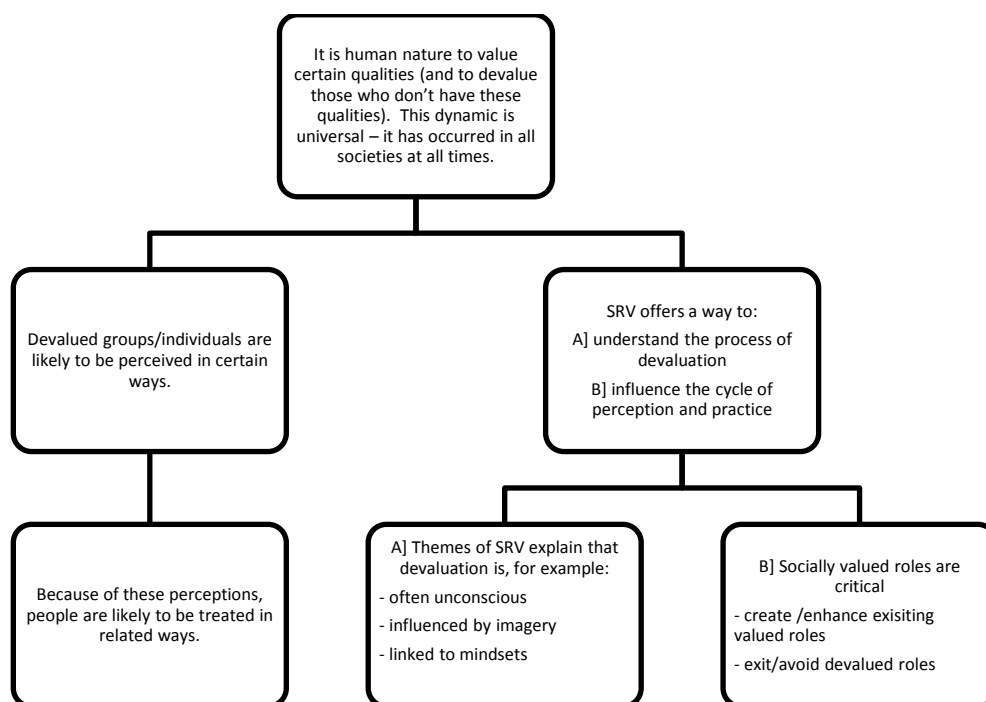
al., 2015). They are serviced by educational systems that can be 'complacent in their obligations to meet their educational needs' (Zigmond & Kloo, 2011, p. 162), and are taught by teachers who may be unprepared and lacking in confidence (Ashman, 2010). Alarming, students with disability are also vulnerable to physical harm, and even death, while in the care of educators (National Disability Rights Network, 2009). It must be acknowledged that such negative outcomes are not experienced universally, and that inclusive reform has been of benefit in opening up schooling opportunities; however, the evidence is clear that disability labels increase the likelihood of educational risk.

While it is widely accepted that students continue to experience disadvantage because of disability, it would also be widely agreed that children with disability should enjoy similar school lives to those who don't have disability. Schools should be places where all children have access to the elements of an optimal school life. The components of a child's school life, however, have not been a strong focus of research with the literature typically addressing features associated with an 'effective' or 'successful' school (see, for example, Cohen-Vogel & Harrison, 2013). While it could be argued that school quality and children's experience of schooling life are deeply connected, the distinction between them is important. Thinking in terms of what constitutes an 'effective school' can be problematic, particularly with regard to controversial and political issues such as schooling for children with disability (Fulcher, 1993). Educational exclusion, for example, remains firmly within our midst despite the plethora of information about inclusive school characteristics (Slee, 2012). Turning our attention to understanding children's lives rather than school features is a significant change of focus (Thin, 2009). Consideration of an optimal school *life*, rather than an optimal school, is important if we seek to ensure that students with disabilities experience school similarly to their non-disabled peers.

Understanding the school lives of children with disability using an SRV framework

Underlying this study is the premise that an SRV framework will be useful in considering the differences in perceptions of an optimal school life when children have disability. SRV explains the impact of disability on people's lives. It has been identified as a 'key theoretical position' regarding the lives of those with intellectual disability (Yates, Dyson, & Hiles, 2008, p. 247) and an important influence in producing positive changes for marginalized people (Shevellar, Sherwin, & Mackay, 2012). Within his formulation of SRV, Wolfensberger (1998) outlined the interplay between how people are perceived and what is thought possible. From this perspective, the 'universal "good things of life"' (i.e., those things that most people would desire e.g., a home of one's own, friends, employment) are less likely to be considered possible for, let alone made available to, and therefore experienced by, people with disability (Wolfensberger, Thomas, & Caruso, 1996, p.12).

The dynamics that Wolfensberger outlines are not age-specific. Perceptions about disability are relevant across the lifespan and will impact on children's lives including their experience of school. For an outline of some basic principles of SRV see Figure 1.

