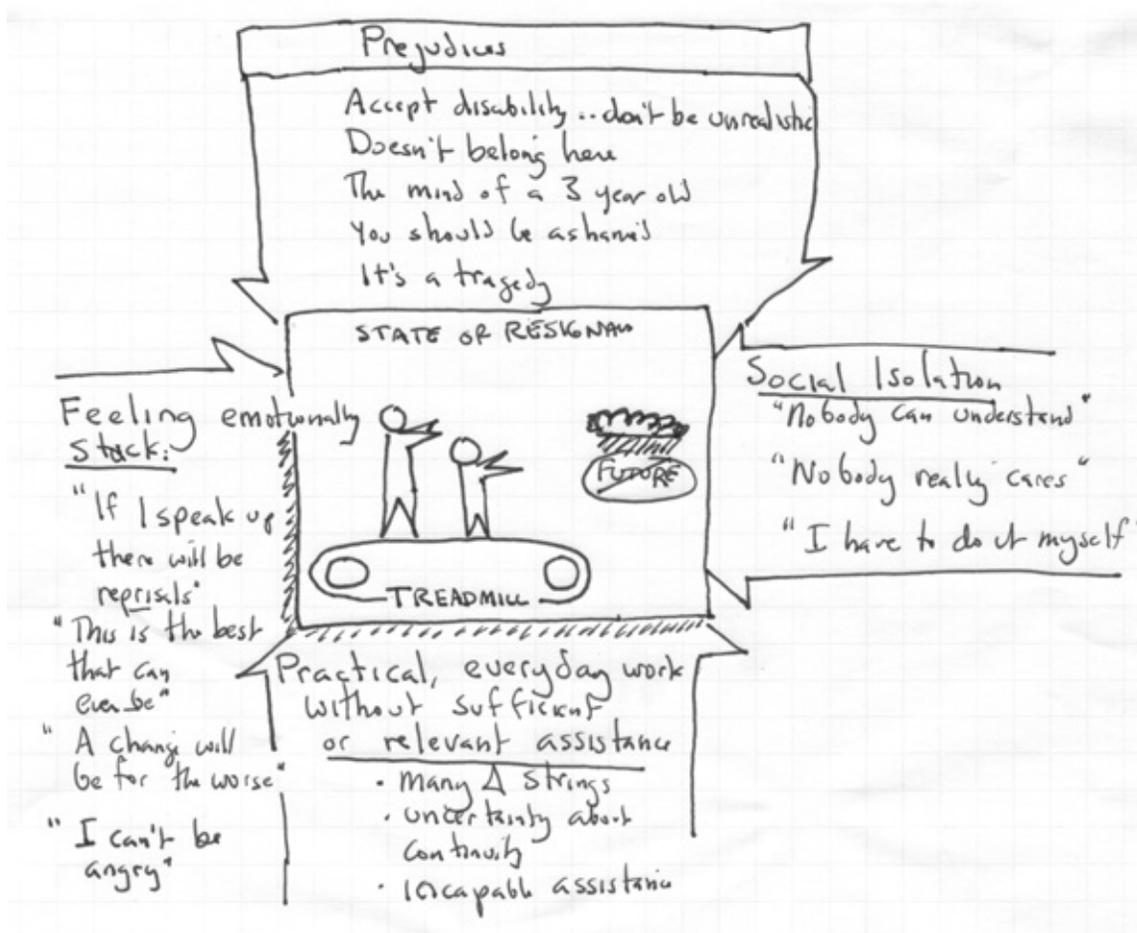


- Many parents resign themselves to low expectations for their sons and daughters. It is possible to describe some common signs and likely causes of this state of resignation in a way that parents will find helpful in re-framing positive possibilities for their children and themselves.



- The state of resignation is a deeply felt sense that things are as good as they can be and that it would somehow be dangerous to even think about better alternatives. Because it has understandable sources in the social devaluation of people with disabilities and the underdevelopment of the systems intended to provide assistance, few parents will avoid spending some time in the state of resignation. It can be a state that comes over parents from time to time when the work is exhausting or barriers seem to grow stronger rather than more yielding. More dangerously, it can color a parent's perceptions and limit their range of activities for months and years.

- Positive action is possible in the state of resignation. A parent may work hard to maintain or improve a service that seems “good enough” or fight for service or systems changes that will protect or expand existing kinds of services. What is difficult is defining, holding and acting on a vision of a positive community future for their son or daughter. Separation from ordinary life seems the only reasonable option. Developmental possibilities seem very modest. Opportunities for real contribution to community life seem like silly dreams. Services that reflect and reinforce these low expectations fit and perpetuate the state of resignation. Services that offer a greater challenge and more personal control seem unrealistic and threatening.
- In the state of resignation, parents don’t sense a viable connection between the achievements of other people with disabilities and their families and their own future. They may even reject learning about other ways to understand their situation and the possibilities for a more positive future, often by discounting other’s accomplishments by assuming “the person that achieved that is far less disabled than my child is”.
- In the state of resignation, parents may feel isolated and victimized by services, their communities, by their extended families, and even by their disabled son or daughter. This sense of victimization may become almost permanent (“they” will never do right by me) or it can sometimes lead to the pursuit of illusions (if we had proper support facilitators, everything would be ok) and lead people to connect only with others who share their sense of victimization.
- Parents who recognize the state of resignation and its long term effects can find their own individual ways to a state of realistic hope. The way into a state of realistic hope involves at least four sorts of action:
  1. Organizing personal support for themselves and their daughter or son to develop their unique gifts and contribute to their communities. Personal support includes relationships with family and extended family, friends and family friends, local community associations. Convening a circle of support is a way to organize personal support. Exchanging child care with another family or cooperative group of families is a way to organize personal support. Arranging a job in a family friend’s business is a way to organize personal support. Helping a

community association to welcome a person as a contributing member is a way to organize personal support. Personal support is mutual: over time, the person and family are contributors and helpers as well as receivers.

2. Learning about positive and possible alternatives by building a network of connections with the experience of other families, people with disabilities, and service providers. Such connections can be made through study visits, face-to-face discussions, participation in workshops or conferences, telephone and e-mail correspondence, and watching video or reading. Effective connections are reciprocal; over time, the person and family share their the lessons of their experience and their practical wisdom with others.
  3. Negotiating relevant assistance from human services. Relevant assistance matches personal requirements and supports a person and family in taking positive action. The time scale for negotiation may be immediate (how do we assure the best use of current services?) or longer term (how do we make progress toward the day when our daughter will move into her own home?) Human services include not only disability services and education but also housing resources, social services, local specialists and medical practitioners, and others.
  4. Contributing to social and political change by getting involved in defining and moving a local, regional, and state agenda for improved opportunities and supports for people with disabilities and their families. This may involve organizing and supporting other parents to work for change, lobbying, and participating in advisory, planning and governance groups.
- The purpose of this training is to build parents' confidence and competence in taking positive action by creating a group that will support them to...
    - ...discern when they are in the state of resignation and when they are in a state of openness to action toward a positive future and adopt a personal understanding of the role that the social devaluation of people with disabilities plays in forming the state of resignation
    - ...develop practical strategies that will allow them more freedom to move out of the state of resignation by practicing the skills of seeking personal support, re-framing

- dead-end understandings of disability and services and community, and recognizing and accepting and moving through ~~emotional~~ stress into positive action
- ...discover positive and possible alternatives by building connections to others who living hopefully and creatively
- ...define and guide positive action through the use of straightforward person-centered planning tools, including “Aligning what works” or “What those who provide services must know about me and my family”
- ...link their personal concerns into local, regional, and state efforts for system’s change.