Figure 1**Figure 1. Basic principles of Social Role Valorization (based on Wolfensberger, 1998)**

Foundational to the theory of SRV is the concept of devaluation (i.e., the attribution of low/negative value), and the understanding that when a person is devalued, that person is less likely to be accorded what ordinary citizens (e.g., school children) take for granted (e.g., access to local schools). Central to devaluation is perception of difference, negative judgment of that difference, and subsequent 'ostracism and atypical life experiences' (Sherwin, 2011, p. 22).

While SRV is grounded in a number of principles, and holds the importance of social roles at its core (Wolfensberger, 2012), three concepts in particular were identified as highly relevant to discussions about an optimal school life: the power of mindsets and expectancies, the elements of 'personal social integration and valued social participation' (hereafter, 'valued social participation'), and the experience of wounding.

The power of mindsets and expectancies

In the context of a school life, SRV posits that what parents and/or educators expect a child to be like, or expect will/won't happen, or believe a child can/can't do, will strongly influence the sorts of opportunities afforded to that child (Wolfensberger, 1998). Mindsets are made up of a 'combination of beliefs and observations of the world and therefore a series of expectations about what should happen in any situation' (Race, 1999, p.120). In such a way, mindsets about children (how children are perceived) will strongly influence parental beliefs about what would be optimal in a child's life and, therefore, the schooling opportunities and experiences hoped for and expected.

The relevance of role expectancy and role circularity

A noteworthy influence on the mindsets and expectancies of parents is the social roles that are imposed on their children. Once children are established in a role such as 'special school student' or 'regular school student', for example, the role itself (established through markers such as where children go to school, who they go to school with, what activities they engage in, etc.) creates its own expectancies and has the power to influence parental beliefs and expectations (Wolfensberger, 1998).

'Valued social participation'

Exploration of what is believed possible and/or desirable for children with disability inevitably leads to the question of special vs. regular schooling. It is not unusual for this to be discussed as a simple dichotomy (e.g., Elkins, van Kraayenoord, & Jobling, 2003), *and also* as a difficult issue to explore due to the ambiguity around inclusion (see, for example, Graham & Spandagou, 2011). SRV's theme of valued social participation has potential to be of benefit in this arena, being similar to the concept of inclusion (Lemay, 2006), and providing both insight into the complexity of being truly 'included', and also a clear, explicit

definition of '(a) *valued* participation, (b) with valued people (c) in valued activities that (d) take place in valued settings' (Wolfensberger, 1998, p.123).

Wounding

In seeking to explain the life experiences of, and the process of devaluation for, people with disability and their families, SRV uses the analogy of 'wounding' (Race, 1999). Wolfensberger's (1998) exposition of the hurtful things that are associated with disability (e.g., rejection, segregation, congregation, loss of control) is relevant to all stages of life, and will be useful for understanding the impact of damaging school experiences on parental perceptions of what might constitute an optimal school life.

Given the research described earlier which illustrates the connection between disability and educational disadvantage, SRV's insights into this link provided a useful framework for this study.

Purpose of the study

The issue of equitable schooling for children with disability remains current. Advocacy, legislative change, policy development, and discussions about the features of a school that would address this issue have not produced the outcomes anticipated by those involved in inclusive education reform. The aim of this study, therefore, was to investigate the features that make a school *life*, rather than a school, optimal, and whether there are differences when children have disability. These questions are important for the 8.8% of children with disability in Australia (Australian Bureau of Statistics, 2010), and particularly critical for children in Queensland (where this study took place) who are categorised as intellectually impaired, and therefore eligible for special school enrolment (Queensland Government, 2013).

Parents have a natural authority in their children's lives (Kendrick, 1996) and their views on an optimal school life are important, given their role in schooling decisions. The perspectives of parents were therefore sought to investigate this topic.

Method

Participants

Thirty Queensland parents participated in the research; 28 mothers and two fathers. Of these participants, two couples attended in pairs. All parents lived in the South-east of Queensland; the majority from the Brisbane area and one group from a semi-rural area just north of Brisbane. See Table 1 (at the end of this article) for information about the participants.

Views were sought from a range of parents; participants represented children with and without disability, a variety of schooling choices, and a range of ages. Eleven participants had children without disability; four of these were in primary school and seven in secondary. Nineteen participants had children with disability; nine in special schools, five in regular primary school, and five in regular secondary. While there were 30 participants, there were two couples; the number of children represented is therefore 28, 19 of whom had intellectual impairment. Ten children with disability were enrolled in regular schools and nine in special schools. All children with disability were eligible for enrolment in special schools, that is, they had been categorised as intellectually impaired. Some had additional impairments (e.g., autism). See Table 1 for further information.

Data Collection

Data were collected through the use of focus group interviews which were considered appropriate for seeking a range of ideas, and for trying to understand different group

perspectives. Group, rather than individual, interviews were preferred because of the interactive effect of a group process (Stewart, Shamdasani, & Rook, 2007), and the shared nature of this data gathering strategy. Interaction between participants can help to identify 'the precise influence of particular words or phrases' (Kitzinger, 1994, p. 115) and this was deemed advantageous to the study.

Data collection procedures

After obtaining ethical clearance from The University of Queensland (#12-056), participants were recruited, initially, through the first author's networks. Friends, acquaintances and neighbours were approached, and information was distributed through local disability organisations. Parents who responded to the initial recruiting drive were invited to distribute the invitation through their own networks, so that a snowballing strategy developed.

Six focus group interviews were held between March and May 2013. The number of participants ranged from three to seven per group. Each group was homogeneous with respect to children's school placement, and consisted of participants in the six categories listed below:

- Group 1 (primary/no disability): Children without disability in primary
- Group 2 (secondary/no disability): Children without disability in secondary
- Group 3 (primary/disability): Children with disability in regular primary
- Group 4 (secondary/disability): Children with disability in regular secondary
- Group 5 (special/grp5): Children with disability moved from regular to special school
- Group 6 (special/grp6): Children with disability always enrolled in special school

Grouping of participants homogeneously was an important strategy as decisions about school settings may arouse strong emotions in parents of children with disability. Mixing parents from special and regular schools had the potential for raising fiercely opposed views. Stewart et al. (2007) warned against the troublesome nature of such groups.

Based on the argument by Kitzinger (1994) that in established groups, conversations are likely to flow more easily, groups were formed around existing friendships. To foster natural conversations, most interviews were held in family homes as it was hoped these would be more relaxed locations. One interview was held in a school meeting space; this was preferred by participants and was familiar to the group. Focus groups were approximately two hours long with a break in the middle.

Signed consent forms were collected at the start of each session and interviews began with a discussion about confidentiality and other ground rules. Interviews were audio-recorded.

The focus group interview moderator

The moderator (the first author) had prior experience of focus group interviews as a participant and as an assistant. She has worked extensively with parents and is a parent of children both with and without disability, and was considered a suitable moderator for the interviews. While her own schooling experiences had the potential to introduce moderator bias, they also gave a deeper insight into participants' stories, and a personal understanding of the issues raised. Familiarity with parents potentially made them more comfortable with volunteering and participating openly in group conversations. Care was taken so that questions and responses to questions did not favour particular views, thereby affecting the validity of the interviews. Attention was paid, for example, to tone of voice and facial expression so that these did not indicate the moderator's personal position on matters being discussed. In addition, a co-facilitator assisted with each group and affirmed that interviews were conducted without indication of the moderator's own views.

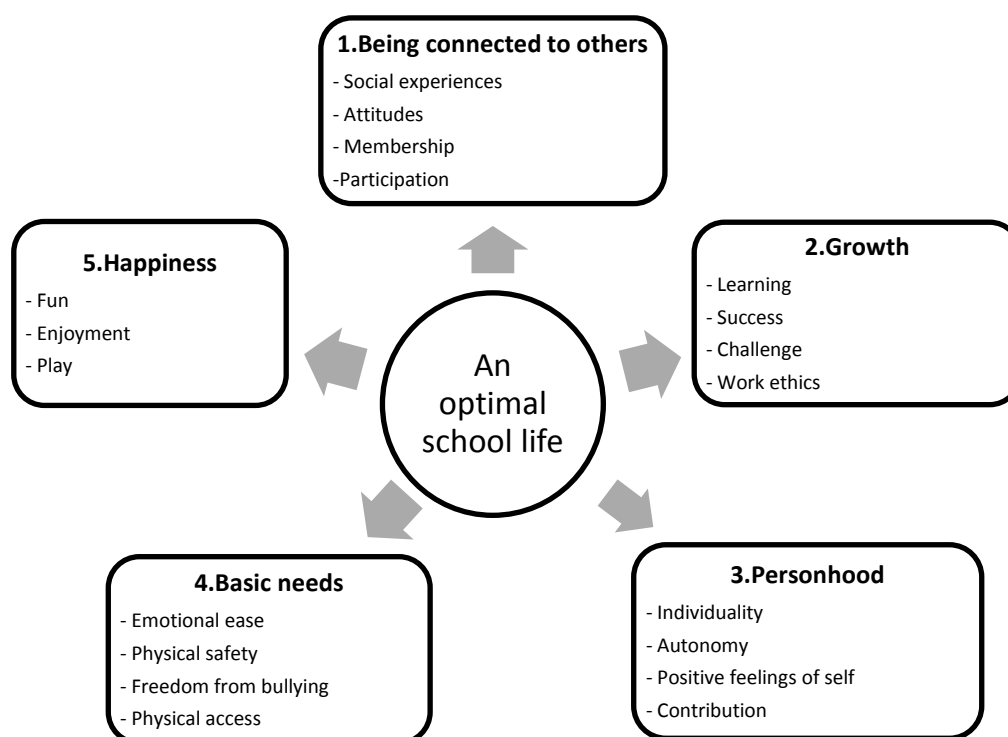
Focus group interview questions

Interviews began with a warm-up question. This was followed by a drawing activity which acted as a stimulus for talking about an imagined optimal school day. Subsequent questions were open-ended (refer to Appendix 1), and invited discussion on parents' understanding of the term 'optimal', and the components of an 'optimal school life'.

Data Analysis

Recordings of focus group interviews were transcribed and de-identified. Pseudonyms were used for participants, children and locations. Member checking was carried out. Fifty percent of participants checked and responded, and all responded that the record was accurate.

Transcripts were read for familiarity, and organised using NVivo (version 9). A preliminary identification of themes was undertaken and these were compared to the 'good things' that had been identified by Wolfensberger et al. (1996). The latter were modified in order to better reflect the data and school life. See Figure 2 for final themes and sub-themes.

Figure 2**Figure 2 Categories and sub-categories of the features of an optimal school life**

Data were then coded deductively based on the final categories. Positive and negative referrals to themes and sub-themes were included; that is, when parents referred to experiences that were not optimal these also gave an insight into parents' views. The comments included in the coding referred to hypothetical views and also real school experiences. Sometimes parents spoke of concepts that were not aspects of the child's life in themselves, but could lead to, or were connected with, an optimal school life, for example, specific teaching methods or resources. These were also coded but will not be reported here.

As the usefulness of SRV lies in its explanation of what happens to people with disability, the theory was not used in the design of the coding categories but in the analysis of the views of parents when their child had a disability.

Reporting on the data

The elements of an optimal school life

Whether the final categories of an optimal school life also applied to children with disability was a key question of the research. It was found that *all* parents wanted similar things out of school life for their children. However, some parents felt that an optimal school life *is* different when a child has a disability. Also, some differences were identified in emphases and in the sub-themes. The elements of an optimal school life that were discussed by parents have been summarized in Table 2 (at the end of this article) and have been illustrated using participants' own words. The order in which themes have been listed reflects their prevalence in the conversations overall. The more notable differences for children with disability have been included in the Table.

SRV and parents' views of an optimal school life when their children had disability

Analysis of the data to ascertain if there were differences associated with disability revealed the applicability of the SRV themes outlined earlier to parents' views and experiences. Using these three SRV principles enabled a deeper examination of participants' conversations. This will be elaborated below.

The power of mindsets and expectancies on what is seen as possible. Discussions repeatedly suggested links between parents' perceptions of children and views on an optimal school life. Some parents indicated that they saw their child with disability as the same as/similar to other children. They consistently spoke of their children in terms of commonality with children who don't have disability. 'All of us, *all* of us, have our own little idiosyncrasies that may need to be supported in different ways. Most typically developing kids just, you know, shut up and suck it up' (Jill, primary/disability). These parents were explicit that an optimal school life is the same for all. 'I want an ordinary life for all my children and I want them to be

treated equally...so, yeah, the same; there isn't an extra category to tick for my children that's different' (Shelly, secondary/disability).

In contrast, some parents spoke of their children in terms of difference. '... perfect world would say I have no expectations, different expectations...real world says absolutely...You face different things and so you have to tackle different things' (Jess, special/grp5). These parents were more likely to believe that an optimal school life is different for children with disability. 'It's got to be more flexible. It's not as rigid ... and it's completely different like ... it's pretty well individualised' (Laura, special/grp6).

According to SRV, a perception of difference is not unusual when a person has a disability. The theory outlines common views; for example, seeing people with disability as a medical problem, as a menace, as a burden, as unable to grow and learn. Some focus group conversations suggested these mindsets; for example, discussions about sons and daughters as problems ('the teachers are more taxed', 'the teachers are stretched'); or threats ('[My son] becomes evil'); or eternal children ('It's like having a six-year-old baby'). These perceptions were more usual in the special school groups and were linked to hopes for specialist, alternative places, programs and teachers.

How parents' mindsets and expectancies are influenced. SRV suggests that the way parents think about their children is the result of parents' own deep-seated beliefs and values *and also* those of influential others, for example, other parents and the professionals who work with families (Wolfensberger, 1998). How others speak about children, the advice they give, and the way children are treated will influence the mindsets of parents, and what they hope for and think is optimal. Examples of different influences on parents' mindsets were found in the data.

Two parents from a special school group indicated that they were directed to specific schools by medical rather than educational professionals. The link in parents' minds between education and therapy/specialist treatment had been established early in their children's lives. Similarly, professionals had conveyed the message of 'burden' or 'menace'. 'They [the teachers] were just looking at Gabe as if he was an evil young man. They weren't looking at his issues; he has issues. He couldn't help what was happening' (Pam, special school/grp6). Other parents alluded to professionals who were 'enlightened' (Mary, secondary/disability) and who had encouraged them to think in terms of regular lives.

Many participants (those who perceived their children to be the same as others as well as those who perceived their children to be different) spoke of the influence of other parents on what they thought would be optimal. 'One of the teachers ... had Blake in preschool and her son has Down syndrome who was older and had gone through the system so I took a lot of guidance from her' (Linda, special/grp5).

It was evident that, as the principle of role expectancy and role circularity predicts, the mindsets and expectancies of parents were influenced by the social roles that were established for children. Once children were in the role of 'special school student', for example, the role embedded parents' perception of children as different and their belief that optimal means alternative, 'special' provision. Similarly, when children were in the role of 'typical school student', this reinforced a perception of commonality and a belief that typical schooling is an important element of school life. The principle of role expectancy and role circularity (Wolfensberger, 1998) was a particularly interesting concept to consider with regard to those who had changed from regular to special schooling (grp5). Most parents in this group indicated that, earlier in their child's schooling, an optimal school life had meant local, family schools and/or relationships with regular peers. Conversations about changing,

or rearranging, expectations about school life were a common feature in this group's discussions. 'I know it's a cliché ... thinking going to Italy but you've ended up in Holland ...but you rearrange the mental furniture to fit ... I don't think it's about lowering your expectations ... It's about changing the expectations you have...' (Barb, special/grp5). While once they saw regular schooling as preferable, all but one from this group now spoke in terms of special schools, children and activities. The dynamics of role circularity were quite evident in this group as parents reassessed their views, and children became more embedded in the 'special school student' role. 'I don't think *he* misses it ... I don't think he saw the loss that *I* was worried about... I think that *I* mourned that loss of that little community ... and ... moving on [Jess: starting over again] Yeah!' (Wendy, special/grp5).

Valued social participation. Parents of children with disability considered additional topics in their discussions; for example, special vs. regular schooling. While all parents highly valued belonging and connectedness, whether this was in terms of local, regular schools or special school communities was a complex and critical point. Elements of SRV's definition of valued social participation were clear in conversations about this issue (i.e., the who, what, and where of schooling), and it was evident that parents were intuitively considering these elements in their judgments about whether regular or special schools provided an optimal life.

Many parents indicated that being with peers without disability (an element of SRV's valued social participation) was important. This was referred to in both special and inclusive groups and had clearly been significant to most parents at some time. Going to a regular school, at the same place other children would go (another element of valued social participation), was also viewed by many as an element of an optimal school life. Even those parents whose children were in a special school alluded to this. Linda (special/grp 5) remembered the 'tears and the tears and the tears' when her child left the regular school and

Jess (special/grp5) felt she was going against 'everything [she] represented' when her son did the same. In group 6, which focused heavily on specialist schooling, one parent spoke about leaving her options open regarding the possibility of regular school in the future, to which a second parent responded that this would be a good thing. Parents in this group spoke of the stigma attached to special school and while they rejected that stigma (and were very happy with their children's enrolment), one parent at least seemed to be resigned to special school rather than preferring it. 'I think the sooner you accept that, the easier your life becomes because you are not fighting with demons' (Pam, special/grp6).

For parents whose children were in a regular school, the matter of whether inclusive schooling was optimal was similarly complex. Being in a typical school was one of many factors in their child's school life and for most parents, even those with a commitment to inclusion, this was outweighed by the desire for acceptance and belonging. 'We weren't going to force him in there if he wasn't going to be welcome' (Lizzie, secondary/disability). Being in a regular school did not guarantee that a child's life would be optimal. 'Unfortunately ... [negative experiences have] been the main experience we have had' (Shelly, secondary/disability). These parents' views illustrate perhaps the most crucial aspect of SRV's valued social participation which is that a child's participation with typical people, in typical activities, and in typical places must be *valued*. Parents of children without disability seemed to assume that their sons and daughters were valued; this was not discussed in their groups. When children had disability, however, parents were very aware that, for school life to be optimal, a regular school enrolment was insufficient. The presence and participation of their children had to be wanted and appreciated if their children were to have an optimal school life.

The influence of wounding on what is seen as optimal. SRV posits that hurtful things (i.e., wounding) are likely to be associated with disability, and that these damaging experiences (or fear of them) impact on families, and influence what parents see as optimal for their children. Rejection is an example of a wound described by many parents. The impact of this wound (and the fear of this) was illustrated powerfully by Jess (special/grp5) who, even though her child was no longer in a regular school, spoke many times about her panic when the phone rang, and her dread that her son would be expelled from special school. It was evident that her son's rejection had severely impacted on both her own and his life and that all other hopes for school life had become subsidiary. 'So therefore, along the way...your expectations; what is your goals, your optimum ... "Okay, let's just hope he's happy enough to get to school today and that the teacher won't call me at the end of it"'. Pam, too, (special/grp6) reflected on the impact of exclusion: 'We've had a lot of kids come back to special school... I can't imagine how they feel when they've been in a mainstream school and then they're forced back into here. The cultural shock alone must be horrendous.'

The holding of low expectations is another wound described by parents. Jill (primary/disability), for example, spoke at length about the years wasted at her son's first school and her sadness at leaving their local community in order to find a school that would teach him. Although she was clear that an optimal school life meant inclusion at their local school, she felt forced to move away from their neighbourhood in order to avoid further damage.

A notable wound was the damage to the parent-child relationship when participants had to struggle to secure an optimal school life. This was particularly so in the regular school system. While many parents related stories of this struggle, two parents spoke specifically about how difficulties with the school negatively impacted on their relationship with their

child; that is, seeing one's child as someone who brings stress into the house: 'you see your child for who they are more ... rather than something that you're trying to help or fix or advocate for... It's your child then. It's like any other child ... someone to have fun with and enjoy...' (Ellen, primary/disability).

Discussion

Findings that children with disability continue to experience educational disadvantage (e.g., Anderson & Boyle, 2015; Mithen et al., 2015) highlight the critical nature of information about an optimal school life for these children. As important decision-makers and witnesses to children's lives, parents are well-positioned to provide authoritative views on this topic; not just those who have children with disability, but all parents. Vital to the usefulness of this research were the common themes identified in the views of all groups. Insights into the elements of an optimal school life (that all parents hope for), provide a foundation on which a school life for children with disability can be imagined and shaped. If an optimal school life for children with disability is to be pursued, the findings of this research identify the elements that will make up that life: warm, positive, valued connections within a range of school groupings (including friendships, classes, and teams); growth and development (and high expectations for learning); the recognition and expression of one's individuality and autonomy; a fundamental sense of safety and ease; and enjoyment of the experience. Conversely, the findings are also a reminder of the need to be vigilant against school lives of isolation, loneliness, time-wasting, boredom, missed opportunities, unhelpful stereotyping, unnecessary dependence, fear, stress, and/or unhappiness.

Current inclusive philosophy suggests that, for inequities to be addressed, students with disability must be educated in regular school settings. Many scholars in the field have argued that for school life to be optimal, it is best pursued in the educational main arena (e.g.,

Slee, 2012; Allan, 2007; Forlin, Chambers, Loreman, Deppeler, & Sharma, 2013). Likewise, SRV is also clear that regular school settings (provided children are in valued social roles) are inherently optimal. Being disconnected from typical places and people, and congregation with others on the basis of disability, according to SRV, are damaging life experiences (Wolfensberger, 1998). The results of this study indicate, however, that the issue of whether regular schooling is part of an optimal school life is not so straightforward for parents. Like others before them (see, for example, Wendelborg & Tossebro, 2010), participants indicated that educational disadvantage (e.g., social isolation, academic failure,) happens in all schools. Enrolment in a regular school does not currently guarantee an optimal school life.

The value of SRV as a framework for understanding parents' views. SRV was useful in providing insights into the complexity inherent in parents' beliefs about regular/special schooling. Firstly, as the theory predicts, some of the things taken for granted by most parents of typically developing children were not as readily available when children have disability (including being able to assume that a child can attend their local school, which was important to many parents). Findings suggest that parents had to weigh up the elements of an optimal school life; sometimes this meant giving up on some to gain others. Compromise is a theme that has also been reported by others (e.g., Byrne, 2013). Parents who named 'regular' and/or 'local' as critical elements of an optimal school life, indicated that pursuing these came at a price. For some, the price had been too high and other elements of an optimal school life became more central. Being wanted by the school community was a particularly important element when children had a disability. This is a critical element of SRV's valued social participation, which makes clear that true social integration cannot occur when a child's presence is coerced or he/she is not wanted/valued (Wolfensberger, 1998).

Secondly, SRV helped to explain the link between perceptions and parents' views about what would be optimal in their children's school lives. A perception of 'difference' is, according to SRV, a common response when people have disability, and a foundation for thinking that alternative, rather than typical, provision is necessary/optimal. The important link between perceptions of difference and expectations for life experience was also highlighted by Benincasa (2012). Findings illustrated this effect, showing links between parental perceptions of difference (such as those described by Wolfensberger, 1998, e.g., illness, burden, menace) and a desire for segregated, specialist support. Understanding how these views are, and can be, influenced is essential, given the role that parents play in school enrolment and the authority they are accorded regarding school choice (especially when choosing special school enrolment). SRV was helpful in identifying some ways in which parents' mindsets and expectancies about what is optimal were shaped, for example, by influential others.

Thirdly, the dynamics of SRV's 'role circularity' were of relevance to the findings that, except for one parent, all participants connected an optimal school life to their child's current setting (i.e., regular or special). A similar pattern was identified in earlier research by Jenkinson (1998). It was interesting to note the change of focus in group five (children who had moved from regular to special), as most of these parents spoke about regular school in a positive way. It could be argued that, in making the change to special school, these parents applied what SRV calls the 'conservatism corollary' (Wolfensberger, 1998); that is, due to the heightened vulnerabilities of people with intellectual disability, seeking to ensure an optimal life for them entails more than would typically be required (Race, 1999). Parental discussions indicate that they were instinctively applying this principle when they talked of having the same expectations as they would have for other children *and also* recognizing that their children need more than what is usually available to others. A point of interest is the

lack of parental confidence in regular schools to provide the extra that is required. Parents seem to be anticipating future wounding (e.g., time wasting, disconnection from peers); a well-founded fear given the findings outlined in the introduction. They traded (but perhaps still valued) features that a regular school could give their children (e.g., belonging to neighbourhoods, relationships with regular children) for those which they thought were more likely in special settings (e.g. safety; meaningful learning; a sense of belonging/acceptance).

Considerations for generalizing this data

While findings from this study contribute important understandings of parents' views, they cannot be taken to represent parental perspectives in general, as the number of participants was only small. It must also be noted that there are disadvantages in using focus group methodology in that group conversations can be dominated by specific individuals, and topics not raised in a group may still be important but overlooked. The fact that similar themes were apparent in all groups, however, gives a degree of confidence in the findings.

Other factors also need to be taken into consideration when looking at the usefulness of the findings; firstly, parents with university degrees are heavily represented and so views of others might be missing. Secondly, it must also be noted that, while focusing on the individual characteristics of students can be considered to be unhelpful within today's inclusive education paradigm, the type and severity of disability have been linked in previous studies to variations in parental views (e.g., Byrne, 2013). In this study, it was considered inappropriate to ask parents about the severity of their child's disability, as this is a difficult question to answer with any degree of reliability and also assumes a deficit view of disability.

Conclusion

This study indicates that what parents want for their children is a rich tapestry of experiences, feelings, and opportunities. The details may differ, but the threads of connection,

growth, individual expression, ease, and happiness are important to all, including those whose children are described as intellectually disabled. Specific features of the tapestry reveal insights into experiences of school and the influences on parents' hopes and dreams when children have disability. These insights are important because of the pivotal connection between what parents see as possible/desirable and what they seek and support regarding their children's schooling.

Findings indicate parents' views are complex. As has been evident in the investigations of researchers such as de Boer et al. (2010) and Gasteiger-Klicpera et al. (2012), this is particularly so when children have disability. Eagerness for welcome and acceptance is interwoven with the fear of rejection; desire for challenge and engagement entwines with stories of wasted time and low expectations; hopes for recognition as an individual interlink with stereotypes and labelling. With sobering predictability, the backdrop for the optimal school life that parents imagine remains a place divided. For some, an optimal school life plays out in a milieu of typical school communities, friends and activities; while for others, special places and others with disability make up the fabric of school days. In a time when inclusive education reform has become a legal and policy issue, it is critical to understand the complexity of this parental divide. Findings indicate that parents' views are not as simple as a choice between regular or special schools.

SRV has been used in this study to offer insights into the dynamics that come into play when a child has an intellectual disability. The theory has been applied to the focus group data to highlight the role of parents' perceptions and expectancies in children's schooling. While not using SRV theory as such, other research has similarly noted the influence of parental perceptions on children's lives (e.g., Mouzourou, Santos, & Gaffney, 2011). It is true that, in contrast to an inclusive approach, SRV makes no claim as to what

parents should or shouldn't do (Wolfensberger, 2012). It can, however, explain the link between perceptions, what is seen as possible/desirable, and schooling decisions. It also offers an insight into how the mindsets of parents are influenced, and particularly the impact of children's school roles (both valued and devalued); this is an important understanding if typical schooling options are to be pursued. Therefore, SRV can be an important and useful tool for understanding and addressing the inequities that have been described in schooling for children with disability.

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Appendix 1. Focus group interview questions

1. Imagine an optimal school day (encompassing drawing activity)

- What age would your child be on this imagined optimal day?
- Who would your child be with, and what would he/she be doing?
- What would the teacher have in his/her hand for your child?
- What would the teacher be saying to your child?
- What would the teacher be saying to you?

2. I am interested in hearing about what the term 'an optimal school life' means to you.

What do you think of when I say that?

3. What are the "good things" that make up an optimal school life?

4. Tell me about a time when school life has not been optimal for your child.

5. What was it like for you as a parent when school life was not optimal?

6. What is it like for you as a parent when school life IS optimal?

7. Do you think an optimal school life is different in any way when a child has a disability?

Tell me about that.

Table 1**Table 1 Participant details**

Name	PA	PE	CG	SS	YL	Dis
Group 1 – primary (no disability)						
Alice	50-59	4	F	SS	7	NA
Gwen	30-39	3	F	SS	7	NA
Sharon	50-59	1	F	SS	6	NA
Rosie	30-39	5	M	SS	5	NA
Group 2 – secondary (no disability)						
Naomi	40-49	5	M	PS	10	NA
Prue	50-59	4	M	CS	12	NA
Joanne	50-59	4	F	SS	9	NA
Fran	50-59	3	M	SS	12	NA
Pete	50-59	4	M	SS	12	NA
John	50-59	4	M	PS	11	NA
Elizabeth	50-59	5	M	PS	11	NA
Group 3 – primary (disability)						
Jill	-	3	M	SS	5	II
Mandy	40-49	4	M	CS	7	II
Kate	40-49	4	M	CS	6	II
Julie	40-49	4	M	SS	5	II+ASD
Ellen	40-49	4	F	SS	1	II+ASD
Group 4 – secondary (disability)						
Emma	40-49	4	M	CS	9	II
Mary	50-59	5	M	SS	11	II
Lizzie	50-59	3	M	SS	11	II
Shelly	40-49	4	M	SS	11	II
Sarah	50-59	5	F	CS	8	II
Group 5 – special (transferred from regular)						
Denise	40-49	3	M	SS	10	II
Barb	50-59	4	M	SS	10	II
Jess	40-49	1	M	SS	11	II+ASD
Linda	40-49	5	M	SS	10	II
Wendy	40-49	4	M	SS	9	II+PI
Nelly	40-49	5	M	SS	2	II
Group 6 – special (always enrolled in special school)						
Sandi	30-39	1	F	SS	2	II
Pam	40-49	1	M	SS	11	II+PI
Laura	40-49	3	M	SS	1	II+ASD

Key: Abbreviations: PA (parent age group); PE (parent education); CG (child's gender); SS (school setting); YL (year level); Dis (disability category)

Parent education: 1 (Year 10); 2 (Year 12); 3 (TAFE/Certificate); 4 (U/grad Degree); 5 (Postgrad Degree)

School Setting: SS (State school); CS (Catholic school); PS (Private school)

Disability category: NA (not applicable); II (intellectual impairment; ASD (autism spectrum disorder); PI (physical impairment)

Table 2**Table 2 Aspects of an optimal school life**

Major themes	Sub-themes	Differences when children had intellectual disability
1.Connection to others	1.1 Social experiences (e.g. friendship) 1.2 Attitudes (e.g. being viewed positively and warmly) 1.3 Membership (e.g. school member, class/team member) 1.4 Participation (e.g. involvement in school activities)	Numerous references to rejection and exclusion Desire for welcome, acceptance, and for their children to be wanted
	<i>I think relationships are incredibly important. You know, you can have a lot of things but if you don't have relationships ... so for me, I think good, solid relationships that are going to last into his future</i> (Barb, special/group5)	<i>In the end it was them going, clearly, "We don't want you here."</i> (Jill, primary/disability)
2.Growth	2.1 Learning (e.g. learning generally, academic, non-academic) 2.2 Success (e.g. achievement, doing well, positive outcomes/results) 2.3 Challenge (e.g. high expectations, opportunity, widening horizons) 2.4 Work ethics (e.g. trying hard, effort, being responsible)	Importance of not underestimating children's potential and capacity for learning; having high expectations Connection made between learning and specialist staff, equipment, therapy, programs
	<i>I actually think it's not so much about learning for knowledge. It's actually learning for behaviours and what you really hope is going to happen in your school environment is they actually learn behaviours that will lead them to be nice people</i> (Elizabeth, secondary/no disability)	<i>My only negative experience of school was a teacher with very low expectations ... except for [my daughter], she had the most wonderful year googling Justin Bieber and learning dance moves; so my experience that was negative was fantastic for her because she did no work whatsoever</i> (Sarah, secondary/disability)
3.Personhood	3.1 Individuality (e.g. recognition and use of interests and strengths) 3.2 Autonomy (e.g. independence, making choices, leadership, taking risks) 3.3 Positive feelings of self (e.g. confidence, pride, feelings of self-worth) 3.4 Contribution (e.g. contributing to the school community in some way)	Being seen as a disability rather than as an individual Stereotypes
	<i>We actually had to make sure that we got those messages through because it is such a big school; he's just one in a crowd. And once the messages got through, the whole thing changed. But, you know, for him it was a real struggle, you know, really, that the label's very hard to shift.</i> (Fran, secondary/no disability)	<i>Not to just go through the motions because this is what you do with these children ... not to pigeon hole them, and not to say 'They can't do that because they've got Down syndrome'</i> (Ellen, primary/disability)

Table 2 continued

Major themes	Sub-themes	Differences when children had intellectual disability
4.Basic needs	4.1 Emotional ease (e.g. calm, comfort, stress-free) 4.2 Physical safety 4.3 Freedom from bullying (e.g. physical, verbal) 4.4 Physical access (e.g. for wheelchairs)	Discussion about physical accessibility was the only difference between groups. <i>That was the ultimate for us, to make sure that he felt safe and we felt safe because otherwise ... I don't know; I even toyed with the idea of home schooling just to keep him out of harm's way (Barb, special/group 5)</i>
5.Happiness	5.1 Fun 5.2 Enjoyment 5.3 Play <i>I think it's important that you can see when kids come into the school sometimes, you know, if they all have smiles on their face. Are they happy to show up? (Rosie, primary/no disability)</i>	No differences

